Cordon Sanitaire or Healthy Policy? How Prospective Immigrants with HIV are Organized by Canada’s Mandatory HIV Screening Policy

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Abstract
Since 2002, the Canadian state has mandatorily tested applicants for permanent residence for HIV (Human immune deficiency virus). The policy and practices associated with this screening have never been critically scrutinized. Authoritative claims about what happens in the conduct of the immigration medical examination are at odds with the experience of immigrant applicants living with HIV. This is the analytic entry point into this inquiry that is organized within the theoretical and methodological frame offered by institutional ethnography and political activist ethnography. Analysis is connected to broader research literatures and the historical record.

The goal of this study is to produce detailed, contextualized understandings of the social and ruling relations that organize the lives of immigrants to Canada living with HIV. These are generated from the material conditions of their lives. An assumption about how organization happens is the social and reflexive production of knowledge in people’s day-to-day lives through which connections between local and extra-local settings are empirically investigable. I investigate the organization of the Canadian immigration process. How is this institutional complex ordered and governed? How is immigration mandatory HIV testing organized, and with what consequences to HIV-positive applicants to Canada? This is a text-mediated organization where all the sites are connected by people’s work and the texts they circulate. The positive result of an immigration HIV test catalyzes the state’s collection of medical data about an applicant. These are entered into state decision-making about the person’s in/admissibility to Canada.

I focus on a key component of the immigration process, which is medical examination and HIV testing with this, along with the HIV test counselling practices that happen (or not) there. The reported absence of the latter form of care causes problems and contradictions for people. This investigation adopts the standpoint of these persons to investigate their problems associated with HIV testing. The main empirically supported argument I make is that the Canadian state’s ideological work related to the HIV policy and mandatory screening ushers in a set of institutional practices that are highly problematic for immigrants with HIV. This argument relies on data collected in interviews, focus groups, observations, and analysis of texts organized under Canada’s Immigration and Refugee Protection Act (S.C., 2001, c. 27) and textually mediated, discursively organized concepts that shape people’s practice. Canadian immigration medical policy makers should make use of these findings, as should civil society activists acting on behalf of immigrants to Canada living with HIV. I make nine specific recommendations for future action on HIV and immigration in Canada.

Keywords: Canada, HIV/AIDS, immigration medical examination, Immigration and Refugee Protection Act, institutional ethnography, mandatory HIV testing, political activist ethnography, policy, ruling relations, social organization, textual mediation
**Dedication**

I am indebted to the following people to whom I dedicate this study, which was a labour of love:

Immigrant and refugee persons to Canada living with HIV, whose knowledge enabled this research, and without whom there would be no study. Your resourcefulness, cleverness and strength deeply motivated me. *Je suis reconnaissante de votre intérêt pour ce travail, et je vous remercie de votre partage ô combien généreux.*

My mother, Luann Howlett Bisaillon (1943-1994), whose luminous, magical spirit inhabits me. I forever miss your love, language, and laughter. My other mother, *Weizeiro* Malka Ghebrekrastos Fkak (1945-2012), who gave life and leadership to my sisters and wonderful extended family. Your blessings meant so much, and we will not forget your grace and courage.

And, finally,

My husband, Dawit Assier, who is the earliest and most fervent supporter of this research. Your kind ways, encouragement, and patience of an angel sustain me, and I am infinitely indebted to you, *yenné Negus*, for your faith and inspiration.
Let no one believe that landing on the shores . . . is a pleasant experience; it is a hard, harsh fact, surrounded by the grinding machinery of the law which shifts, picks, and chooses; admitting the fit and excluding the weak and hopeless . . . Much ignorance needs to be dispelled regarding these immigrants.

Edward Steiner, *On the Trail of the Immigrant* (p. 72)

From the perspective of an uninformed and apprehensive public, for whom elected representatives want to be seen as ‘doing something’ [about HIV] screening [for HIV and exclusion of people living with HIV] seems an easy enough and necessary way by which to raise a barrier to the spread of disease and to protect the public purse.

Guy Goodwin-Gill, “AIDS and HIV, Migrants and Refugees: International Legal and Human Rights Dimensions” (p. 64)

The promise and implications of a policy are not transparent and easily evident in its text . . . the ‘architecture of meaning’ of a policy is revealed by the systematic investigation of policy categories and labels, metaphors and narratives, programs and institutional places.

Dvora Yanow, *Conducting Interpretative Policy Analysis* (p. v)

I think of all the immigrants who go through the process to the end, just like me — who are intelligent, with good experience, wanting to immigrate — but who would get blocked because of a low CD4 count and a high viral load. This troubles me.

Immigrant to Canada living with HIV
# Table of Contents

**Abstract** .......................................................................................................................... ii

**Dedication** .......................................................................................................................... iii

**Table of Contents** ................................................................................................................ vi

**Acknowledgements** ........................................................................................................... xi

**Notes to the reader** ............................................................................................................. xiv

**Acronyms** ........................................................................................................................... xv

**Ancestry of Canada’s HIV testing policy** ........................................................................... xvi

**Map of the first thirty days in Canada for refugee applicants** ............................................ xx

**Glossary explaining how words are used in this study** ....................................................... xxi

Part 1: General and methodological terminology ............................................................... xxi

Part 2: Canadian immigration-related terminology ............................................................ xxxxi

**Preface** ................................................................................................................................... xxxix

**Chapter 1. Introduction** ..................................................................................................... 43

Emergence of the study’s problematic and argument .......................................................... 45

Context and questions ........................................................................................................... 49

Discovery of a disturbing disjuncture ................................................................................... 50

  Contesting the claims of consent, counselling, referral .................................................... 53

A critical approach to the social ............................................................................................ 58

Potential contributions of this study .................................................................................... 59

“Forward reflexivity” ............................................................................................................. 61

  Researcher standpoint ......................................................................................................... 62

  Textual mediation of “gender-based violence” work with women refugees .................... 64

Dissertation organization ....................................................................................................... 66

**Chapter 2. Considering the literature** ................................................................................. 69

Early database searching ....................................................................................................... 69

Later database searching ....................................................................................................... 71

Exploratory work .................................................................................................................... 73

  Findings and challenges ....................................................................................................... 74

Discussion of findings ............................................................................................................. 77

What does mandatory immigration HIV screening consist of? ........................................... 77

Authority for Canadian immigration health practices ....................................................... 78

  Immigration legislation from 2001 .................................................................................... 80

  Three significant changes in policy and practice ............................................................. 83

  The HIV testing policy’s official (and inferred) purpose ............................................... 85

Data on immigration and HIV in Canada ........................................................................... 88

Pathways to Canada .............................................................................................................. 90

Mobility restrictions for people living with HIV ................................................................. 92
**Chapter 3. Institutional ethnography as method of inquiry** ............................................. 97
- Anti-positivist paradigm ................................................................................................. 97
- Materialist method ......................................................................................................... 98
- Reflexive epistemology ................................................................................................. 100
- Activist project of research ............................................................................................ 103
- Deciding to use institutional ethnography ..................................................................... 105
  - Ruling relations of research as praxis ........................................................................ 106
  - “Targets for intervention” ........................................................................................... 107
- Qualities of inquiries using institutional ethnography .................................................. 109
  - Methodological rigour ................................................................................................ 110
  - Nine methodological terms ........................................................................................ 111
  - Social relations ........................................................................................................... 111
  - Social organization ..................................................................................................... 112
  - Ruling relations ........................................................................................................... 113
  - Texts and documents ................................................................................................... 114
  - Discourse .................................................................................................................... 116
  - Standpoint and standpoint politic ............................................................................... 117
  - Problematic .................................................................................................................. 119
  - Experience .................................................................................................................... 120
  - Work .............................................................................................................................. 121

**Chapter 4. Ethnographic fieldwork** ................................................................................. 123
- Preparing for and entering the field ............................................................................... 123
  - Standpoint informants ............................................................................................... 123
  - Extra-local informants ............................................................................................... 126
  - Working with texts during fieldwork ......................................................................... 128
  - Recruiting standpoint informants .............................................................................. 131
  - Recruiting extra-local informants .............................................................................. 133
- Immersing in the field .................................................................................................... 133
  - Phase One ..................................................................................................................... 135
  - Phase Two ..................................................................................................................... 138
  - Moving locations ......................................................................................................... 138
  - Capturing data .............................................................................................................. 140
- Working with the data .................................................................................................... 141
  - Reading and deliberating phase .................................................................................. 141
  - Marking up and sorting phase .................................................................................... 143
- Reflecting on fieldwork and challenges ....................................................................... 146
  - Interviews and the social features that shape them .................................................... 147
  - Ideological versus material talk .................................................................................. 150
  - Exploring my industrial capture .................................................................................. 154

**Chapter 5. Hunting out the human immunodeficiency virus** ......................................... 157
- ‘What’s in an HIV antibody test?’ .................................................................................... 157
  - No test, no virus? HIV test and the body politic ......................................................... 161
What is involved in testing positive for the Canadian state? ........................................164
Alem Tareke Yacob ........................................................................................................165
“Some doctors tell you, and some doctors do not tell you about the HIV test”...........165
“If I were not a sponsored person, I would still have to live with HIV” .........................166
“They consider HIV to be different than other diseases” ...........................................167
Susanne Kunene ...............................................................................................................167
“Here, I believe that all the systems and networks are connected” ...............................167
“Maybe he is fed up with immigrants coming in with HIV” ........................................168
“Time was running out for me” .......................................................................................169
“You are not supposed to offer better interest rates” ..................................................170
“God used him by not giving me that interview” ............................................................171
“Why is the government spotlighting HIV, anyway?” ..................................................171
“Informed and rigorous debate” .....................................................................................173
Institutional discourses: Canadian AIDS organizational milieu .................................177

Chapter 6: The state’s immigration medical in/admissibility work ......................... 184
Institutional discourses: Immigration and Refugee Protection Act ..............................185
The economy as a discursive organizer .........................................................................186
Health as a discursive organizer ...................................................................................189
Safety as a discursive organizer ....................................................................................192
Organization of the state’s immigration medical work .................................................195
Doing the work of medical assessment .........................................................................196
Textual production and projection ................................................................................201
The HIV testing policy framework ...............................................................................202
Authoring the HIV testing policy ..................................................................................203
Inscriptions within the HIV testing policy ....................................................................205

Chapter 7. Doctoring work and contradictions experienced by immigrants with HIV 214
“Taken-for-granted” efforts to immigrate ......................................................................216
“You will have to do this and that for work” ..................................................................217
“Immigration says that this is a non-adversarial event” ...............................................220
“It would be great to have you move to Canada” .........................................................224
“I did not ask him direct questions about immigration” .................................................226
“You just had to fill in the normal paperwork” .............................................................229
“We are the guys in the trenches” ..................................................................................230
“You must pass the ‘Maple Leaf’ test” ..........................................................................236
“They were hoping to tell me something I didn’t know!” .............................................244
“It’s the same language” ...............................................................................................246
“You do not know these people as patients” ..................................................................252
“I hope that I am not a financial burden to the economy of Canada” ..........................258
“These things are a little bit complicated” ......................................................................263
“I hold this paper in high moral value” .........................................................................266
“They know I am kind of a health hazard” .....................................................................267

Chapter 8: Discussion, conclusions and recommendations ................................. 269
Thoughts on study findings .............................................................................................270
And the significance of this for standpoint informants? .............................................. 274
Reporting to extra-local informants, policy makers, and the public .......................... 275
Nine evidence-informed recommendations .................................................................. 277
Several possibilities for future research ...................................................................... 280
Reflections on the method of inquiry ........................................................................... 282

Translations of verbatim statements .............................................................................. 285

References ..................................................................................................................... 288

Appendices ..................................................................................................................... 320
Appendix A: Mandatory testing policy and articles informing study’s disjuncture ....... 321
    A1. Canada’s HIV testing policy (CIC, 2002) ................................................................. 321
    A2. Zencovich et al. (2006) article .................................................................................. 328
Appendix B: Data collection ............................................................................................ 330
    B1. Organizations encountered during exploratory phase .......................................... 330
    B2. Immigration medical assessment and inadmissibility under health grounds ...... 331
    B3. Citizenship and Immigration Canada HIV Testing Policy .................................... 332
    B4. Recruitment notice and letters of introduction to the study .............................. 333
    B5. Frequence VIH website posting, September 3, 2009 ........................................... 338
    B6. Association canadienne des infirmières et infirmiers en sidologie newsletter
        posting, Spring 2010 ............................................................................................... 339
    B7. Sample questions explored with standpoint and extra-local informants .......... 340
    B8. Consent forms ....................................................................................................... 344
Appendix C: Ethics approvals .......................................................................................... 345
    C1. Certificate from August 27, 2009 ......................................................................... 350
    C2. Certificate from October 28, 2009 ............................................................................. 351
    C3. Certificate from May 27, 2010 ............................................................................... 352
Appendix D: Data analysis ............................................................................................... 352
    D1. Text and document worksheet ............................................................................. 353
    D2. Analytic mapping (1) .............................................................................................. 354
    D3. Analytic mapping (2) .............................................................................................. 356
    D4. Canada’s HIV Testing Policy (With my annotations) ........................................... 362
Appendix E: Citizenship and Immigration Canada Forms ............................................. 365
    E1. IMM 5419 Medical Report: Section B .................................................................... 369
    E2. Emphasis on post-test counselling for HIV ............................................................ 370
Appendix F: Permissions to use ....................................................................................... 371
    F1. Huan Tran, September 29, 2011 ........................................................................... 371
    F3. Morgan McConnell, July 6, 2011 ......................................................................... 373
    F4. No One is Illegal Vancouver, February 3, 2011 ................................................ 374
Appendix G: Publications I have produced in connection with this research ............... 375
    G1. Mandatory HIV testing policy and everyday life: A look inside the Canadian
        immigration medical examination, 2011 ................................................................. 375
    G2. Le dépistage obligatoire ceinture nos frontières, 2011 ....................................... 376
G3. Human rights consequences of mandatory HIV screening policy of newcomers to Canada, 2010 ................................................................. 378
G4. Examining bodies: Putting the HIV testing policy to the test, 2010 ................................................................. 379
G5. Working from within endemic HIV stigma, 2010 ................................................................. 380
G6. Politics and pragmatics in fieldwork using institutional ethnography, 2012 ................................................................. 381

List of Tables
Table 1. Study overview ................................................................. 47
Table 2. Themes from reviews of the literature ................................................................. 71
Table 3. Trends in the literature on HIV and immigration ................................................................. 74
Table 4. For what is the state searching? ................................................................. 82
Table 5. HIV-positive test results in Canadian IME, Jan. 2002 to Mar. 2010 ................................................................. 89
Table 6. International mobility restrictions for people living with HIV ................................................................. 94
Table 7. ‘How to look’ when doing institutional ethnographic research ................................................................. 109
Table 8. Study's standpoint informants ................................................................. 124
Table 9. Study's extra-local informants ................................................................. 127
Table 10. Official agents’ work on immigrants with HIV ................................................................. 130
Table 11. Orienting features in institutional ethnographic research ................................................................. 137
Table 12. Organizing and working with the data ................................................................. 145
Table 13. AIDS and HIV in the 1980's ................................................................. 159
Table 14. Tensions, contradictions, experiences with immigration HIV testing ................................................................. 178
Table 15. Social organizers of the in/admissibility work of state medical officers ................................................................. 209

List of Figures
Figure 1. State's reference to HIV counselling work practices ................................................................. 56
Figure 2. Immigration application categories ................................................................. 78
Figure 3. Cost determination for required services ................................................................. 85
Figure 4. Principles animating Canada's HIV testing policy ................................................................. 87
Figure 5. The Canadian refugee application process ................................................................. 93
Figure 6. Dorothy Smith's standpoint informant drawing ................................................................. 118
Figure 7. Colour-coding interview transcripts ................................................................. 144
Figure 8. Study's standpoint informant diagram ................................................................. 153
Figure 9. Textual hierarchy organized by IRPA ................................................................. 188
Figure 10. State’s policy on notification of a partner’s HIV status ................................................................. 194
Figure 11. Processing of an immigrant applicant's medical file ................................................................. 197
Figure 12. Text-act-text sequence ................................................................. 202
Figure 13. State’s HIV post-test counselling form ................................................................. 247
Figure 14. Post HIV test counselling in state’s educational materials ................................................................. 258
Figure 15. ‘Outsourcing’ the work of HIV counselling ................................................................. 259

List of Illustrations
Uprooted Lives by Huan Tran, 2006 ................................................................. i
The Dark Angel by Morgan McConnell, 2011 ................................................................. iv
The Nest by Morgan McConnell, 2011 ................................................................. 319
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My defense of this research in Ottawa on December 16, 2011 necessarily provoked anxiety. At the same time, however, it was an enjoyable and memorable experience. I thank those colleagues, friends, and family who graciously travelled to attend the auspicious event; those who indicated that they participated in spirit, if not in body; and, those who travelled a great distance to raise a toast in the aftermath (Craig Dale, Laurie Clune, Marilyn Garnett, Michael Bailey, and Ron Garnett). Roseline Savage, *dout l’expertise en matière de l’administration universitaire m’a été d’une aide durant le cheminement de mes études.*

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concerns of people living with HIV, can offer the latter, and those who care about them, socially useful research results.

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Notes to the reader
I offer the following eight notes to assist the reader in her or his reading of this dissertation.

Direct quotations appear in double quotes (e.g., “Blais said . . . ”). Terms to which I seek to call the reader’s attention and emphasize are given in single quotes (e.g., ‘Work’ is defined as . . . ). An important example of the use of single quotes is the frequent usage of the rather confusing notions ‘excessive demand’ and ‘non-excessive demand’ (and their derivatives). These are inside quotes to emphasize that they are technical terms of art created by the Canadian state.

I identity myself with an italicized “L” when quoting informants from transcripts and other materials. I identify the informant with a regular case “l”. For example,

L: My question to the informant
I: Commentary/response from the informant

I have altered all names and assigned pseudonyms so that informants are not identifiable. Since I mention this here, I only remind the reader of this at the first mention of the use of an altered name (i.e., see Preface). I do not repeat this point in the body of the dissertation.

I designed the Acronym, Glossary, Ancestry, and Map of the first thirty days documents as handy references for the reader to refer back to in her or his reading. Note that I generally avoid using acronyms or abbreviations in-text. Designated Medical Practitioner (DMP), HIV and AIDS are the notable, recurrent exceptions.

For economy of space, full citations for sources listed in footnotes are given in the References section.

All tables and figures are my creations unless otherwise referenced. Permissions to use visuals other than my own appear in Appendix F.

In quoting informants, I preserve the language of original communication in the body of the dissertation. See Translations of verbatim statements on pages 285-287 of this dissertation for English-language meaning. In the References section, I have provided translations of French-language book and article titles.

I distinguish between HIV, AIDS, and HIV/AIDS by using each term carefully with attention to the specific context (historical, social, medical).
**Acronyms**

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired immune deficiency syndrome</td>
</tr>
<tr>
<td>ASO</td>
<td>AIDS service organization</td>
</tr>
<tr>
<td>CBSA</td>
<td>Canadian Border Services Agency</td>
</tr>
<tr>
<td>CD4</td>
<td>Cluster of differentiation antigen 4</td>
</tr>
<tr>
<td>CIC</td>
<td>Citizenship and Immigration Canada</td>
</tr>
<tr>
<td>DMP</td>
<td>Designated Medical Practitioner</td>
</tr>
<tr>
<td>EDE</td>
<td>Excessive demand exempt</td>
</tr>
<tr>
<td>Handbook</td>
<td>Handbook for Designated Medical Practitioners</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>IFH</td>
<td>Interim Federal Health Program</td>
</tr>
<tr>
<td>IE</td>
<td>Institutional ethnography</td>
</tr>
<tr>
<td>IME</td>
<td>Immigration medical examination</td>
</tr>
<tr>
<td>IRB</td>
<td>Immigration and Refugee Board of Canada</td>
</tr>
<tr>
<td>IRPA</td>
<td>Immigration and Refugee Protection Act (S.C., 2001, c. 27)</td>
</tr>
<tr>
<td>Non-EDE</td>
<td>Non-excessive demand exempt</td>
</tr>
<tr>
<td>OP</td>
<td>Operational or Overseas Processing Instructions</td>
</tr>
<tr>
<td>PHA</td>
<td>Person living with HIV</td>
</tr>
<tr>
<td>PIF</td>
<td>Personal Information Form</td>
</tr>
<tr>
<td>Regulations</td>
<td>Immigration and Refugee Protection Regulations (SOR/2002-227)</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>VL</td>
<td>Viral load</td>
</tr>
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</table>
Ancestry of Canada’s HIV testing policy

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1867</td>
<td>Canadian Constitution Act divides powers between federal and provincial governments, while not specifically mentioning health. Both levels of government exercise legal authority over public health.</td>
</tr>
<tr>
<td>1869</td>
<td>First Canadian Immigration Act specifies diseases, and bearers of these are generally excluded for immigration for concerns that they will be dependents on the state.</td>
</tr>
<tr>
<td>1906</td>
<td>Second Canadian Immigration Act creates categories of diseases, and a prospective immigrant person should not have any of these diseases to be admissible for immigration.</td>
</tr>
<tr>
<td>1966</td>
<td>Publicly funded universal health insurance system, Medicare, is created under the Medical Care Act.</td>
</tr>
<tr>
<td>1974</td>
<td>A New Perspective on the Health of Canadians, the Lalonde report, emphasizes the legal framework and division of powers relating to public health in Canada.</td>
</tr>
<tr>
<td>1976</td>
<td>Third Canadian Immigration Act removes references to specific diseases. Focus turns to the state’s anticipation of how much care for the prospective immigrant would cost the state. The term “excessive demand” appears.</td>
</tr>
<tr>
<td>1981</td>
<td>First human deaths in North America associated with AIDS-related illnesses.</td>
</tr>
<tr>
<td>1982</td>
<td>Canadian Charter of Rights and Freedoms specifies individual rights against infringement by government.</td>
</tr>
<tr>
<td>1984</td>
<td>Canada Health Act is introduced.</td>
</tr>
<tr>
<td>1985</td>
<td>First HIV antibody test approved.</td>
</tr>
<tr>
<td>1986</td>
<td>First edition of the Medical Officers Handbook is published.</td>
</tr>
<tr>
<td>1987</td>
<td>CD4 tests begin to be used in the care for people living with HIV.</td>
</tr>
<tr>
<td>1987</td>
<td>United States introduces entry, permanent residence and citizenship ban for people living with HIV.</td>
</tr>
<tr>
<td>1987</td>
<td>First pharmaceutical treatments available for people living with HIV azidothymidine (AZT).</td>
</tr>
<tr>
<td>1989</td>
<td>Australia introduces mandatory HIV screening for applicants for permanent residence for people 15 years and older. Restrictions on immigration for people living with HIV, with refusals based on anticipated cost to health system (see <a href="http://www.immi.gov.au/media/fact-sheets/22health.htm">http://www.immi.gov.au/media/fact-sheets/22health.htm</a> and</td>
</tr>
<tr>
<td>Year</td>
<td>Event</td>
</tr>
<tr>
<td>------</td>
<td>-------</td>
</tr>
<tr>
<td>1991</td>
<td>Margaret Somerville publishes “The Case Against HIV Antibody Testing of Refugees and Immigrants” in the <em>Canadian Medical Association Journal</em>. In a policy statement, the Canadian government ceases to consider people living with HIV as threats to public health because of their infection. The state later clarifies its position in 1994.</td>
</tr>
<tr>
<td>1993</td>
<td>The term “AIDS exceptionalism” begins to appear in public health and colloquial usage.</td>
</tr>
<tr>
<td>1994</td>
<td>Refusal of a permanent resident visa because of excessive demand successfully appealed by an HIV-positive couple, The case of Keels vs. Canada is one of the first HIV-related refusals on record.</td>
</tr>
<tr>
<td>1996</td>
<td>Highly active anti-retroviral treatment (HAART) is available in high-income countries such as Canada. Legislative Review Advisory Group is appointed to evaluate Canada’s immigration system, and publishes <em>Not Just Numbers: A Canadian Framework for Future Immigration</em> in 1998.</td>
</tr>
<tr>
<td>1997</td>
<td>First viral load tests are approved and used on people living with HIV. Research shows that HAART is not a cure for HIV.</td>
</tr>
</tbody>
</table>
| 1998 | Canadian HIV/AIDS Legal Network publishes *HIV Testing and Confidentiality* that presents arguments against mandatory HIV testing of immigrants to Canada. United States Department of Health and Human Services releases the first *Guidelines for the Treatment of HIV in
<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>Adults. New Zealand introduces mandatory HIV screening only for people who intend to stay for two years or more. Persons with HIV are considered “public health risks”. Restrictions on immigration for people living with HIV, with refusals based on anticipated cost to health system. Report of the Auditor General criticizes Citizenship and Immigration Canada for not testing prospective immigrants for hepatitis and HIV screening at immigration medical examination. Health Canada advises Citizenship and Immigration Canada to mandatorily test and exclude all prospective immigrants who test positive for HIV. The Canadian HIV/AIDS Legal Network publishes <em>An Ethical Analysis of the Mandatory Exclusion of Refugees and Immigrants who Test HIV-Positive</em> authored by Barry Hoffmaster and Ted Schrecker.</td>
</tr>
<tr>
<td>2002</td>
<td>Mandatory HIV testing is integrated into Canadian immigration medical examination. Romanow and Kirby reports, <em>Building on Values</em> and <em>Health of Canadians</em>, respectively, are published. First reports of Canadians dying from severe acute respiratory syndrome (SARS).</td>
</tr>
<tr>
<td>2004</td>
<td>New Zealand introduces tighter screening policies directed at people with hepatitis, HIV and TB where more prospective immigrants are tested for “ill health and disability indicators”. The government extends evaluation</td>
</tr>
</tbody>
</table>
criteria for “likely” public costs for care. Canada and Australia are cited as countries influencing policy changes (http://www.beehive.govt.nz/node/18795).

The Public Health Agency of Canada is created.

A sustained, vigorous, and coordinated advocacy effort led by individuals and numerous civil society groups succeeds in having the question requiring short-term visitors to Canada to disclose their HIV-positive status removed from the Canadian visitor visa application form. This mobilization was in preparation for the 16th International AIDS Conference in Toronto in 2006 (see http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=95).

The connections between HIV and disability start to become increasingly associated in national and international discourses, research, and civil society advocacy work.

An estimated 65,000 people live with HIV in Canada (see http://www.phac-aspc.gc.ca/aids-sida/publication/survreport/estimat08-eng.php).

**Fourth** edition of the *Handbook for Designated Medical Practitioners* is published.

**2010**

United States repeals entry ban on people living with HIV that had been in place since 1987. It does this by removing HIV from its list of “communicable diseases of public health significance”.

**2011**

62 of 192 countries impose restrictions on people living with HIV for stays over 90 days.

Map of the first thirty days in Canada for refugee applicants

MAP OF FIRST 30 DAYS IN CANADA

Refugee applicant at border or in Canada
- Interrogation by / registration with federal govt
  - CIC or CBSA database
  - CIC database

IFH 'Brown Paper'
- @ CIC office
- Claim accepted by CIC agent
- Interrogation by / registration with federal govt
  - CIC or CBSA database
  - CIC database

HIV testing
- Results
  - HIV clinic
    - social worker
    - nurse
    - HIV physician
  - CD4
  - VL
  - DMP medical report to CIC
  - ME #1
  - ME #2

Public Health sent result

Interview with Public Health Nurse (Ontario, not Quebec)

PIF sent to IRB

Law office - lawyer

Results
- File
- Hospital card

File
- Application for HIV-specific social service benefits
- PIF sent to IRB

Find temporary housing
Move to shelter
- Find DMP Schedule IME

Certificate
- Certificate of IME (maybe)
- Referral to HIV clinic (maybe)

Apply for federal work permit

Other services
- Legal Aid
- Social Services
- Refugee Services

File
- Medical Form
- PIF (blank)
- Info Package
- ID #
Glossary explaining how words are used in this study

Note: There are no universally accepted definitions of many of the words below. In preparing this glossary, I intend to show the reader how I understand and use the terms that appear in this dissertation. The glossary is in two parts: general and methodological, followed by Canadian immigration-related vocabulary.

**Part 1: General and methodological terminology**

<table>
<thead>
<tr>
<th>Term</th>
<th>Elaboration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acquired immune deficiency syndrome (AIDS)</td>
<td>A term, in biomedical usage, that refers to the later symptomatic stages of HIV infection when the CD4 count has dropped below a certain level. For critical social scientists, AIDS also designates broader social fields that circulate around and in which AIDS-related infections and illnesses are situated (see Waldby, 1996).</td>
</tr>
<tr>
<td>Biomedicine</td>
<td>In this study, I draw from understanding of this term as deployed in the work of medical anthropologists Margaret Lock and Vinh-Kim Nguyen (2010). They write that biomedicine is a “body of knowledge and associated clinical and experimental practices grounded in the medical sciences that were gradually consolidated in Europe and North America from the 19th century on . . . [Biomedicine] is an assemblage of activities at many sites ranging among doctors’ offices, clinics, hospitals, laboratories, research consortia, technological units, public health sites, and so on . . . [Biomedical technologies are] those technologies developed in association with biomedical research and practice” (p. 365, note 1).</td>
</tr>
<tr>
<td>Body</td>
<td>Understood in this research to be a vessel that is permeated by material, political, historic, and biologic influences. The body is a deeply social entity with changing and situational or circumstantial rather than universal properties (see Farnell, 1996).</td>
</tr>
<tr>
<td>Boss or governing text</td>
<td>This is a methodological term that denotes an official document that authorizes and coordinates the work practices of designated persons. It supplies categories and concepts, and, in turn, enables subsidiary texts. There is layer after layer of them. In this research, the</td>
</tr>
</tbody>
</table>
**Immigration and Refugee Protection Act** is identified as the boss text.

This is a type of white blood cell that all people have. The CD4 count measures the strength of person’s immune system. CD4 lymphocytes cells coordinate immune systems and ensure that other immune cells function properly. A normal CD4 count is generally between 500 and 1,500 cells per cubic millimetre of blood. HIV infection infects the CD4 cells. The count will influence when a person might start ARV therapy to slow the progression of HIV infection. Generally, the higher the count, the healthier a person’s immune system. Where CD4 counts are above 200, persons are generally not at risk of becoming ill (see http://www.catie.ca/eng/myh/ch9.shtml). Counting CD4 depletion has become the “gold standard in tracking HIV disease progression and decline in immune response” (see http://www.thefreedictionary.com/CD4).

Information and a form of care provided to a person who will undergo and who has undergone HIV testing. “Pre-test counselling is widely regarded as the best way to provide the level of information needed to ensure informed consent, which is required as part of sound, ethical practice and Canadian law” (Canadian HIV/AIDS Legal Network, 2007b, p. 1; see also Canadian HIV/AIDS Legal Network, 2007a). Since 2003, the Canadian state has framed as very important the delivery (by Designated Medical Practitioners) of counselling to prospective immigrants who test HIV-immigration through immigration testing. In the material circumstances of the immigration medical examination, however, counselling practices do not occur, which causes problems for standpoint informants.

This is the “social character of language and its connection with relations of social power. Discourse upholds that we can only speak about topics in certain ways” (Frampton et al. 2006, p. 30). People participate in discourse, and it is through their actions that discourses are brought into being. Looking at how people participate in discourse, how they talk about what they do, what texts they circulate, and what is reproduced in people’s labour is of analytic interest in research using institutional ethnography. Discourse in this application builds from Foucault’s (1981; see Rabinow, 2010) use where language is organized in certain ways to shape knowledge and understanding.
Disease

A physiological process.

Disjuncture

This is a term used in institutional ethnography to refer to disconnection and separation between people’s everyday social experiences and official representations of these. In this study, the disjuncture between standpoint informant experiences with mandatory immigration HIV testing and official reports about what happened during this screening was the starting point for critical investigation. Institutional ethnographies inquire into how disconnections are put together to understand how they are socially organized.

Embodiment or embodied

A concept from anthropology that emphasizes people’s knowing from the social experience and familiarity of their lives. The purpose of using this term in this study is to draw attention to the social features and material events of people’s existence; bringing into view how people know and speak based on the actions and activities that their bodies engage in. The term is a methodological tool to help the researcher remember to start in the local particularities of people’s bodily existence. Embodied knowledge is a process of knowing that is “an alternative to accepting external authority” (Frampton et al., 2006, p. 30). Margaret Lock and Vinh-Kim Nguyen (2010) refer to the concept of embodiment as a dynamic process of the “lived entanglement of local biologies, social relations, politics and culture” (p. 2).

Empirical approach

An approach to understanding the social world from the starting point of people’s material circumstances and observations of their everyday activities and experience.

Epistemology

A term meaning the theory of knowledge. It refers to the how we know what we know about the social world, and it underlies and grounds all theoretical approaches. What we know is socially organized.

Ethnography

A qualitative research approach with origins in anthropology and sociology defined as a process, design, and product of research. As a process, ethnography involves extended observations, often of people and their surroundings, where the researcher immerses in and records the events of people’s everyday lives. Interviews are also often part of ethnographic
fieldwork. Historically, ethnographies have focused on interpreting and learning about people’s cultural qualities, behavioural traits, and their subjective experience (see Creswell, 2007, pp. 68-72). Examples of critical ethnography are outside of this classical frame since they displace culturalist approaches in anthropology (see Good et al., 2010; Fassin, 2007; Fassin & Pandolfi, 2010; Nguyen, 2010).

Evidence

On its face, this is “that which can be repeated, independently verified and measured according to standards upon which we can all agree” (Murray, Holmes & Rail, 2008, p. 273). In this study, it is understood that there is no unbiased or objective observation or analysis.

Experience

The starting place for research using institutional ethnography is within people’s social experience. In this application, the intent is to make visible the socially coordinated character and organization of people’s lives. Hence, experience is seen neither as individual nor a claim of ‘truth’.

Explicate

This means to clarify the meaning of something that is obscure or implicit, and bring that something out of the shadows and into view so that it can be investigated. In doing this, new and explicit forms of knowledge are generated. Explication of ruling relations as found in the data is the goal of an institutional ethnography (see Campbell & Gregor, 2004, pp. 8 and 86).

Extra-local informant

A person who participated in and informed this project during the second phase of fieldwork. These include informants who maintain the HIV testing policy, and those people who advise and work with refugee and immigrant applicants living with HIV. My choice of language underscores that informants are located, socially, at different places within knowledge and ruling relations. Informant’s social worlds are “shaped by other local interactional worlds that connect together to form more extended social relations” (Frampton et al., 2006, p. 33).

Health

From the World Health Organization, “health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (as per https://apps.who.int/aboutwho/en/definition.html). A socially constructed concept with more than one meaning. “Health is . . . an amorphous topic . . .” (Schneider v. British
The aetiological agent that causes AIDS.

This test is a medical diagnostic tool that detects the presence of antibodies to the virus’ proteins that an infected person’s body produces in protective response to HIV infection. It is also a social and political practice that accomplishes the management of people living with HIV.

This is a social form of knowledge that is uprooted and ungrounded from the social circumstances in which it was produced. As per Mikhail Bakhtin’s understanding of this idea, my use “is not to be confused with its politically oriented English cognate. [I]t is simply an idea-system” (Bakhtin, 2004, p. 429). Critique of ideological practices is a key constituent in Marx’s analysis of social relations and in this study.

The social experience of living with a disease.

This term refers to the relations and interdependence of texts that are hierarchal. “[H]igher level texts establish the frames and concepts that control and shape lower level texts” (D. Smith, 2005, p. 226). As developed in institutional ethnography, this concept is developed in chapter six of this dissertation.

In this study, these are defined as the processes and complexes that extend across multiple sites to coordinate people’s local activities and experiences. These “identify complexes embedded in the ruling relations that are organized around a distinctive function, such as education, health care [and, in this study, immigration medical screening and assessment]” (D. Smith, p. 225). These do not refer to research on or in specific types of institutions in the way that the work of Erving Goffman, Howard Becker, Herbert Gans, Robert Castel and René Lourau in prisons, asylums, hospitals, and factories did.
In institutional ethnography, this is a process where we, researcher and researched, are drawn into the ruling relations of the milieus where we work, live, teach or research; the settings with which we are familiar; the social organization of which we can take for granted. When this happens, we can fail to interrogate the words, concepts, or ideas that we easily and commonly employ. In so doing, we can lose sight of informants (and our own) experientially based knowledge. Aware of the possibility of such capture, the researcher explores the discursively organized contours of what can be said and written as products of the social relations and organization in which the research is seated.

A theoretically informed research strategy that draws on Marxist and feminist theorizing to lay a course for critically interrogating the social world. The method of inquiry is often associated with the work of Canadian sociologist Dorothy Smith who developed it. Analytic attention is turned to understanding and articulating how people are ruled and regulated by society's institutions. The intent is to open up possibilities for transforming dominant relations that oppress people. IE produces explications of how things are socially coordinated and constructed to happen to people as they experience them, which distinguishes the approach from conventional anthropological or other sociological forms of ethnography.

Numerous sorts of ethnography are ontologically consistent with IE. Some of these include: extended case method (Burawoy, 1991); global ethnography (Burawoy, 2000); multi-sited ethnography (Marcus, 1998); political activist ethnography (G. Smith, 1990); and, political ethnography (Schatz, 2009). Research using these ethnographies endeavour to explore the world from within people’s activities; they are concerned with understanding power asymmetries; and, they use these imbalances as entry points to opening up and investigating social processes and ruling arrangements that transcend local boundaries.

In this study, this term refers to happenings and forms of knowledge in particular sites that are connected to systems, processes, and events that occur elsewhere. Linkages between the local or immediate and extra-local or translocal always exist, though they are not always readily apparent to us.
<table>
<thead>
<tr>
<th><strong>Mandatory HIV testing</strong></th>
<th>“Requiring HIV testing as a condition of obtaining a certain status, service or benefit, such as employment or health services” (Canadian HIV/AIDS Legal Network, 2007d, p. 1).</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Materialism</strong></td>
<td>From the method of inquiry developed by Marx in the 19th century, which he developed in juxtaposition to what he experienced as philosophical idealism. Materialist inquiries are based within people’s actual experiences as these occur ‘on-goingly’ and every day. These experiences are socially produced within particular historical, economic and political contexts that materialist inquiries examine and investigate.</td>
</tr>
<tr>
<td><strong>Method</strong></td>
<td>This refers to the design, framework and process through which a study is undertaken.</td>
</tr>
<tr>
<td><strong>Ontology</strong></td>
<td>A term evoking the assumptions of how the social world comes into being that informs all theories. The perspective of research using institutional ethnography is that the social world is produced and created through people’s activities and practices.</td>
</tr>
<tr>
<td><strong>Opt-in HIV testing</strong></td>
<td>Where a person accepts to be tested for HIV, and gives her or his consent for this to happen.</td>
</tr>
<tr>
<td><strong>Opt-out HIV testing</strong></td>
<td>Where a person will be tested for HIV, usually in a clinical situation, unless she or he actively declines to be tested. About documented problems associated with opt-testing, see the Canadian HIV/AIDS Legal Network, 2007f.</td>
</tr>
<tr>
<td><strong>Person living with HIV (PHA)</strong></td>
<td>An abbreviation to designate people living with HIV. In Canada, because of the availability of medicines that lengthen lives, colloquial speech no longer incorporates AIDS into the nomenclature for people living with HIV. Within biomedicine, this is a person who has tested positive for HIV antibodies.</td>
</tr>
<tr>
<td><strong>Praxis</strong></td>
<td>This is the fusing of theory and practice where the two mutually constitute and inform each other. This merging encourages researchers (and others) to both interpret and act within the social world (see Marx &amp; Engels, 1846, 1970).</td>
</tr>
</tbody>
</table>
**Problemsatic**

A problem arising in relations between people and the world in which they live. The problem resides in how the social world is organized in contemporary society. It “organizes inquiry into the social relations lying ‘in back of’ the everyday worlds in which people’s experience is embedded” (D. Smith, 1981, p. 23). The problematic is uncovered through fieldwork in the activities of people’s lives.

**Public health**

“Public health is what we, as a society, do collectively to assure the conditions for people to be healthy . . . [The role of public health is to] assure the conditions for people to be healthy” (Institute of Medicine, 2003 in Gostin, 2005, p. xi).

**Public policy**

This is a “system of laws, regulatory measures, courses of action, and funding priorities concerning a given topic promulgated by a governmental entity or its representatives” (http://www.musc.edu/vawprevention/policy/definition.shtml/). For example, state actors make decisions about the regulation of a country’s borders or about measures to contain public expenditure. Decisions are summed up and formulated into policy documents, which generally relate to legislation (e.g., as is the case with Canada’s HIV testing policy).

**Reflexivity**

The mutually determined, interactive character of the social world and the knowledge produced about it. The term comes from ethnomethodology, an approach that conceives of people as skilled practitioners and knowers of their social worlds. The approach sets out to understand how people make sense of what they do (Garfinkel, 1967). The term also refers to “[a]n effort to foreground the place of the researcher in the process of conducting research and writing scholarly texts as a means to disrupt and undermine notions of objectivity” (Haggerty, 2003, p. 155).

**Routine HIV testing**

Where HIV testing is integrated into the habitual, taken-for-granted practices of health care providers as part of a protocol of policy.

**Ruling relations**

“Ruling relations demonstrate the connections between the different institutional relations organizing and regulating society” (Frampton et al. 2006, p. 37). These relations are textually mediated through print, film, television, other media, and the professions, for example. The
state, corporations, professional bodies, formal organizations, agencies, the academy, science, for example, are involved in a web of relations through which ruling is organized. Ruling relations enables organization that “generates specialized systems of concepts, theories, categories, technical languages” (D. Smith, 1996a, p. 47). Marie Campbell and Ann Manicom (1995) employed this concept to move to a language stretching beyond ‘power’ and the ‘state’.

**Science**

The organization of practices on which we build reliable knowledge.

**Social**

Defined as people’s on-going actions and practices as these happen in coordination with the activities of others in “across-time-and-place conversations” (D. Smith, 1996a, p. 46).

**Social organization**

Where the coordination of people’s activities is reproduced, socially, over time and location. The interplay of social relations constitutes social organization.

**Social relations**

A concept in institutional ethnography that means the organization of sequences of activities that shape people’s daily activities and connect their immediate activities to the actions of people who are located elsewhere.

**Standpoint and standpoint politic**

The particular social location from which an inquiry is conducted. An investigation (and a researcher) starts from within the local conditions of somewhere, and institutional ethnography makes this social and political position explicit. Standpoint politic refers to the intent of creating “knowledge from [people’s] standpoint that provides maps or diagrams of the dynamic of macrosocial powers and processes that shapes their/our lives” (D. Smith, 1996a, p. 55).

**Standpoint informant**

The study is taken up from the perspective of people living with HIV who are immigrants and refugees to Canada, and it is they who are the study’s standpoint informants. I coined this term that on one level refers to this group of people, and on a second level, emphasizes that the research is anchored in their relevancies. My choice of language emphasizes the ontological point that I endeavoured to ground my project in the activities of their everyday,
interactional, local worlds. These informants were most significantly involved in the first phase of fieldwork (so as to inform later stages).

These are material artefacts that can include (but are not limited to) print, film, photos, television, mass and electronic media, radio. In this study, these include legislation, Immigration and Refugee Protection Regulations, policy directives and instructions (e.g., *Handbook for Designated Medical Practitioners*, Operational Processing Instruction 2002-004, etc.). They have a replicable, social character. How people use, interact, and reproduce texts in their actions is of analytic interest because it is understood that texts mediate ruling relations and organize and shape what people can say and do. A distinguishing characteristic of projects using institutional ethnography is how texts are understood and used.

This refers to the organization of knowledge within which is sets of ideas and principles that we use to decide what we pay attention to and what we consider data. Political scientist Patrick Chabal (2009) points out that theory is “constructed within historically bounded contexts and it is applied in specific ways” (pp. 2-3).

The VL is a measure of the amount of HIV in a person’s blood plasma. The VL test measures the number of copies of HIV in a millilitre of blood (though VL can also be measured in other bodily fluids). The VL test might show significant changes over time in people not receiving medication. Generally, the higher the VL, the faster HIV will disable the immune system. When a person starts effective HIV medication, the VL should decline until it is undetectable, which is the goal of treatment (see http://www.catie.ca/eng/myh/ch9.shtml).

This refers to when a person decides to undergo a test for HIV of her or his free will. It is also an HIV prevention intervention.
In this study, I use this concept as it has been developed in institutional ethnography: to bring attention to anything that people do that “takes time, effort, and intent . . . [it] orients the researcher to what people are actually doing as they participate, in whatever ways, in institutional processes” (D. Smith, 2005, p. 229).

**Part 2: Canadian immigration-related terminology**

| **Canadian Border Services Agency (CBSA)** | A federal government agency whose agents are employed to manage, control and secure Canadian borders “in support of national security priorities . . . [as] part of the [government’s] public safety portfolio” (Immigration and Refugee Board of Canada, 2006, p. 4). Agents are trained to admit, refer, detain or remove people who present themselves at ports of entry. With Citizenship and Immigration Canada and the Immigration and Refugee Board of Canada, this agency constitutes Canada’s immigration and refugee system. |
| **Citizenship and Immigration Canada (CIC)** | A federal government department that has overall responsibility for managing immigration and refugee matters. Its agents select who can immigrate to Canada. It grants citizenship and issues official documents such as visitor, worker, and student visas. With the Canadian Border Services Agency and the Immigration and Refugee Board of Canada, this department, based in Ottawa, constitutes Canada’s immigration and refugee system (see http://www.cic.gc.ca/english/index.asp). |
| **Convention refugee** | A person who meets the definition and criteria established for a refugee as per the 1951 text, *United Nations Convention Relating to the Status of Refugees* (see http://www.unhcr.org/pages/49da0e466.html). |
| **Designated Medical Practitioner (DMP)** | A physician, often a general practitioner, who is hired on term contract by Citizenship and Immigration Canada to medically examine people who make an immigration application to Canada. The DMP is charged with reporting on the health status of prospective immigrants, including diagnosis and prognosis of identified conditions. Examinations are conducted in designated medical offices in Canada and overseas. The Health Management Branch of |
Citizenship and Immigration Canada oversees the work of the DMP.

Common, colloquial reference used by standpoint informants in this study to describe themselves. This evokes the concept of medical inadmissibility within the Immigration and Refugee Protection Act. It also implies the work of Citizenship and Immigration Canada agents such as Designated Medical Practitioners, medical officers, immigration, and visa officers whose work is coordinated to determine a person’s inadmissibility based on anticipated cost to the Canadian public systems of treating a diagnosed medical condition.

A person who is selected by Citizenship and Immigration Canada as a permanent resident based on their skills and ability to contribute to Canada’s economy. Skilled workers, business immigrants, live-in caregivers and provincial or territorial nominees are examples of economic immigrant or applicant categories.

A technical concept developed by the Canadian state that is defined in Canada’s Immigration and Refugee Protection Regulations (SOR/2002-227) (s. 1(1)). The definition reads: (a) A demand on health services or social services for which the anticipated costs would likely exceed average Canadian per capita health services and social services costs over a period of five consecutive years immediately following the most recent medical examination, unless there is evidence that significant costs are likely to be incurred beyond that period, in which case the period is no more than ten consecutive years; or (b) a demand on health services or social services that would add to existing waiting lists and would increase the rate of mortality and morbidity in Canada as a result of an inability to provide timely services to Canadian citizens or permanent residents. See non-excessive demand exempt for opposite meaning.

A technical term to describe the state’s consideration of whether an immigrant applicant’s medical condition would pose an excessive demand on health or social services in Canada does not apply to this person as a reason for excluding her or him from Canada. Persons who are exempt from this consideration include family class and refugee persons. See non-excessive demand exempt for opposite meaning.
A person who applied for Canadian permanent residence and who is sponsored by a Canadian citizen or permanent resident living in Canada who is eighteen years old or above. This includes spouses, partners, parents, grandparents and certain other relatives, but does not include fiancé(e)s. The state’s consideration of whether this person’s medical condition would pose an excessive demand on health or social services in Canada does not apply to this person as a reason for excluding her or him from Canada.

The United Nations Convention relating to the status of refugees signed in 1951, along with the Convention’s Protocol signed in 1967 (see http://www.unhcr.org/pages/49da0e466.html).


According to the Immigration and Refugee Protection Act (s. 38), an applicant can be denied Canadian permanent residence on public health grounds if Citizenship and Immigration Canada agents determine that she or he is likely to be a danger to public health or safety or that she or he might reasonably be expected to cause excessive demand on health and social services in Canada. Certain applicants are exempt from the excessive demand consideration, and these include family class immigrant applicants and refugees. This latter point is an important consideration in this dissertation.
<table>
<thead>
<tr>
<th>Health Management Branch (HMB)</th>
<th>The unit within Citizenship and Immigration Canada where medical officers, who are physicians, do the work of assessing medical files of applicants to Canada. Employees of this branch oversee the work of Designated Medical Practitioners.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immigrant</td>
<td>A person who moves to a country to settle. In this study, an individual who chooses to settle in Canada (see Immigration and Refugee Board of Canada, 2006, p. 4).</td>
</tr>
<tr>
<td>Immigration and Refugee Protection Act (IRPA) and Regulations</td>
<td>This is Canadian legislation that came into force on June 28, 2002. IRPA (S.C., 2001, c. 27). With the Immigration and Refugee Protection Regulations (SOR/2002-227), these texts govern immigration and refugee protection matters in Canada, including the immigration medical examination and health activities. These regulations are adopted under IRPA and are subsidiary to it. Such texts govern and regulate the lives of applicants to Canada and organize the work practices of applicant people, their lawyers, and government agents. Throughout this dissertation, I use the Immigration and Refugee Protection Regulations valid from April 1st to June 15th, 2011.</td>
</tr>
<tr>
<td>Immigration application</td>
<td>A documentary package comprised of many forms that a person who applies to remain in Canada must collect, compile, and submit for the review and consideration of Canadian government agents. In this study, standpoint informants’ work to fulfill the application requirements set out by the Canadian state is examined as a work process.</td>
</tr>
<tr>
<td>Immigration and Refugee Board of Canada (IRB)</td>
<td>An administrative tribunal of the federal government composed of four divisions that report to Parliament through the Minister of Citizenship and Immigration Canada. The IRB is independent of Citizenship and Immigration Canada and Canadian Border Services Agency. IRB agents make decisions that affect the lives of persons who appear before it at hearings, interviews, and reviews. With Citizenship and Immigration Canada and Canadian Border Services Agency, this tribunal constitutes Canada’s immigration and refugee system. Four divisions are the Refugee Protection Division, Refugee Appeal Division, Immigration Division, and Immigration Appeal Division (see <a href="http://www.irb.gc.ca/eng/pages/index.aspx">http://www.irb.gc.ca/eng/pages/index.aspx</a>).</td>
</tr>
<tr>
<td><strong>Immigration Medical Examination (IME)</strong></td>
<td>An encounter between the Designated Medical Practitioner and prospective immigrant through which the person’s body is examined against set criteria. The goal of the immigration medical examination is the detection of conditions that will guide state medical officers in their decision-making about an applicant’s “medical inadmissibility” (Gushulak &amp; Williams, 2004, pp. I-28-I-29).</td>
</tr>
<tr>
<td><strong>Immigration officer</strong></td>
<td>An employee of Citizenship and Immigration Canada who works in Canada and communicates with an applicant about the acceptance or denial of her or his immigration application. Equivalent work function to a visa officer, but who works within Canada.</td>
</tr>
<tr>
<td><strong>Interim Federal Health (IFH) Program</strong></td>
<td>A program managed by Citizenship and Immigration Canada that provides temporary health insurance to refugees, persons in need of protection, refugee applicants, and their dependents; persons who are in Canada, but who are not yet covered by a provincial or territorial health insurance plan. Standpoint informants who participated in this study colloquially called the official document issued to them through this program the ‘brown paper’. Often times, it serves as a refugee person’s only source of official identification until permanent residence status is granted.</td>
</tr>
<tr>
<td><strong>International Organization for Migration (IOM)</strong></td>
<td>An intergovernmental organization with one hundred and thirty two member countries established in 1951. Its purpose is to provide services to governments and non-governmental organizations on matters related to the migration of people. It works mainly with and through national governments and non-governmental organizations (see <a href="http://www.iom.int/jahia/jsp/index.jsp">http://www.iom.int/jahia/jsp/index.jsp</a>).</td>
</tr>
<tr>
<td><strong>Medical in/admissibility</strong></td>
<td>The state’s language to describe state agent decision-making about excluding an applicant for Canadian permanent residence based on three criteria: her or his likely danger to public health; likely danger to public safety; and, reasonable expectation of excessive demand on health or social services of the person’s identified medical condition. A concept within the <em>Immigration and Refugee Protection Act</em> (s. 38).</td>
</tr>
</tbody>
</table>
Medical officer

A physician employed by Citizenship and Immigration Canada to review medical files of applicants to Canada. This person assesses the medical files of applicants whose health is problematic against the three criteria listed above (see medical in/admissibility). The medical officer recommends to an immigration or visa officer, who is also employed by Citizenship and Immigration Canada, whether the applicant person should be in/admissible based on calculation of anticipated costs of care for identified medical condition(s).

Migrant

A person who moves across an international border for the purposes of settling, working, seeking protection, studying, or visiting. Immigrants, refugees, and temporary residents are examples of migrants.

Non-excessive demand exempt

A technical term developed by the Canadian state. This refers to the state’s consideration of whether an immigrant applicant’s medical condition would pose an excessive demand on health or social services in Canada applies to this person as a reason for excluding her or him from immigration to Canada. All persons other than family class and refugee applicants fall into this category. See excessive demand exempt for opposite meaning.

Operational Processing Instruction 2002-004

The document referred to in this dissertation as Canada’s HIV testing policy (CIC, 2002). Citizenship and Immigration Canada’s senior Health Management Branch medical staff authored it in July 2002, six months after mandatory HIV testing was introduced. It is among the tools that shape the work of Citizenship and Immigration Canada medical officers in their assessment work of an HIV-positive applicant’s medical file.

Permanent resident

A person who has been granted permission by the Canadian government to live permanently in Canada. This person has the same rights as a citizen with the exception of the right to vote. After living in Canada for a number of years (at this time approximately five years) the person might apply for Canadian citizenship. Economic, family, and refugee class are the three categories of permanent resident as outlined by the department of Citizenship and Immigration Canada. A prior term for permanent resident that remains in colloquial parlance is ‘landed immigrant.’
Personal Information Form (PIF)

An official form issued by the Refugee Protection Division of the IRB. Refugee applicants receive this form from government agents employed by either Citizenship and Immigration Canada or Canadian Border Services Agency. The text that a person writes into the form explains her or his need for protection from the Canadian state. The person fills out the form in triplicate, and submits it to the Immigration and Refugee Board of Canada within twenty-eight days of receiving it. While all applicants for Canadian permanent residence supply detailed, personal information when they complete their application forms, the PIF is only directed to and used by refugee applicants.

Refugee

A person who fears returning to her or his home country and who seeks protection from the government of another country (fear of persecution, cruel and unusual treatment, punishment). The definition in Canada’s Immigration and Refugee Protection Act reflects the 1951 Geneva Convention definition of a refugee (s. 96). Refugees can include government-assisted persons, privately sponsored persons, persons applying from within Canada to remain in the country, or dependents of persons making a refugee application. The state’s consideration of whether this person’s medical condition would pose an excessive demand on health or social services in Canada does not apply to this person as a reason for excluding her or him from Canada.

Anthropologists have suggested that the term ‘refugee’ embodies tensions created between concepts of hospitality and hostility; and between generosity and suspicion; where the latter often “wins out” to the individual’s disadvantage (Fassin & Rechtman, 2009, p. 273). The term as commonly understood today appeared at the turn of the 18th century (Marrus, 2002).

Refugee determination or adjudication hearing or interview

Colloquially referred to by standpoint informants as a ‘refugee hearing’. An event or series of events through which a member of the Refugee Protection Division of the Immigration and Refugee Board of Canada decides on an applicant’s refugee claim or application.

Temporary resident

A person who is authorized to enter and remain in Canada on a temporary basis, including visitors, foreign students, and foreign temporary workers.
United Nations High Commissioner for Refugees (UNHCR)

An agency of the United Nations that was established in 1951 that sets out to lead and coordinate actions to protect refugee people and resolve problems. Its stated purpose is to protect the rights of refugee people, and it works in over one hundred countries. Anthropologists who have studied this agency and the ruling relations in its organization observed that UNHCR is bound up with the politics and “power plays between states” (Fassin & Pandolfi, 2010, p. 14).

Visa

An official government document issued by an immigration or visa office(r) that is generally affixed inside a person’s passport.

Visa officer

An employee of Citizenship and Immigration Canada who works outside of Canada and communicates with an applicant about the acceptance or denial of her or his immigration application. Equivalent work function to immigration officer, only working outside of Canada.
Preface

In my former workplace at an AIDS (Acquired immune deficiency syndrome) service organization for women, I occasionally found myself listening in silence and keenly observing women refugee applicants living with HIV as we sat in the recreation room. Women talked about issues of concern to them, many of which were common to all: underemployment, financial insecurity, poor housing, obstacles bringing family members to Canada, and challenges with being alone or being single heads of households. There was much humour and irony in their stories. While all of the women were living with the human immunodeficiency virus (HIV), health concerns and the topic of HIV were rarely, if ever, directly broached in a group conversation. If the subjects did come up, it was likely by someone outside of the group of immigrant women of colour.

One summer day Patience Ngabo, whom I knew had been a doctor in her country, began to talk about her earliest days in Canada where she had lived for some months in a shelter. She was a tall woman and we were roughly the same age. (Had my skin been black or hers white, we could have passed for sisters). I listened attentively to her. I recall being surprised that a relatively affluent woman, albeit unemployed and alone in Canada, would need to reside in a shelter. I was curious about how Patience had come to live in these quarters, and I asked her to tell us about her experiences in this place. Patience thoughtfully responded that what was most memorable about the shelter where she had lived for a month was that it was there that she first suspected, and then learned, that she was living with HIV.

When she made this point, the half dozen women in the room, which included a Catholic nun, stirred. Only the nun and I looked directly at Patience. She explained that shortly after her arrival at a land border in Canada, she had been instructed to see an immigration doctor, which she did. He did a short examination composed mostly of a set of questions, and his nurse drew blood. The doctor told her that if there were problems, his office would contact her.

Patience said that approximately ten days later, a yellow ‘post-it’ note bearing her name and a hand written inscription: “Patience: Urgent. Contact the doctor” appeared on the shelter’s communal bulletin board. She quickly tore the note off the board. Since living in the shelter, Patience learned that the general chatter among residents, all people recently arrived in Canada from developing world societies, was that if a person received a call back from the immigration doctor’s office, then this signalled HIV. Patience said that her heart sank; she assumed the worst. The yellow announcement had made her feel exposed.

In telling us her story, Patience went on to make evaluative statements about her interactions with and treatment by the immigration doctor who tested her blood and

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1 Like all names and possible identifying information used in this dissertation, this is a pseudonym. See Notes to Reader at the beginning of this dissertation.
diagnosed her with HIV. Patience had been distressed about how brief the examination was. She was displeased about how little verbal interaction there had been with the doctor following his disclosure of her HIV-positive status. She had had a good deal of expectation about what the visit to the doctor could or should have involved. As an aside, Patience told us that in her country, people were encouraged to get tested for HIV, and a part of the process of such ‘voluntary’ testing was post-test counselling. Patience explained that she had walked away from her second visit to the immigration doctor with a slip of paper that listed the name of a hospital and bus line that would take her there. Patience was told to report to that hospital, which she did the same day.

Patience was the most assertive woman in the room during that particular summertime gathering, which might have reflected her training as a doctor. While she told her story of life in the shelter, immigration medical testing, and the experience of testing HIV-positive, which had come as a surprise and shock, we all maintained silence. Despite the distinct lack of talk, I noticed that several women in the group nodded their heads. Perhaps they had had similar experiences with this testing. After Patience had finished speaking, the conversation returned to other, lighter subjects.

It was a half-year later during university coursework that I learned that the practice of immigration HIV testing was part of a mandatory screening program to which immigrant applicants to Canada were subject. Patience’s story came to mind. I remembered the other women’s hushed reactions to her descriptions of her HIV testing experience. From the women’s stories, I gathered that some immigrants were diagnosed with HIV through the Canadian immigration medical examination, while other people knew of their condition before coming to Canada. Through the fieldwork for this study, and to my astonishment, I would discover that some applicants to this country are unaware that they are being tested for HIV at immigration. Still others just expect that HIV will be among the tests performed in a routine fashion, since, according to the understandings of immigrant and refugee people to whom I spoke, many countries impose HIV testing as a pre-requisite for immigration.

Despite the knowledge about immigration medical procedures that I had acquired from the women refugees, I had failed to notice or understand the obligatory characteristic of the testing: prospective immigrants could not opt out of being tested for HIV. I came to think of this as an important point because it meant that the test was carried out whether a person wanted it done or not. Added to this, though, I was concerned with people’s everyday experience with the HIV screening. I did not have a grasp on the everyday practices and details of what immigrants experience through the mandatory HIV testing. What was happening to people through the process and as a result of a positive diagnosis? Patience did mention how she learned that she had to undergo immigration medical testing. I would later conduct interviews with refugee applicants and I learned that medical screening is among the first steps that the Canadian government requires of them. Medical testing is evidently among the highest of government priorities.
I wondered what decision Patience would have made had she been asked whether or not she wanted to submit to an HIV test as part of her immigration process. She had been in Canada less than a week when she was tested, and under three weeks by the time she was told she was living with HIV. I began to wonder, what was it about immigration HIV testing that gave rise to the extremes of the women’s silence and Patience’s musings and consternation that summer day in June? How was HIV handled within a person’s immigration application process? What was life like for the applicant to Canada who was diagnosed with no choice in the matter? What activities did the HIV-positive immigrant have to engage in after diagnosis? What was known about the social organization of the institutional contexts in which people were tested for HIV, and the procedures, protocols and rules that operated therein? On testing positive for HIV, immigrant and refugee people enter into a complex of institutional and social relations. How does this work, and what does this complex look like from the inside?

As I would come to find out, mandatory HIV screening is a recent addition to the Canadian immigration medical examination. Its place within this examination has not been officially reviewed since before the policy came into effect. Those who enforce it have not reviewed the policy and practices associated with it. By all quasi-official and official accounts, which are few in number, the policy and its practices are functioning well. I wondered, functioning well for whom, in whose interests, and for what purpose? It was surprising (to me) that in an era of evidence-informed practice where there is emphasis on government efficiency, productivity and accountability, that there would not have been scrutiny about the functioning of this public policy. What logic prevails that sees immigrants submitted to a test that would be unlawful to impose on Canadians except by court order (Canadian HIV/AIDS Legal Network, 2007d)? What organizing rationale exists that sees an immigrant transformed into medical test results so that a negative calculation can be made about her or his in/admissibility to Canada?

All of these questions crystallized into one main research topic, which provides the title of this dissertation. The title reveals that in this study I question some of the assumptions that are embedded in the policy and under which the policy operates. For one thing, I do not take for granted that HIV screening of immigrants is necessary either for population health or disease control reasons. In my review of available information on Organisation for Economic Co-operation and Development countries, I found that most of these states do not operate a mandatory HIV screening program of prospective immigrants (Wiessner & Lemmen, 2010; Joint United Nations Programme on HIV/AIDS, 2011). How is it that Canada’s HIV immigration testing policy comes to be taken-for-granted as a routine feature of the screening of immigrants to this country? The policy is challenging to unpack precisely because it is normalized within the framework of things that ‘just happen’ to immigrants who apply to Canada.

In my fieldwork I was challenged by the discovery that immigrant and refugee people do not necessarily think twice about their submission to HIV screening for immigration
purposes, or the *mandatory* quality of having to be tested for HIV.\textsuperscript{2} For many people, the doctor’s visit is just one of many necessary and time-consuming administrative hoops through which they are required to jump in their desire to immigrate. A Latin American man whom I interviewed told me that through his immigration process, a foremost concern for him was not drawing attention to himself. He said that generally, he avoided asking direct questions of government officials. How, then, to dislodge the policy from its seemingly normalized position to investigate its functioning and the social organization of practices associated with it? How did immigrant applicants come to talk almost favourably, at least not disparagingly, about being tested, all the while lamenting about their experiences with the immigration doctor at the time of the Canadian immigration medical examination?

\textsuperscript{2} Brandis Anderson (2006) defines ‘voluntary’, ‘mandatory’ and ‘routine’ protocols for HIV testing. She explores arguments advanced by the proponents and opponents of each, examining how well they recognize and protect human rights. Anderson argues that protocols should not be used interchangeably (as they often are) because they each mean something different. Similarly, I respect the boundaries between the three protocols since they each have particular implications for people tested. They also have different policy and legal consequences. In this dissertation, I use these terms as defined in the *Glossary*. For related discussion on how HIV testing protocols have shifted since the 1980’s, see the Canadian HIV/AIDS Legal Network (2007e).
Chapter 1. Introduction
The purpose of this ethnographic study is to produce a detailed and contextual understanding and analysis of the social organization of the day-to-day world of immigrants to Canada who are tested for and found to be HIV-positive as a result of Canada’s mandatory HIV screening policy. Citizenship and Immigration Canada introduced mandatory serologic testing into the Canadian immigration medical examination by way of enacting a policy on January 15, 2002 (CIC, 2002; first page appears below), the full text of which appears as Appendix A1. The state’s policy and work practices of its state agents associated with the policy framework have never been publicly, systematically or critically investigated. Until this study, there was no empirically-informed, documented knowledge base for considering the ways in which the policy and its associated practices are organized and coordinated to shape the lives of persons who are diagnosed HIV-positive through mandatory immigration testing.

The starting point and perspective for this inquiry is the everyday activities and material practices of refugee and immigrant applicants who test HIV-positive through this medical screening process. These are the study’s standpoint informants, a term that I coined that on one level refers to this group of people, and on a second level, emphasizes that the research is anchored in their relevancies (DeVault & McCoy, 2004). I query, delve under the skin, and produce analyses about the social production and organization of standpoint informants’ doings. I do this by investigating the activities of those who maintain the policy, and those people who advise and work with refugee and immigrant applicants. This latter group of participants is called extra-local informants. The language choice seeks to emphasize that standpoint and extra-local informants are situated in different social locations. By virtue of this difference, participants have differing experience with and knowledge about the issues explored in this dissertation. In this study, I begin ethnographically. “That is, not with a theory but with a question that pokes into disciplinary corners and pockets . . .” (Tokarczyk & Fay, 1993, p. 3). The method by which I investigate the organization of events and social relations within the lives of standpoint informants is institutional ethnography. I explain the contours of this method later in this chapter.

This study is concerned with that which is troubling, apprehended, and experienced as contradictory for standpoint informants in relation to immigration HIV testing. During fieldwork in which I interviewed standpoint informants in Montréal and Toronto I discovered to what extent the immigration medical examination was a pivotal moment in their application process. Standpoint informants are troubled with the presence or

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3 In the methodological literature, the first references to extra-local are found in Dorothy Smith (1990b, pp. 1-11) and George Smith (1990).
4 Like these two authors do, I draw from anthropologist Clifford Geertz’s (1983) definition of ethnography that is thick description both in process and final product. The aim of ethnographic work is to “render obscure matters intelligible by providing them with an informing context” (p. 153).
**Operational Processing Instruction 2002-004**

**MEDICAL ASSESSMENT OF HIV POSITIVE APPLICANTS**

**Background:**

Applicants may be divided into two groups:

1. those who are Excessive Demand exempt (EDE), according to section 38(2) of the *Immigration and Refugee Protection Act* (IRPA); and
2. those who are non-Excessive Demand exempt (non-EDE).

EDE applicants who are HIV positive:

- should only be assessed according to public health and public safety health grounds for inadmissibility (IRPA sections 38(1)(a) & (b)).
- should NOT be assessed for excessive demands. Thus, examining physicians or medical officers should NOT request further tests to determine excessive demands, such as CD4 or pVL tests.
- are medically admissible if they meet health admissibility criteria of public health and public safety.

Non-EDE applicants who are HIV positive:

- should be assessed according to public health, public safety, AND excessive demands health grounds for inadmissibility (IRPA sections 38(1)(a)(b) & (c)).

When appropriate, examining physicians or medical officers should request further tests, such as CD4 or pVL tests, to help determine whether an applicant represents excessive demands.

**HIV Positive Non-EDE Applicants - Information Relating to Excessive Demands:**

Non-EDE applicants identified as being HIV positive should be asked to undergo CD4 testing by the examining physician. If an applicant’s CD4 count is less than 350 cells/mm³, antiretroviral therapy (ARV) is required in a Canadian setting and applicant will represent excessive demands. - see Annex A which includes the consultant report “HIV Infection in Applicants for Immigration to Canada”. If an applicant has a CD4 count above 500 cells/mm³, he/she should then be asked to undergo pVL testing. [Note: the consultant report refers to pVL testing for applicants with 500 cells/mm³, but this does not take into account what to do for CD4 counts 350-500.] Those applicants with pVL results over 55,000 copies/mL are not medically admissible, because they meet the current Canadian criteria for ARV treatment. If pVL testing is not available, then a second CD4 test should be obtained approximately two (2) months after the first CD4 test was taken – see #6 below.

Non-EDE applicants who are HIV positive are assessed on an individual basis in order to determine their demand on health and social services if granted entry to Canada. These
absence of certain practices, and they engage in a lot of work associated with their medical visit and broader immigration application process. Grounded in the concerns of standpoint informants, I investigated their day-to-day work activities and that of state agents as these activities relate to and stem from the immigration medical examination and the diagnosis with HIV.

I made everyday, seemingly routine and often taken-for-granted activities the loci of my inquiry. What do immigrant and refugee applicants with HIV face in the material circumstances of their lives in relation to their efforts to permanently reside in Canada? How is the medical visit and associated activities shaped to occur as they do? How is the organization of these linked to broader institutional and social and political contexts? Exploring these questions, always from within the concerns and contradictions experienced by standpoint informants, became the focus of analytic attention. Table 1 provides an overview of the project’s main components, and these are discussed throughout the rest of this chapter.

**Emergence of the study’s problematic and argument**

In institutional ethnography, a research problematic is a methodological term that signifies something different than a research problem as conventionally understood. In this form of research, the researcher uncovers the problematic after immersion in the field; it is not known in advance. The problematic directs analytic attention to sets of questions, “that may not have been posed . . . but are ‘latent’ in the [local] actualities of the experienced world” (D. Smith, 1987, p. 47). ‘Actuality’ is a methodological term that orients analytic attention to “a world of things, activity and experience that includes, but is not coterminous with, texts and language” (McCoy, 2008, p. 705).

In this way, I learned about standpoint informant problems with immigration HIV testing only through listening to their descriptions of the events of their lives. These points of tension, and in some cases contradiction, provided the study’s problematic. Standpoint informants described, often in detail and at length, features of their visits to the state-employed immigration doctor where they were screened for HIV. People talked about components of their visit that were challenging, troubling or bothersome. The central focus of this investigation became apparent through time, after critical reflection, and through a back and forth movement between the field and the literature. “[S]tep-by-step [as if] grabbing a ball of string”, I learned whom to interview, and what texts, narratives and discourses I needed to locate and examine to understand the problematic (DeVault & McCoy, 2006, p. 20).

The main argument developed in this dissertation is that the Canadian state’s ideological work related to the HIV policy and mandatory screening ushers in a set of institutional practices that are highly problematic for immigrants with HIV. The organization of the Canadian immigration process is under investigation so as to answer the following questions: How is this institutional complex organized? What is involved organizationally? How are the contexts governed? How is immigration mandatory HIV
testing organized, and with what consequences to HIV-positive applicants to Canada? I provide an empirical basis for this argument by making analytic use of data collected in interviews, focus groups, observations, and through textual analysis key documents.

The immigration complex in Canada is a text-mediated relation shaped by legal concepts that originate in Canada’s Immigration and Refugee Protection Act (S.C., 2001, c. 27) (hereafter IRPA) (Minister of Justice, 2001). These concepts shape the work practices of HIV-positive immigrant applicants, immigration doctors contracted by the Canadian government called Designated Medical Practitioners (DMPs), medical officers, and other state employees. Within the process, a critical moment is the result of an HIV test, which, if positive, catalyzes the collection of medical data about the applicant that are entered into decisions about the person’s in/admissibility for Canadian permanent residence. The basis for this decision-making is an official medical report produced by a DMP based clinical lab results. This report advances through the application process, passing through many hands, where all sites are connected by people’s work and the texts they circulate.

I focus on a key component of the Canadian immigration process, which is medical examination and HIV testing with this, along with the HIV test counselling practices that happen (or not) there. The reported absence of the latter form of care causes problems and contradictions for immigrant applicants living with HIV. Understandings are produced about 1) how people are diagnosed with HIV by the state, and how this knowledge enters into their immigration application process; 2) how the state’s internal medical in/admissibility work is organized and the ruling relations found there; and, 3) how the practices that occur (or not) in the immigration medical examination following an HIV-positive diagnosis are organized.

In this research, I worked to open and understand the organizational features of the federal state’s work apparatus around the diagnosis, management, and assessment of immigrant applicants living with HIV. I did this by focusing on the everyday work practices that DMPs do as they carry out the immigration medical examination of immigrant applicants. I also focused on the day-to-day work activities of medical officers and senior civil servants employed by the federal department of Citizenship and Immigration Canada. Standpoint informant work comes into view and is organized around the idea of immigration application work — a process that is shown to occur over time, require skill and planning, and which takes places across many sites. From my data, much (much) more can and should be said about the organization of immigration application work that standpoint informants engage in as part of their effort to remain in Canada. What I have done in this dissertation is focus on the events of the immigration medical examination and provide an ‘explication’ of what happens there.
<table>
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<tr>
<th>Table 1. Study overview</th>
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<tr>
<td><strong>Disjuncture</strong></td>
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<tr>
<td>Chasm between experiential versus authorized knowledge about what happens in relation to mandatory immigration HIV testing</td>
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<td><strong>Problemsitic</strong></td>
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<tr>
<td>The difficulties and contradictions experienced by HIV-positive immigrants with state practices occurring (or not) at positive diagnosis in immigration medical examination</td>
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<tr>
<td><strong>Goal</strong></td>
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<tr>
<td>Generate useful understandings about the social organization of HIV-positive immigrant and refugee people’s experiences with mandatory immigration HIV testing</td>
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<td><strong>Main objective</strong></td>
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<tr>
<td>Produce an explication in the form of an analytic report of how the problematic arises institutionally</td>
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<td><strong>Specific objectives</strong></td>
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<td>1. Stay within applicant’s knowledge of HIV testing so as to ground analysis in her or his everyday world of practice</td>
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<td>2. Learn about the policy framework and other key texts, situating these within broader social, political and ideological circumstances</td>
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<td>3. Investigate Canadian immigration and health systems, as textually mediated processes, fit together to rule people</td>
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<td><strong>Questions</strong></td>
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<tr>
<td>1. How is the Canadian immigration application process organized? What work do people with HIV do to immigrate?</td>
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<td>2. How is mandatory HIV testing organized? What are the consequences for applicants with HIV?</td>
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<td><strong>Sub-questions</strong></td>
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<td>1.1. What is happening in the daily activities of applicants for permanent residence who live with HIV?</td>
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<td>2.1. What does the HIV policy text tell us about its production and what it intends for the work of those who implement it?</td>
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<tr>
<td>3.1. What are the work practices of state agents (with associated others) who maintain the HIV policy?</td>
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Part of this work involved using established techniques from institutional ethnography to interrogate the work that comes into being and is coordinated by IRPA (appearing below) and its derivative texts such as the HIV testing policy and the *Handbook for Designated Medical Practitioners* (Minister of Public Works and Government Services Canada, 1992, 2003, 2009). Texts are understood to be central coordinators of people’s daily work, and as such, documents are important parts of this analysis. The concepts and terms that are given meaning and communicated in these texts are investigated for the ways in which they influence the day-to-day experience of informants. In this study, I analyze a variety of texts that people use in their work associated with the HIV testing policy. I examine these for what they reveal about the processes in which they are constituent parts rather than in isolation from what people do with them. The organizational features of the state’s work apparatus around HIV are shown to have consequences for the way in which HIV is constituted as an exceptional disease category and a moral state, with broader implications for how the person living with HIV is understood and processed by state agents employed by Citizenship and Immigration Canada.

I did not design this study to provide a theoretical critique of mandatory HIV screening of immigrants. Findings reported herein are primarily based within the material circumstances of people’s lives, and the arguments are empirically informed. There are larger and relevant questions that should be thoroughly investigated in relation to Canada’s mandatory HIV testing policy. While this study does not interrogate these, study findings could usefully inform such a project of research. For example, what is the fairness or adequacy of the financial reasoning and basis of which the Canadian state currently denies applicants with HIV (and other health conditions) permanent residence? How does HIV compare with other diseases and medical conditions for which applicants to this country are denied permanent residence on the basis on medical in/admissibility (such as cancers, heart disease, liver conditions, various forms of autism including Asperger’s, among others; on the latter health condition see Keung, 2011). Some of this critical investigation has begun (Coyte & Thavorn, 2010), and, it would be useful if research dating from some time ago in this area would be made current (Zowall et al., 1990, 1992). Findings from this study can usefully inform such important programs of critical research.

Study findings could also provide an empirical basis for an inquiry into a principle-based bioethics critique of HIV screening of immigrant applicants. In later sections of this dissertation, I point out the available critiques of the idea that mandatory HIV screening of immigrants is necessary from public and population health, financial, moral, legal, and bioethical points of view. While most of these critiques pre-date the introduction of the mandatory HIV testing policy in 2002, their findings and analyses remain of concern and inform this research.\(^5\)

\(^5\) I recently published an article challenging, through a human rights framework, the rationality and de facto necessity of Canada’s practice of mandatory immigration HIV screening of
Immigration and Refugee Protection Act

S.C. 2001, c. 27

Assented to 2001-11-01

An Act respecting immigration to Canada and the granting of refugee protection to persons who are displaced, persecuted or in danger

Her Majesty, by and with the advice and consent of the Senate and House of Commons of Canada, enacts as follows:

SHORT TITLE

1. This Act may be cited as the Immigration and Refugee Protection Act.

INTERPRETATION

Definitions

2. (1) The definitions in this subsection apply in this Act.

"Board"
« Commission »

"Board" means the Immigration and Refugee Board, which consists of the Refugee Protection Division, Refugee Appeal Division, Immigration Division and Immigration Appeal Division.

"Convention Against Torture"
« Convention contre la torture »

"Convention Against Torture" means the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, signed at New York on December 10, 1984. Article 1 of the Convention Against Torture is set out in the schedule.

"foreign national"
« étranger »

"foreign national" means a person who is not a Canadian citizen or a permanent resident, and includes a stateless person.

"permanent resident"
« résident permanent »

"permanent resident" means a person who has acquired permanent resident status and has not subsequently lost that status under section 46.

"Refugee Convention"
« Convention sur les réfugiés »

Context and questions

The Canadian immigration medical examination submits and subjects the bodies of non-citizens to medical diagnostic procedures first at blood, and if HIV is discovered, at cellular levels in the state’s pursuit of HIV. This medical inspection would be unlawful if exercised on Canadian citizens without their prior informed consent, with only highly specified, court-ordered exceptions (i.e., for examination of mandatory testing of immigrant applicants (Bisaillon, 2010c; Appendix G3). In this article I incorporate some of the problems and contradictions that standpoint informants reported experiencing as a result of being diagnosed with HIV through the immigration medical examination (see Table 14). I problematize the idea and claim that mandatory HIV screening of immigrants protects the health of Canadians by preventing spread of infection. I make four recommendations for addressing the central human rights problems associated with the HIV testing policy, including how to monitor immigration medical screening and the practices to which it gives rise.
health-care workers, compulsory testing of prisoners, and same following occupational exposure or assault see Canadian HIV/AIDS Legal Network, 2007d. For consent practices in relation to HIV testing see the Canadian HIV/AIDS Legal Network, 2007a).

Applicant immigrants for Canadian permanent residence are tested and singled out for a condition that is otherwise invisible and hidden: HIV is often devoid of palpable symptoms for up to a decade, and the virus is otherwise totally concealed at the level of the social (and possibly cellular) body. These are important points. The discovery of HIV totally redirects the life of the prospective immigrant person living with HIV who seeks to remain permanently in Canada, whether or not the person knew or suspected her or his serostatus in advance of undergoing the mandatory HIV test commissioned by the Canadian state.

The health condition and medical diagnosis carefully isolate a highly specific, not random, pathogen: the Canadian state’s hunt is precisely fashioned to uncover the secret identity and presence of a virus that has been likened by cultural critics to the ‘007 of viruses’ (Treichler, 1999). HIV occupies an unfortunately exceptional place in both the social and historic human imagination and in the way that people design and carry out policies and practices aimed at HIV/AIDS and people living with HIV. This is particularly the case in the collective social psyche (and practices) generally, and the epidemiological mind’s eye (and practices) more specifically.

The Canadian immigration medical screening intends the detection of HIV, and once located, enable the state’s singling out of immigrant applicants with HIV from other applicants. Prospective immigrants with HIV occupy and come to experience a distinct social location that is apart from other applicants, whether the latter are ‘healthy’, visibly disabled, diagnosed with a disease by standardized tests, unidentified as ‘sick’ by the DMP, or otherwise. The unique place in which applicants with HIV come to reside is evidenced in the empirical practices of government employees; the working documents produced for and used by the latter, and the range of government policies authored and enacted specifically for HIV; all of these are tailored to non-citizens living with HIV who apply to permanently reside in Canada.

**Discovery of a disturbing disjuncture**

My interest in this study began with the discovery of a discrepancy between what I knew of immigrant and refugee people’s accounts of and experiences with Canada’s mandatory immigration HIV testing versus the authoritative representations of these.

Throughout 2007, women such as Patience (described in the Preface) who had tested positive for HIV antibodies through Canadian immigration testing had described their activities related to immigrating to Canada to me. They told me about the particular place of HIV within their application process. They experienced chronic uncertainty about how their HIV was perceived by decision-makers. They suspected that HIV triggered particular activities and practices that HIV-negative people applying to Canada
did not face. They were aware of their difference that stemmed from their diagnosis. Through the women’s descriptions of the efforts they took to immigrate, I heard details of what happened to them and the steps they took as a result of an HIV-positive diagnosis. Within the women’s accounts were abundant descriptions of interactions with state agents employed by federal institutions of health and immigration. Women also outlined some of their relations with provincial institutions of employment and non-profit organizations funded through provincial and/or federal programs for women, people living with HIV, new immigrants, and/or combinations thereof.

Were refugee and immigrant people in other parts of Canada experiencing any of the same challenges associated with HIV diagnosis through mandatory HIV testing? I came to find out that some community-based research provided insight into the answer to this question. The Committee for Accessible AIDS Treatment (2006) in Toronto had inquired into what happens to refugee, immigrant, and undocumented persons during the immigration medical examination after an HIV-positive diagnosis. The Réseau des chercheuses africaines (Network of African Women Researchers; my translation) had investigated health, immigration, and legal issues facing francophone immigrant and refugee women in numerous cities across Canada (RÉCAF, ca. 2005). Results from both reports were familiar to me because they resembled stories HIV-positive women in Montréal had talked to me about. The following statements are attributed to informants living with HIV who participated in work led by researchers from the Committee for Accessible AIDS Treatment (2006).

[The doctor] called me, he said that there was a problem. He just told me [my HIV status]. I was depressed. I was shocked. I was in denial. So, it was like my head was going to like explode (p. 43).

What happened to me was, the doctor, he calls me, and on the phone he’s telling me, you’re HIV positive (p. 43).

In the same report, I read about an employee of an AIDS service organization in Ontario who reflected critically on her or his understanding of the work of DMPs and immigrant people’s experiences with mandatory immigration HIV screening.

It is mandatory already that they [DMPs] have to do the pre- and post-testing counselling, but it’s not happening and . . . It’s in the policy but it’s not happening. And, . . . there doesn’t seem to be anybody who is ensuring that it’s happening. So, whose [sic] overseeing these medical doctors to say, did pre- and post-test counselling happen? How did it happen and where were they referred to? And so, there needs to be some overseeing of that process. Because most of my clients say it didn’t happen. Or they got a phone call saying, ‘by the way, you’re positive’. And that’s it. And then they’re left with this news with no idea where to go. And then it starts them off with this feeling of going underground instead of sort of starting them off on the right note on where you can access . . . giving them some really
positive encouragement that . . . It starts off really bad. And then you’re picking up pieces for a long time. I think it should be mandatory that if they’re going to do the immigration medical then they need to know how to deal with immigrants, they also know about pre- and post-test counselling and they need to know where to refer them. That three things are very important (p. 44).

A woman living with HIV who was diagnosed by the Canadian state during the immigration medical examination told Réseau des chercheures africaines (ca. 2005) researchers,

RÉCAF : Vous a t-on fait passer des tests du VIH ? Et combien de fois ?

I : Je ne me souviens pas que l’on m’a [sic] dit a un moment donné du processus que je devais passer le test du sida. Je suis allée passer les examens chez le médecin que mon avocat m’avait recommandé c’est tout. Il ne m’a pas dit qu’il me passait un test de sida. Au pays je n’en ai pas passé non plus. Nous venions avec mes copines, je sortais de temps en temps avec un diplomate de l’ambassade du Canada là-bas au pays, c’est lui qui nous a refilé le visa sans problème et voilà ! (p. 64).

Another woman informant living with HIV told a Réseau des chercheures africaines (ca. 2005) interviewer,

RÉCAF : Vous a t-on fait passer des tests du VIH ? Et combien de fois ?

I : Ah oui, vous voulez savoir combien de tests j’ai passé. Ok . . . quand je suis arrivée ici, on nous a encore fait passer le test. La première fois ce n’était pas concluant. La deuxième fois mon agent [de l’immigration] m’a demandé d’aller revoir le médecin chez qui j’avais passé les tests.

RÉCAF : Est-ce qu’un agent de l’immigration vous a posé des questions relatives au VIH/sida ?

I : Oui, des questions relatives à mon état de santé; si j’avais eu des relations à risques; combien de partenaires j’avais; si je connaissais le statut sérologique de mon époux, etc. Je ne me souviens plus d’autres détails . . . [rires] Vous savez, demander à une femme qui s’est échappée d’un pays en guerre si elle a eu des relations à risque, il faut plutôt lui demander si elle a subi des relations à risques . . . c’est plus juste . . .

RÉCAF : Connaissez-vous votre état sérologique ?

I : [Silence et soupir] Oui, je connais mon état, je suis testée positive . . . [larmes]. Je croyais que j’étais épargnée quand mon premier test était négatif dans le camp
[de réfugiés]; arrivé ici, tous les tests qui ont été fait sont positifs . . . [les pleurs s’intensifient] (p. 55).

These firsthand accounts of people’s experiences with immigration HIV screening told a less straightforward, and significantly more difficult, puzzling and complex (and even hard to read) story with mandatory screening than the authoritative versions of what happened to people communicated. This disjuncture and dissonance of knowledge claims provided the early impetus for this study.

Contesting the claims of consent, counselling, referral
In 2006, an article entitled “Immigration medical screening and HIV infection in Canada” was published under the rubric “Original Research Article” in the academic journal *International Journal of STD and AIDS* (Zencovich et al., 2006; p. 813) (Appendix A2). The article ambitiously sets out to evaluate and report on the functioning of Canada’s mandatory HIV screening program in its first two years of operation. The article’s four collaborating authors, “senior medical staff” from Citizenship and Immigration Canada, matter-of-factly declared that, “all applicants were counselled [a form of pre- and post-HIV test service and care] and gave informed consent to testing” (Zencovich et al., 2006, p. 814). To this day, this is the only quasi-official, publicly available report accounting for how the policy is said to function from the point of view of the Canadian state. The disclaimer for the Zencovich article states that the “analysis” and “opinions” were “prepared in personal capacity” and solely attributable to the authors (2006, p. 813).

The report is nevertheless authoritative given the scholarly journal in which it is published. Additionally, the authors are state employees of the branch of government charged with enforcing the policy, managing the physicians who carry out the testing, and coordinating the work of medical officers who form a professional opinion on the health of applicants for Canadian permanent residence. By virtue of their social location as state actors, the authors had access to and use of state databases that track immigration HIV-positive test results. Another academic article published two years before that, whose lead author was co-author of the Zencovich article, claimed that the immigration HIV testing policy “focusses [sic] on identifying the disease to expedite counselling and referral to appropriate services” (Gushulak & Williams, 2004, p. I-29) (Appendix A3).

I was surprised to read the claims in this pair of articles. I wondered on what basis the authors informed its readers that consent, counselling, and referral practices were happening in the work practices of state agents. What is more, I knew that gaps between policy and what happens in practice in people’s lives relating to consent, counselling, and referral in the context of HIV/AIDS have been reported since early in the AIDS epidemic in North America (Canadian HIV/AIDS Legal Network, 2007b; MacPherson, 1993; Pomeroy, Sandry & Moldow, 1994; Williams, Terry, Strickland, Pheley & Raze, 1990).
The claim to consent, for example, could quickly be struck down: since early 2002, all applicants for permanent residence to Canada have no choice but to be screened for HIV as part of the mandatory immigration medical examination if they are intent on immigrating to the country. Thus, there is no meaningful informed consent process. The claims about counselling, in turn, were inexact, at worst, or in need of serious nuance, at best. The material circumstances of how things happen to people who are diagnosed HIV-positive through mandatory screening was neither as seamless nor as straightforward as these official, ‘scientific’ articles portrayed. Not only were the experiences of people I knew whose bodies had been subjected to mandatory testing dissonant from the author’s claims, the everyday workplace experiences associated with this HIV policy of health service providers such as nurses and social workers among whom I had also worked challenged the ‘scientific evidence’ presented in these articles (see Duchesneau, 2004; Lacroix, 2004a, 2004b).

Nurses and social workers, as well as others working with HIV-positive immigrant and refugee people in clinical settings, had spoken to me about increases in HIV-positive clients starting in January 2002. These workers had not been notified about the introduction of serotesting by the federal government. They were, however, obliged to address and accommodate the implications of this policy change, which included dealing with greater numbers of immigrant people with HIV who presented at HIV clinics and hospitals. Thus, there were grounds to investigate the third claim: that referral to specialty facilities such as HIV clinics was happening consistently, seemingly unremarkably, or without incident.

There was a whole world — if not universe — of activities, practices and actions within these three claims that was not accounted for in these reports. What was actually happening during and in association with the Canadian immigration medical examination for the immigrant and refugee person diagnosed with HIV? How come official accounts about HIV testing consent, counselling, and referral practices were at odds with people’s “lived experience” as I understood it from their stories (D. Smith, 2006, p. 224)?

For insights into the matter, I engaged in two exercises. First, I examined the methods section of the Zencovich et al. article. I learned that the authors reported on HIV-positive test results for the years 2002 and 2003 in numbers, distributions and rates of “HIV cases” by accessing Citizenship and Immigration Canada databases (Zencovich et al., 2006, p. 813). The authors’ discussion of results was articulated around and presented through the lens of IRPA categories. The HIV status of “immigrants”,

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6 On the choice of language and the term “lived experience” Dorothy Smith (2006) writes, “Institutional ethnographers sometimes refer to lived experience to locate those interchanges of awareness, recognition, feeling, noticing, and learning going on between body and the world that are prior to and provide sources for experience as it is evoked in dialogue” (p. 224; italics in original). Such an understanding and application is also used in anthropology (Finkler, 2007).
“irregular applicants”, “refugees” and “Convention refugees” were discussed along geographic and sex lines (Zencovich et al., 2006, p. 813). It occurred to me that this particular account “of the first two years of an active, immigration medical screening programme for HIV antibodies in applicants . . .” was disembodied (Zencovich et al., 2006, p. 814). The knowledge produced for the article was accomplished through numbers, texts, and formulae.

In her critique of language practices within sociology, sociologist Dorothy Smith writes that separating social phenomena from real human effort “suspends the presence of the subject” (1999, p. 59). Smith writes that this obscures people’s everyday experience, where suspension is achieved by using categories and linguistic devices that objectify people (see discussion on pp. 59 to 62). “Characteristic [of this process] are methods of representing people’s activities, talk, relations, and thinking without the subjects who act, talk, relate, and think” (D. Smith, 1999, p. 59). People do not directly appear in the two articles discussed here. Instead, immigrant and refugee people who live with HIV are abstracted, and their presence is inferred.

Second, I considered the social organizers of the Zencovich et al. article by looking into its reference section. There are seventeen references cited by the authors, and none of these make use of lived expertise or empirical evidence. There was no fieldwork done in the preparation of this article, either among people tested, health providers, DMPs, or other Citizenship and Immigration Canada medical personnel. Instead, the authors framed their analysis and reporting within epidemiological fact sheets, official statements, and conventions and protocols from four bodies of the United Nations plus the International Organization for Migration; legislation, official lists, regulations, statutes, operational bulletins, and epidemiological reports issued by three Canadian government departments; and, five articles jointly authored by two of the four authors that were published in medical, health, and international organization journals on the topics of infectious disease spread, health promotion, migration, and ‘risk’. The authors did not have empirical evidence to support their claims that consent, counselling, and referral practices were occurring in the work practices of state agents. Instead, the authors were informed by the state’s claims about itself and its work practices that these activities were occurring. Recent public education materials produced by Citizenship and Immigration Canada reveal that pre-test counselling for HIV is done “minimally” because HIV screening is a “mandatory test for immigration purposes” (CIC, 2011b, p. 7) (see Figure 1). This is consistent with standpoint informant experience, contrary to good medical practices, and in violation of CIC’s own guidelines on the matter (in particular see Minister of Public Works and Government Services Canada, 2009).
Anthropologists Mary-Jo DeVecchio Good, Byron Good and Jesse Grayman (2010) postulate that numbers matter when “arguing for particular policies . . . [And while] stories have tremendous power — to describe, to move, to provoke . . . any sense that statistics imply depoliticization . . . misses the power of numbers” (p. 258). I agree that statistics do not necessarily or inherently depoliticize. In fact, they can be actively used to politicize issues in particular ways. However, it remains that dominant approaches to reviewing policy rely on quantitative frameworks that use cost-benefit and regression analyses, among other tools (see Yanow, 2000). Starting in people’s everyday expertise of living, practicing, and engaging with the activities stemming from and regulated by public policy challenges conventional ways of thinking about the implications of policy. Such an alternative approach offers contextualized understandings from the perspective of those at whom public policy is directed.

Official reports communicate a certain type of knowledge about, in this case, the immigration medical examination and mandatory HIV testing. Accounts by health professionals in sources such as professional magazines, academic journals, and scholarly conferences carry weight. They are influential. But, they are not necessarily accurate portrayals of what happens for people. Such accounts are often generated through audits of people’s textual practices; a tick in a box beside ‘counselling provided’ becomes a counselling fact that then produces a set of statistics or a report about counselling practice. Although distanced from or possibly even at odds with empirical
events, accounts such as those outlined above nevertheless tend to stand as authoritative versions of happenings.

Left unchallenged, the Zencovich et al. (2006) and Gushulak and Williams (2004) articles present a certain form of knowledge and version of how things happen for people that enter into officialdom. These are reproduced over time and across place. For example, students and academics will refer to a report such as the one printed in the *International Journal of STD and AIDS* when they use it in reference sections of their articles destined for print in peer-reviewed journals. Such a report will be accessed via on-line holdings and virtual catalogues. For example, French- and English-language Google Scholar searches show that the Zencovich et al. (2006) article has been cited in fourteen peer-reviewed and grey literature publications since its publication (excluding my own). It will be used and activated by health and policy makers and practitioners in government offices all over the world. The findings from this article will be accepted as accurate portrayals and ‘evidence’ of what goes on in relation to the policy and practice of HIV screening of refugee and immigrant applicants to Canada. For example, the article is referenced in a recent ‘scoping review’ of policies and practices related to HIV testing and counselling of migrants in Europe (European Centre for Disease Prevention and Control, 2011). Through such examples of recursion and reproduction, certain forms of knowledge are foregrounded, while others are masked and possibly subjugated.

Since the Canadian immigration HIV test is mandatory and inscribed into the official practices of DMPs, persons tested, persons testing, and the Canadian public seldom reflect on it: practices associated with the test are taken-for-granted. Combined with the fact that HIV testing is normatively framed as good practice by health providers and medical professionals (De Cock, Mbori-Ngacha & Marum, 2002; see critique by Kehler, 2006), critical investigation of the policy and its organization is challenging precisely because of this normative position as a practice beneficial to individuals who are tested, and to the health of the Canadian general public.

The data and findings presented in Zencovich et al. (2006) and Gushulak and Williams (2004) are likely accurate from an epidemiological perspective. However, the dissonance between knowledge forms is problematic because the knowledge produced through them elides peoples’ experiences with immigration HIV testing. The authors are only able to tell a partial — and thus incomplete — story of the implications of Canada’s mandatory HIV testing policy on the organization of the lives of people whose HIV status is exposed. Left unchallenged, these accounts become accepted representations and ‘evidence’ that certain practices, procedures, and state advised ‘standards’ are happening in the material conditions of people’s practice. Herein lies the analytic entry point for this investigation. This study provides evidence of a different sort about what happens within the social organization of immigrant people’s experience as coordinated

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7 Findings in date of January 1, 2012. The authors of the Zencovich article have most often referenced the article in their subsequent publications.
in relation to Canada’s mandatory immigration HIV testing policy. It focuses on the experiences of people and humanizes and contextualizes knowledge; filling out the picture of what is going on.

**A critical approach to the social**

This study uses institutional ethnography to produce a “formal, empirically based scholarly” analysis of how standpoint informants’ experiences with immigration HIV testing are socially organized (Mykhailovskiy & McCoy, 2002, p. 20). The method of inquiry emerged during the consciousness-raising period of the North American women’s movement during the 1960s and 1970s. It is most commonly associated with the contributions of feminist Dorothy Smith who devised and developed the method that has been applied to investigate the construction of a wide variety of organizational processes (D. Smith, 1987, 1990, 2005, 2006; Campbell, 2003; Campbell & Gregor, 2004). These include, but are not limited to, professional expertise as a social relation (Mykhailovskiy, 2001); health management policy reform (Rankin & Campbell, 2006); management of nursing homes (Diamond, 1992); municipal decision-making (Turner, 2002); coordination of gay male high school student experience (G. Smith, 1998); and, educational systems and the work of single mothers (Griffith, 2006).

In this brand of ethnography, knowledge is framed as socially organized and relational. The project begins in the experiences and concerns of standpoint informants, and from within these, focuses analytic attention on the institutions of health and immigration in Canada. An understanding is that “experiential knowledge can facilitate a critique of prevailing institutional norms that may be contributing to the marginalization of groups or perspectives” (Orsini & Scala, 2006, p. 115). Social organization, defined more fully in chapter three, is the systematic coordination of social phenomena, “more or less mysteriously outside a person’s knowledge, and for purposes that may not be theirs” (Campbell & Gregor, 2004, p. 18). For example, health care and education programs depend on the coordinated actions of patients, management personnel, and family members to carry out programming and care in the home. University of Victoria’s Debra Brown (2006) described how the work of mothers is key to the success of “risk management strategies” initiated by child protection workers (p. 352). Yet, Brown found that the varied home-based work of mothers was not conceived as such in case files. Quite to the contrary: mothers were written up as objects of suspicion and scrutiny.

Brown’s work usefully illustrates the coordination of work practices and activities across different places and through time that is uncovered in research using institutional ethnography. Where activities occurring in these sites are investigated, in Brown’s study in the home and at the workplace, the connections and interdependency of institutional processes and sequences of action that would otherwise be understood as unrelated are made explicit. This is how institutional ethnography as a mode of investigation illuminates processes in which “[p]eople and events are actually tied together in ways that make sense of abstractions of power, knowledge, capitalism, patriarchy, race, the economy, the state, policy, culture, and so on” (Campbell & Gregor, 2004, p. 17).
Institutional ethnography tends to show us the trees that were hidden in the forest; once we can see the trees (ruling relations), they can never again recede. And once we can see the ruling relations, we can begin to interrogate and challenge them (Taber, 2010, p. 20).

In this study, investigating the social organization of knowledge relating to the HIV testing policy involved critically examining how and why the policy was developed, and explicating how certain forms of knowing about the policy relate to, replace, and undermine other forms of knowledge. The usefulness of this type of inquiry is that it leads to discoveries about how the work of institutions involved in maintaining and carrying out the mandatory HIV screening policy are connected in ways that are not obvious. These linkages organize the everyday activities and circumstances of refugee and immigrant persons living with HIV, and within this organization are puzzles, troubles and contradictions. In this way, we can intervene to change the effects of public policies in the *particular places* (rather than general, generic others) that are problematic for the people that are subject to them.

*Potential contributions of this study*

Engaging in critical social science research is not without challenges. One challenge is the idea that critical research is a criticism of individuals who come into view in the research. While this can certainly be a goal or a by-product of a study, it is my understanding that critical social scientists are usually concerned with understanding and exposing the taken-for-granted events and practices that constitute the social world we inhabit since they are interested in redressing inequalities, inequities and injustices through their work. It is the avid interest in making visible the implicit features of how contemporary society works that motivates critical social scientists to explore the lineaments of the social relations of power, patriarchy, capitalism, heterosexism, and inequities of all kinds.

In this study, I set out to document standpoint informants’ experiences with mandatory HIV testing. I mentioned that a detailed and systematic collection of people’s experiences had yet to be done. Bound up in people’s experiences with this testing are the work activities and ideological practices of a range of state actors and others employed in institutions of immigration health, and national health and legal systems. I took a deliberate look beyond people’s local experience with mandatory testing to critically examine the coordination and social organization of these experiences, as situated in the actions and activities of a range of extra-local informants: immigration health policy personnel, medical officers, health workers in clinical settings, state doctors, and so on. This particular focus allowed features of people’s personal experiences to be generalized beyond the site in which the experience occurred, thus entering the personal into the realm of the social and political worlds to which subjective experience is always connected.
This analysis unfolds from the perspective of immigrant applicants with HIV who are conceived of as expert knowers of their local worlds. In this study, I produce a knowledge base informed by empirical evidence collected by a variety of means. Standpoint informants’ bodily experience with immigration medical screening, and the accompanying work of successfully immigrating to Canada while living with HIV in which they engage, makes them expert knowers of how testing, diagnosis, and disclosure of positive test results occur. Standpoint informants’ knowledge base challenges conventional ways of knowing and speaking about Canada’s HIV testing policy (CIC, 2002). This provides an important and insightful counterweight to accounts relying on statistical data and authoritative reports; the basis of which are abstracted forms of knowing divorced from experience, such as the reporting in the pair of articles discussed above. This study breaks ground to produce new understandings about the social organization of the state’s work that is articulated around HIV and immigrants living with HIV from the standpoint of people tested.

The analytic gaze is on institutional processes and the ruling relations that exist both within and between organizational sites. The focus on making explicit the social nature and production of standpoint informant experience is especially useful because the most common terrain for social science research on and among people living with HIV has involved personal level and behavioural inquiries. I argue that research focused on making connections with broader social and political circumstances, work that seeks to understand how things happen as they do, is most useful to population health practitioners, communities of people living with HIV, and those who work with or on behalf of the latter; in juxtaposition to research that remains within people’s inner, emotive, and subjective experiences. In fact, an objective of this work is to produce knowledge useful to several audiences, including: refugee and immigrant people living with HIV; people who work with them in social, legal, and health services capacities; those who are invested in advocacy (and activism) on behalf of persons living with HIV; and, those who work in immigration health policy milieus inside and outside Canada.

My intent is to produce analyses and explications that can be presented to standpoint informants so that they can better understand the social organization of their activities related to their immigration medical testing, specifically, and challenges with their immigration application work process, more generally. As will become clear later in this dissertation, standpoint informants are most often unclear and unsure about how, as people living with HIV, their immigration application is being processed by the state. At the outset, I was interested in establishing a “scientific basis for the political strategy of grass-roots community organizing”, which can be achieved by making visible how things are put together, socially, to function as they do (G. Smith, 1990, p. 629). I was concerned with providing “analytic help for activists in thinking about and determining an effective direction for activism” (Campbell, 2006, p. 87; italics in original). In a similar spirit, Brown (2006) could use her findings, mentioned above, to inform activist work in child welfare since her research directs attention to the home-based work that mothers do to support children, showing how this work is mischaracterized in the textual work
practices of state agents. By shining light on mothers’ labour in support of their children, Brown establishes that their efforts are necessary parts of the success of the state’s health care and education programming. In uncovering and informing about the connections between domestic labour and its support of state programming, Brown’s work opens up specific places for intervention and change to take place.

At the same time, I am aware that “research that has not been commissioned by the organization and is not under its control may be seen as potentially disruptive of the smooth operation that it is aimed at” (Campbell & Gregor, 2004, p. 63). I wish to clarify that this study is not a critique of the individual actors involved in maintaining and carrying out the practices related to immigration HIV screening. Findings from this research offer insights into the ruling relations that organize and govern standpoint informants. It is of these latter arrangements and asymmetries that come into being in the coordinated actions and discursively organized practices of the state and other actors that I am critical. This said, findings from this project point to deficiencies in care and service that state agents deliver to immigrants living with HIV. These gaps create problems for standpoint informants. There is need for improvement in care and service to this population, and so a further practical intention of this work is to bring these deficiencies, located in policy, practice and process, to the attention of institutional actors within the federal department of Citizenship and Immigration Canada.

This study provides the following:

- Important corrective to the authoritative claims about the functioning and practices related to the HIV testing policy
- Empirical basis for nine evidence-based recommendations
- Theoretically-informed analysis of the consequences of the HIV testing policy
- Critique of inner workings of the medico-administrative practices regulating Canada’s immigration process
- Lines of future inquiry into the practices governing immigration to Canada, including the contradictory role of doctors working for the state and the troubling work practices they produce
- Knowledge in HIV-related social policy
- Insights into the interfaces between ruling practices and various forms of knowledge
- Methodological contribution about the organization of medico-legal governance in Canada
- Rich and compelling ethnographic repository of data to be mined

“Forward reflexivity”

Like any report, this dissertation is a social and historical construction. In this reflexive piece, I explore some social organizers of the approach I take since these coloured my investment with the issues and my understanding of the people who informed the project. In critically discussing the ethics and political aims of this research, I endeavour
to put into practice what feminist scholars Val Gillies and Pam Alldred (2002) call “forward reflexivity” (p. 49).

Interest in the issues investigated in this research grew out of my experience, academic training, and career prior to my return to graduate school in 2007. I discuss some of these to situate myself; a choice that joins with the work of feminist scholars who introduce themselves into the narrative as an explicit research decision. This is partly because in this way, there can be little confusion that a report is distinctly from somewhere if this is exposed (see Fraser & Nicolson, 1990). “[V]alidating what ‘I’ say is . . . different . . . philosophically [and] scientifically from validating what ‘the interviewer says’” (Angrosino & Mays de Pérez, 2000, p. 688). Redefining ethics “to encompass knowledge relations as well as the relations set up within the practices of research, collapses established boundaries between political activism and ethical feminist research” (Gillies & Alldred, 2002, p. 33).

In this dissertation, I draw from sociologist Laurel Richardson’s (2000) work on narrative styles in qualitative research and poststructuralist forms of ethnographic writing. Richardson writes, “[p]oststructuralism links language, subjectivity, social organization, and power . . . it directs us to understand ourselves reflexively as persons writing from particular positions at specific times” (pp. 928-929). Also, I adopt a writing style that keeps people visible. Richardson (2000) presents arguments in favour of qualitative researchers experimenting with “evocative” writing practices and reporting techniques (p. 931). One such mode is autoethnography where the writer relates accounts from her lived experience (Anderson, L., 2006; Naples, 1996; Taber, 2010, 2011). I use features of this strategy as a way of connecting the personal, institutional and social as relevant. “[E]vocative writing touches where we live, in our bodies . . . We find ourselves attending to feelings, ambiguities, temporal sequences, blurred experiences . . . “ (Richardson, 2000, p. 931).

Researcher standpoint
Bilingual undergraduate education in political studies and international relations equipped me with strong theoretical training. Graduate work in urban planning and population health was interdisciplinary, technical, and pragmatic in so far as both fields train students to be practically minded, focused on problem solving, and attentive to inequities. I worked as a social scientist in low-income settings to find solutions to people’s insecure land tenure and develop good quality housing for low-income urban dwellers in Trinidad and Senegal, respectively. Through this work I saw, learned and thought about the influences that law, regulation, policy and practice had on people and their immediate setting. All of these state tools linked — in complex, significant, and above all mysterious ways — the local and extra-local worlds in which I worked, and in which my colleagues were permanent members.

I was introduced to the Canadian AIDS organizational milieu in 2007 in my role as caseworker at le Centre de ressources et d’information sur la santé et sexualité in
Montréal’s east end (Health and Sexuality Resource and Information Centre; my translation). I managed the Réfugié Plus project (Refugee Plus; my translation) funded by the Public Health Agency of Canada’s AIDS Community Action Programme. The project aimed to support women refugee applicants living with HIV in their post-migration settlement.⁸ This experience was in many ways the catalyst for my return to school, my choice of graduate programmes, and the issues on which I decided to focus research attention. I will not soon forget the remarks made by several people to whom I spoke about my fledgling academic interests and work at le Centre de ressources et d’information sur la santé et sexualité. Among the most memorable, and I paraphrase from memory: Wouldn’t you rather work with people who are sick with ailments that are not of their doing? If there are not many immigrants with HIV admitted to Canada, why does their health matter? And, they aren’t even Canadians! They are lucky to be tested for HIV and to be seen by a doctor.

Dorothy Smith (2006) writes that one needs to “think organizationally” to conduct an institutional ethnography (p. 24). This orientation comes somewhat naturally to me in part because of a working class background that aligns me to some degree with certain experiences of working people. The essays by twenty-one women in Michelle Tokarczyk and Elizabeth Fay’s (1993) volume on women, class, and the academy explore how challenges posed by these three intersections formed “working-class women” contributors’ social consciousness in distinct ways (p. vii). The contributors develop new ways of thinking about class privilege and their particular social positions; about the use of language and theory in their everyday personal and professional lives; and, about the “renegotiation of one’s background as resource rather than as detriment” (p. vii). A strong subtext in this volume is the authors’ shared awareness, attributed in part to their working class roots that linked them, about life for people in marginalized positions. Awareness about and concern for persons in the margins were motivations for me regarding interest in this particular program of doctoral research.

The authors in Tokarczyk and Fay’s collection shed light on the workings of dominant institutions from their experiences and knowledge first outside and then inside the academy. In these essays, as in the work of Dorothy Smith, I recognized a quality that resonated with my thinking: concern for the tensions that people feel when their social

⁸ Unfortunately, the project fell short in many respects. In reading Roxana Ng’s (1988) PhD dissertation, which was an institutional ethnography of the social organization of immigrant women’s work opportunities, I gleaned clues as to possible institutionally organized explanations for the project’s, and host organization’s, shortcomings. I published a critique of the project, where the intended audience was the federal government (Bisaillon, 2008). I hoped that persons accountable for managing the AIDS Community Action Programme and programmes funded through it would take a responsible role in reviewing how le Centre de ressources et d’information sur la santé et sexualité actually organized its resources around supporting women immigrants with HIV. Unfortunately, this did not happen. Le Centre de ressources et d’information sur la santé et sexualité collapsed and closed in fall 2007, and I was its last employee.
experience happens differently from how the events of their lives are reported. Such ways of knowing are sometimes (if not often) organized in ways that are unhelpful to people who are socially disadvantaged. Like the women contributors to Tokarczyk and Fay’s collection, my ‘insider-outside’ (see Naples, 1996) knowledge about the workings of things in the AIDS milieu positioned me to know certain things about immigrants’ experiences with mandatory immigration HIV testing that were not accounted for in official accounts. This experiential knowledge placed HIV-positive immigrants (and me) on one side of what the late Canadian sociologist late George Smith (1990) referred to as a “line of fault”: the contested space between the inside and the outside of the “objective, bureaucratic domain of a politico-administrative régime” (p. 631).

In institutional ethnography, I identified concepts that I could use to begin to make sense of tensions stemming from these differing knowledge claims. These could be used to explore the social organization of everyday experiences of refugee and immigrant persons living with HIV who were new to Canada. Of particular interest was the theorized way of conceiving of the social as existing in the creation and coordination of people’s activities, as these occur in people’s interactions with and use of texts in their day-to-day existence. The following example is used to illustrate how documents are active coordinators of workplace activities. In this case, they mediated how my colleagues and I knew the refugee people on whose behalf we were mandated to work. This example is used to foreshadow how documents are conceived in institutional ethnography, and how I used them in this study as detailed in chapters five through seven.

Textual mediation of “gender-based violence” work with women refugees
In institutional ethnography, textually mediated social relations are understood to be central coordinators of people’s practice. What did this mean, exactly? What, in my experience, could give me the basis to explain this methodological idea in a straightforward way? I reflected on my role as Community Services Officer with United Nations High Commissioner for Refugees in three refugee camps in Djibouti in 2003. This is where and how I was first socialized with forced migrants, displaced persons, and refugee people outside of Canada, and where I became interested in and knowledgeable about the multiplicity of their standpoints and social locations. The chaos that characterized the management of this east African branch office was textually and discursively organized. Speaking to the point about chronic problems with the Djibouti operations, a United Nations High Commissioner for Refugees colleague working in Hargeisa, Somaliland exclaimed, “There is a spell over your Djibouti branch office!” While I did not do an institutional ethnography of the relations embedded in this workplace, I did report on some of the disorienting consequences of poor management on refugee people’s lives (Bisaillon, 2004a, 2007).

Had I had the opportunity to investigate the social organization and ruling relations of this office, I would have found traces of the 1951 Refugee Convention, the United Nations High Commissioner for Refugees Community Services Guidelines, job
descriptions, identity documents, and Djiboutian practices toward refugees (at the time far from clement to foreigners, and Ethiopian nationals in particular) in the day-to-day practices of our work. There would have been other influential texts and documents that were invisible to me in my everyday fieldwork, but that played themselves out in the ‘refugee management’ work practices of my United Nations colleagues and national government employees of the Office national d’assistance aux réfugiés et sinistrés (National Office for the Assistance of Refugees and Displaced Persons; my translation). Whether the staff of this United Nations High Commissioner for Refugees branch office realized it, textual paper trails organized what we did, how we knew what to do, and how most United Nations High Commissioner for Refugees staff knew the people who inhabited the camps.

At the highest level, the 1951 Geneva Refugee Convention structured our professional duties. Only the ‘authentic’ refugee in the sense of the Convention was entitled to be resettled to another country. Problematically, the determination process, which began with interviews with refugees, was conducted with well-intentioned officers who had limited training and exposure to local politics. A person’s referral for resettlement often triggered actions by agents of the International Organization for Migration that filled out paperwork on her or his behalf. How I was to carry out my duties was explained in the job description prepared at United Nations High Commissioner for Refugees headquarters in Switzerland. I was to provide services to refugee women, which included trying to assist women who were victims of “gender-based violence” (Bisaillon, 2004b).

As it turned out, United Nations High Commissioner for Refugees branch office management did not understand the term ‘gender-based violence’ or my terms of hire. This led not only to the progressive disintegration and unraveling of my professional role and purpose, but to a continued absence of programming on the ground to people who needed it. According to the Agency’s community services guidelines, supports should have been in place for people since the camps opened some thirteen years before. In reading institutional ethnographic fieldwork done outside of North America, I came to see that Ethiopian and Somali refugee women were conceptualized in ways that resembled sociologist Adele Mueller’s (1995) findings from her research in Peru. Taking the standpoint of Peruvian women, Mueller explored “the objectifying knowledge production procedures used by development practitioners and scholars to produce information about the category ‘women in Peru’” (Campbell & Manicom, 1995, p. 14). Mueller’s analysis showed how these knowledge-producing procedures were organized for the management of women’s lives from headquarters in distant countries, and she pointed out the problems this arrangement caused for Peruvian women.

In Djibouti, senior United Nations High Commissioner for Refugees branch personnel knew the approximately 23,000 inhabitants of the country’s three camps textually and discursively — by way of the staff’s periodic site reports; senior managers seldom visited the exceptionally hot, parched, and remote camps. Their visits coincided with those
made by senior United Nations officials from Europe or the ‘celebrations’ organized on the annual June 20th World Refugee Day, both occasions for photography, filming, and ribbon cutting. The decision-making processes mentioned above and the distance senior management maintained from refugees produced generally uncomfortable relations between management and refugee people.

Karen Jung’s (2000) institutional ethnography that illuminates the functioning of the University of Victoria’s disability policy from the standpoint of women students with chronic illness parallels the forms of knowing that I seek to bring forth through this example. In her research, Jung explores the efforts that women take to secure benefits under the terms of the institution’s disability policy. She uncovers that discourses and concepts such as ‘unfair advantage’ and ‘scepticism’ are assigned to women who apply for disability benefits. The activation of these concepts in people’s work practices (university administrators) contributes to the women having to demonstrate to management, time and time again through textual evidence, the nature of their disability. This was puzzling and problematic for the women university students.

Similar discourses to the ones identified by Jung coloured our work in Djibouti where the working environment supported a generalized suspicion of refugee persons. Like the women in Jung’s study, refugee people among whom I worked had to attest to their need for United Nations High Commissioner for Refugees protection in a climate that was socially organized to be distrustful of them and sceptical of their ‘authentic’ or ‘legitimate’ needs for resettlement.

**Dissertation organization**

This dissertation, presented in eight chapters, consists of the following:

Chapter **two** provides details about the activities involved in my review of extant research knowledge about immigration testing and HIV. I highlight and discuss findings. This includes providing an overview of what immigration HIV testing consists of and what is known about the purpose of this practice. Practices associated with Canada’s mandatory HIV testing policy are situated within a broader historical context of Canadian immigration medical screening. The origins and current authority for immigration health activities are discussed. Data on immigration and HIV in Canada are given, as is a brief look at the pathways through which standpoint informants in this study applied to Canada. In using the literature, I adopted three methodological techniques, and an overview of these closes the chapter.

Chapter **three** provides an overview of the method. The ontological, theoretical, and epistemological underpinnings of institutional ethnography are explained. Key methodological concepts are discussed. The chapter ends with thoughts on how and why this ethnographic method was a useful research strategy for accomplishing the aims of this project.
Chapter four is a detailed look at the study’s fieldwork. It describes my movement into, through, and out of field sites. Steps that I took prior to entering the field; recruitment of standpoint and extra-local informants; data collection and early analysis; and, techniques and strategies I used to work with the data are discussed. Some of the challenges that I experienced during fieldwork, and reflections on these, are also explained.

Chapter five is the first of the three empirical chapters. I do an archaeology and forensic unpacking of the diagnostic technologies used by the state to detect HIV infection and that it uses to rate the health of the immigrant person’s immune system. Two standpoint informants detail features of their experience with immigration HIV testing and activities stemming from this. An organizing discourse of standpoint informant immigration application work, the Canadian AIDS organizational milieu, is explored.

Chapter six spotlights the organization of the state’s work in implementing and maintaining mandatory HIV testing of immigrant applicants as a text mediated work organization. Three of the conceptual organizers of Canada’s Immigration and Refugee Protection Act that are influential on the day-to-day lives of standpoint informants are examined. The daily work practices of state agent’s medical assessment and determination process of applicants living with HIV are critically explored. The last sections of the chapter look critically at the HIV testing text for what it tells us about certain assumptions buried within it, and its production and projection into the work practices of state agents who are charged with implementing the HIV policy.

Chapter seven is the ethnographic and analytic heart of this dissertation. It presents a detailed look in a composite narrative form of what happens during the immigration medical examination as a central moment in standpoint informant’s immigration application work process. A myriad of activities and standpoint work forms are revealed. These are explored and explicated from within the experiences and activities of a standpoint informant named Anna. The chapter is framed as an interaction between Anna and a Designated Medical Practitioner named Dr. Geta.

Chapter eight is a discussion of the study’s findings. Ideological practices of the state associated with the HIV testing policy, coordinated under the Immigration and Refugee Protection Act, are noted to have negative and contradictory effects on standpoint informants. Assumptions and ideological notions about HIV infection enter into state work practices relative to the care and assessment of immigrant applicants living with HIV. How findings are relevant to standpoint informants, extra-local informants, and other actors is discussed. Thoughts on the method as a critical research strategy and several possibilities for future research bring this
study to a finish. The chapter, and dissertation, end with eight recommendations for future action on HIV and immigration in Canada.
**Chapter 2. Considering the literature**

The review of the literature was a reflexive process in a number of phases that extended from early 2008 to mid 2011. In this chapter, I provide details of the literature search and highlight activities and findings. I provide some details about what Canadian immigration HIV testing consists of, and I sketch out what is known about the policy’s rationale and purpose. I also provide data on immigration and HIV in Canada and outline how refugee and immigrant applicants are defined as per the categories established in the *Immigration and Refugee Protection Act* (S.C., 2001, c. 27) (IRPA). The chapter ends with a brief discussion about the three strategies I adopted to use the literature in ways that are consistent with institutional ethnography.

The earliest literature review I did on immigration and HIV was in connection with a major term paper for a graduate class in population health interventions. The goal of the literature review was to determine what was written and known on the subject of immigration and HIV in Canada and internationally. What was documented about people’s first-hand experience with state-initiated HIV testing?

**Early database searching**

During January 2008 I investigated the Canadian context for research on mandatory immigration HIV testing. I also looked at international academic and grey literatures on the same topics before turning attention to extant publications on entry, stay and residence restrictions for HIV-positive persons in domestic and international settings. Details of these searches are as follows:

**Canada**

2. Hand-searching at University of Ottawa Library and Concordia University Library collections.
3. Google Scholar English and French were also used. French keywords were *VIH, sida, dépistage, migration, Canada*.
4. Abstracts were screened and reviewed based on relevance to mandatory HIV/AIDS testing in the context of Canadian immigration. Articles that mentioned the following were reviewed: entry or residence visa, or related legislation; HIV testing or screening of migrants; and testing and/or counselling in relation to entry requirements.
5. Materials were reviewed, and key references were identified from bibliographies and followed up. Review of full-text articles limited to those available through

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9 This was later published as an article (Bisaillon, 2010c; Appendix G3).
10 See http://www.iasociety.org/AbstractSearch.aspx
University of Ottawa holdings and subscriptions, and those published open-access on the Internet.

6. References in most relevant documents were traced using the ‘related article’ feature in PubMed and the ‘cited by’ in Google Scholar (English only).

International

1. A second phase of searching similar to process and criteria outlined in 1 to 6, above. Keywords included: HIV, AIDS, screening, testing, migration, Africa, Asia, Caribbean, America, and Australia. English language search.

Extended search on mobility restrictions for people living with HIV

1. A third phase of searching similar to and building on processes and criteria above. Keywords included HIV, AIDS, screening, testing, migration, travel, residence. English language search.

2. Abstracts screened in and reviewed based on relevance to entry, stay and residence restrictions for persons living with HIV/AIDS. Articles were screened in and reviewed that mentioned the following: entry or residence visa, or related legislation; HIV/AIDS testing or screening of migrants; HIV-related stigmatization; migration-related stigmatization; perceptions of foreigners in relation to HIV or AIDS; and, testing and/or counselling in relation to visa, entry, or residence requirements (several additions from the Canadian and international searches, above).

A review of the grey literature during February and March 2008 piqued my interest in the social history of the policy’s introduction in Canada. I learned that the policy was introduced after protest from civil society groups that mobilized in the last years of the 1990s. The coordinated efforts of persons in these groups set out to educate state agents from the Canadian ministries of health and immigration about the ethical, legal, and human rights dimensions of federal decision-making relating mandatory HIV testing of prospective immigrants to Canada.

For purposes of coursework, I initiated six telephone discussions with Canadian-based academics, researchers, doctors, lawyers, and HIV and AIDS activists whom I identified as knowledgeable about immigration and HIV. These interviews led me to several unpublished reports and gave me some context to understand the organizing that had gone before the mandatory HIV testing policy came into effect in 2002. During this period I made email and list serve calls for information on immigration and HIV among researchers, people living with HIV, organizations working with gay, bisexual and transsexual persons, and organizations serving refugees and immigrants. These calls yielded additional reports that were not widely in circulation.

11 Two such listserves are Ethnoculture (http://www.ethnoculture.org/) and Coalition MultiMundo (http://ca.groups.yahoo.com/group/Coalition-MultiMundo/?tab=s) that are moderated in Montréal. I made a presentation outlining the contours of this research to members of the former group in early 2009.
Findings from this literature review revealed that my proposed inquiry was original since there were few sources documenting people’s experiences with Canadian immigration HIV testing. In addition, the policy had not been reviewed and little was empirically known about the settings in which prospective immigrants were tested. There was no clear public health goal or clearly stated rationale for the policy. I began to envision a study that involved opening up the historical timeline that pre-dated the policy’s introduction through a review of documents not in wide public circulation; research that would make use of discussions with key informants who had been involved in civil society organizing around the policy’s implementation.

Table 2. Themes from reviews of the literature

- AIDS and scholar activism using institutional ethnography (Herringer, 1998)
- Accounts of peoples’ experiences with immigration HIV testing in Canada (Committee for Accessible AIDS Treatment, 2006; Körner, 2007; Réseau des chercheurs africains, ca. 2005)
- Immigrants, and immigrants with HIV, in Canadian English-language newspapers, 1996 to 2004 (Bauder, 2008)
- Immigrant bodies and the politics of public policy in Canada, France (Barrère, 2006; Fassin, 1999, 2000, 2001)
- Screening foreign nationals with disease and disabilities (Wiebe, 2009)
- Restrictions on the mobility of people living with HIV and AIDS (UNAIDS, 2009a)
- Legal, ethical, human rights challenges of Canada’s mandatory testing policy (Hoffmaster & Schrecker, 2000; Klein, 2001)
- HIV testing among immigrants to Canada in medical literature (Mitra et al., 2006; Ouimet et al., 2008; Pottie et al., 2011)
- Health of refugees living with HIV in Canada in medical literature (Gilmore et al., 2007)
- Economic concerns associated with HIV-positive immigrants (Coyte & Thavorn, 2010)
- Canadian law and HIV-positive immigrants (Klein, 2001)
- Health, national security, and securitization (Ingram, 2008)
- Canadian immigration and health policy (Gushulak & Williams, 2004)

Later database searching

From February to spring 2011 I updated the literature search and consulted the thirteen databases (English, French) listed below. The general themes that emerged from early and later literature reviews are presented in Table 2. It came to my attention that scholarly attention to the issues of immigration and HIV has occurred in successive waves rather than consistently through time (Table 3).

1. ProQuest Nursing and Allied Health Source
2. ProQuest Dissertations and Theses
3. Sociological Abstracts
4. Persée
5. Érudit
6. BioMed Central
7. Canadian Newsstand Major Dailies
8. Google Scholar, français
9. Google Scholar, English
10. Canadian Health Research Collection
11. Canadian Public Policy Collection
12. PubMed
13. Conference Papers, Scholars Portal

**ProQuest Nursing and Allied Health Source**
Keywords: Canada, immigration, policy
9 sources, of which 2 were relevant to subject of dissertation

**ProQuest Dissertations and Theses**
Keywords: Institutional ethnography, HIV/AIDS
1 source, which was relevant to subject of dissertation

**Sociological Abstracts**
Keywords: Immigration, HIV, AIDS, policy, Canada, migration
15 titles, of which 6 were relevant to subject of dissertation

**Persée**
Key words: immigration, VIH, sida, politique
85 articles, of which 3 were relevant to subject of dissertation

**Érudit**
Key words: immigration, VIH, sida, politique
4 articles, of which 1 was relevant to subject of dissertation

**BioMed Central**
Keywords: Immigration, HIV, Canada
56 sources, of which 3 were relevant to subject of dissertation

**Canadian Newsstand Major Dailies**
Keywords: immigration, HIV, Canada, testing, mandatory, testing
21 documents, of which 18 were relevant to subject of dissertation

**Google Scholar, français**
Searches generated from the Canadian National Catalogue
Searches in: Medicine, Pharmacology, and Veterinary Science; Social Sciences, Arts, and Humanities; Biology, Life Sciences, and Environmental Science, Business, Administration, Finance, and Economics
Keywords: Immigration, VIH, dépistage, politique, Canada
From 2000 to 2010
177 titles; review of the first 100 titles, of which 5 were relevant to subject of dissertation

Google Scholar, English
As above
Keywords: Immigration, HIV, screening, testing, policy, Canada
From 1987 to 2010
6,970 hits
Reviewed the abstracts of the first 350
90 sources were relevant to subject of dissertation

Canadian Health Research Collection & Canadian Public Policy Collection
Keywords: immigration, HIV, Canada, government policy
2000+ sources to grey literature. Only first source was directly relevant to dissertation. I reviewed the first 24 dozen entries, of which 5 were relevant to subject of dissertation.

PubMed
Keywords: Canada, immigration, HIV, testing, policy, legislation
39 sources, of which 13 were relevant to subject of dissertation

Conference Papers
Keywords: Canada, migration, HIV
2 sources, of which both were relevant to subject of dissertation

Exploratory work
In fall 2008, I decided to investigate the social organization of the day-to-day lives of immigrant people with HIV associated with Canada’s HIV testing policy as the focus of my doctoral research. I was interested in conducting empirical, critical health research that carried the possibility of being relevant to prospective immigrant applicants living with HIV. Could findings from an institutional ethnography aimed at explicating how things were organized to happen for standpoint informants in relation to mandatory HIV testing be useful beyond my doctoral project?

To gauge this, I initiated numerous exploratory inquiries in the health and AIDS organizational milieus in Québec and Ontario from late fall 2008 to spring 2009 when I defended the dissertation proposal. By telephone and email, I contacted persons and organizations to explore where my research idea could hold relevance for people working in health and HIV milieu. I also had in mind that this early contact could serve to establish rapport with persons who might at a later date become research informants.
In total, I communicated with people working in ten organizations in Ontario and seven in Québec (Appendix B1).

Table 3. Trends in the literature on HIV and immigration

<table>
<thead>
<tr>
<th>Period</th>
<th>Overview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Late 1980s</td>
<td>Ethical critique of immigration HIV testing (Somerville, 1989)</td>
</tr>
<tr>
<td>Early 1990s</td>
<td>Cost-benefit analysis and comparison of heart disease and HIV among immigrants to Canada (Zowall et al., 1990, 1992)</td>
</tr>
<tr>
<td></td>
<td>Cost of testing immigrants for HIV (Angus, 1992)</td>
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<tr>
<td></td>
<td>Québec physicians on mandatory HIV screening of immigrants (Boyer et al., 1990)</td>
</tr>
<tr>
<td>Late 1990s</td>
<td>Justifiability of overseas medical testing of prospective migrants (Weekers, 1997)</td>
</tr>
<tr>
<td></td>
<td>Human rights critique of mobility and immigration restrictions for people living with HIV (Somerville &amp; Wilson, 1998)</td>
</tr>
<tr>
<td>Early- to mid-2000s</td>
<td>Ethical and moral (Hoffmaster &amp; Schrecker, 2000) and legal (Klein, 2001) critiques of mandatory testing and exclusion of prospective immigrants living with HIV</td>
</tr>
<tr>
<td></td>
<td>Legal critique of restrictive immigration policy implemented to bar applicants (Garmaise, 2003)</td>
</tr>
<tr>
<td></td>
<td>Mandatory screening of migrants in the United Kingdom as public health approach (Coker, 2006)</td>
</tr>
<tr>
<td>Late 2000s</td>
<td>Changing immigration patterns in Canada and infectious disease (Johnston &amp; Conly, 2008)</td>
</tr>
</tbody>
</table>

I met with five executive directors and frontline staff of AIDS service organizations in Montréal and Toronto during the period from January to March 2009 to discuss this research. A number of these people were interested in assisting in recruiting immigrant people living with HIV once ethics approval had been granted. The same persons expressed interest in participating in efforts to disseminate findings. Several persons brokered introductions to colleagues in appropriate agencies in the two provinces. For example, an employee at the AIDS Bureau of Ontario provided helpful contact information for persons in AIDS services organizations providing French-language services throughout Ontario. These names and contact information became particularly useful in informant recruitment phases, as detailed in the next chapter.

Findings and challenges
A first finding was that the topics of my investigation, immigration testing and HIV, provoked strong reaction among those people with whom I spoke. It seemed that everyone I spoke with knew someone with an experience with immigration HIV testing, whether positive or negative. People working in AIDS service organizations, persons
living with HIV, and legal personnel found that the topic of the proposed study had the opportunity to produce new knowledge; results of which could potentially be relevant in advocacy work on behalf of HIV-positive immigrant and refugee applicants in Canada. People in these organizations confirmed that, to their knowledge, little research had been done to document people’s experiences with mandatory testing. That the project set out to engage with policy makers, health providers, medical personnel, and a range of others, was identified as analytically useful because a full spectrum of actors would be drawn into the research and provide a fuller understanding of things.

The method of inquiry was largely unknown, and only one person, an executive director of a Toronto-based AIDS service organization, was familiar with institutional ethnography. I provided a brief explanation of the method, pointing out how it had been used in AIDS health work, gay men’s activism and organizing in Toronto specifically, and elsewhere in English Canada more broadly. People found particularly appealing the fact that the proposed ethnography was focused on social organization and knowledge relations rather than the emotive or inner experiences of immigrant people living with HIV in Canada.

A first challenge that I would need to reflect on and possibly contend with in the field was the fact that people living with HIV in Montréal and Toronto expressed concern about the frequency with which they were approached to participate in research. While people living with HIV found financial incentive for participation in research attractive, being objects of research posed ethical problems to others with whom I spoke. An employee of an AIDS service organization in Toronto commented that annually, February was a “particularly busy” because, he explained, there were “a dozen or so researchers” who approached the organization in the interest of researching among members living with HIV.

People working in AIDS service organizations with whom I spoke, particularly those in Ontario, were seasoned in the enterprise of HIV-related research. There are some highly professionalized AIDS service organizations that create and operate research boards through which proposals for projects in association with staff or clients are vetted. I

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12 Institutional ethnography has most often been used by researchers from the English-language realm, and results have most often appeared in English. The method has been introduced to the Chinese speaking world in the writings, research, and teachings of Professors Frank Wang and Li-Fang Liang of the National Chengchi University in Taiwan. Wang reports that to his knowledge, approximately six articles, one PhD dissertation, and six Masters theses have used institutional ethnography in China (F. Wang, personal communication, October 4, 2011). I identified one French-language article that was a translation from English (Harrison, 1997). In a discussion with Dorothy Smith in June 2010, she told me that francophone Swiss researchers were embarking on a translation of her Institutional Ethnography: A Sociology for People (2005). Smith discusses this in her interview with William Carroll (2010, p. 27). I was told that to her knowledge, this would represent the first use of her work in French (see http://www.unil.ch/webdav/site/labso/shared/1935_labso.pdf).
learned that in the last five years, and particularly in Ontario, there have been efforts to ‘empower’ immigrant and refugee people living with HIV (and others) by training and engaging them as peer researchers and co-applicants on funded projects. Through this exploratory work, I came into contact with discourses, concepts, and a world of language connected with the universe of HIV research that are evidently in common circulation in these milieus. Across all the sites of my preliminary investigations people recurrently used a number of concepts: ‘community-based research’, ‘participatory action research’, ‘action based research’, ‘ownership, control, access, possession’, the ‘meaningful and/or greater involvement of people living with HIV’. Many people with whom I spoke during this phase used these terms, and I came to see that they were organizers of how people did and understood their work.

A vivid example that illustrates this point is in a meeting that I had with staff representatives from three immigrant health organizations serving non-White populations. I had identified these persons and their organizations as potential key informants for later fieldwork because of their work with immigrant and refugee people living with HIV. I worked hard to secure an encounter because there appeared to be reticence to meet me. I explained my interest in the subjects of immigration, HIV and public policy, and I contextualized my motivation for conducting the proposed work. I was surprised to learn that the collective of people would work with me on the condition that I: structure the project within a community-based research framework and share data; list the individuals as co-investigators; have these persons “co-own results”; and, strike a community advisory board so that members could oversee the project.

In this one-hour encounter, I was advised about concepts such as ‘anti-colonial’, ‘anti-racist’, and ‘anti-oppression’ frameworks, and about ethical approaches to conducting research among people of colour who live with HIV in Canada. In the end, I did not follow-up with this group because I was both uncomfortable with, not to mention critical of, the approaches suggested. Among other things, these approaches did not suit the aims of the project I anticipated. For one thing, I had begun to recognize that the ideas and concepts activated during this encounter were part of the ideological language that I would work to unpack and understand in this project. The meeting was instructive and left a significant impression on me. It afforded me the opportunity to

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14 For information on the meaningful and/or greater involvement of people living with HIV, see the Joint United Nations Programme of HIV/AIDS policy brief at http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf
learn, first hand, about some of the discourses and ideas that circulate in the Canadian AIDS organizational milieu.

**Discussion of findings**

**What does mandatory immigration HIV screening consist of?**

Since January 15, 2002, all persons aged fifteen years and older who request Canadian permanent residence, such as refugee and immigrant persons, and some categories of temporary residence applicants, such as migrant workers, students, and long-term visitors from designated countries, are required to undergo HIV testing (Canadian HIV/AIDS Legal Network, 2007c, 2011a).¹⁵ Tuberculosis and syphilis are the two other conditions for which people are mandatorily screened, and applicants must ‘pass’ these before they are admissible for Canadian permanent residence.

Designated countries are selected by the Canadian state based on estimates of tuberculosis prevalence, and generally speaking, the countries on this list are of the global south. Foreign nationals from thirty-two of the thirty-four Organisation for Economic Co-operation and Development countries who apply for temporary residence do not submit to mandatory HIV testing (exceptions are for persons from the Republic of Korea and Portugal). All applicants who self-declare as having received blood products, and persons born to a mother living with HIV, independent of their age, also submit to HIV screening for Canadian immigration medical screening purposes.

Applicants to Canada undergo a physical medical examination carried out by physicians called Designated Medical Practitioners (DMPs) who are employed by Citizenship and Immigration Canada. The goal of the immigration medical examination is to “determine medical inadmissibility” (Gushulak & Williams, 2004, pp. I-28-I-29). Applicants to Canada can be tested in Canada or outside of the country, depending on where the person files an immigration application. For example, an applicant who is outside of the country is medically examined overseas. For the refugee class applicant who files an application in Canada, the person undergoes an immigration medical examination in the city of application. Figure 2 illustrates the various immigration application categories through which prospective immigrants apply to Canada. Much of the health information collected on applicants by the DMP is self-reported by the applicant, with the exception of the mandatory three tests listed above for which laboratory reports are produced. In this study, I spoke with people who had been medically examined in Montréal and Toronto. I also interviewed standpoint informants who had been medically examined by a DMP in foreign medical offices sanctioned by the Canadian state in Brazil, Kenya, Russia, and Sudan.

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¹⁵ For information about the Canadian state’s designation of countries and the current list of its designated countries, see http://www.cic.gc.ca/english/information/medical/dcl.asp. See also CIC, 2010b, p. 3.
In the following section, I elaborate on Canadian immigration medical practices. These activities are outlined and sanctioned in the *Immigration and Refugee Protection Act* (S.C., 2001, c. 27) (IRPA) and the *Immigration and Refugee Protection Regulations* (SOR/2002-227) (hereafter the Regulations) (Minister of Justice Canada, 2011) rather than in domestic health legislation (see Ries, 2005, pp. 7-37, and Bobinski, 2005, pp. 165-217). The authority for determining a refugee or immigrant person's in/admissibility to Canada on health grounds is vested in IRPA and the Regulations. There is no mention of HIV or AIDS in either of these documents.

**Figure 2. Immigration application categories**

![Diagram of immigration application categories]

**Authority for Canadian immigration health practices**

Immigration practices related to health issues are not a component of national health legislation in Canada. The rationale for this can be traced to the constitutional division of authority between federal, provincial and territorial governments. Under the *Canadian Constitution Act*, responsibilities for public health are not specifically assigned to a particular level of government, and “both levels of government may legislate in regard to public health matters” (Ries, 2005, p. 10). Within this organization, provincial and territorial governments “have authority over all Matters of a merely local or private nature in the Province” (Minister of Justice, Constitution Act 1967, s. 92(16)). This means that provincial and territorial governments have principal authority over health care and service delivery; they are vested with “public health legislation that establishes the powers of public health officials to carry out various functions including health hazard and communicable disease control” (Ries, 2005, p. 15). The federal government regulates several areas of public health, including who is allowed to enter and remain in the country, and on what terms people are granted entry and stay.

The medical screening of non-citizens and policies related to the screening, vetting, and exclusion of people wanting to immigrate to Canada pre-date Confederation in 1867.
The denial of permanent residence status to unhealthy people, including those with discernable disability, has been practiced for just as long. In fact, health-based refusals were practiced before health and immigration legislation and publicly funded health care service were ever in place in Canada.\textsuperscript{16} The country’s first immigration act came into force in 1869 and its organizing logic was to prevent the immigration of people with diseases or disabilities since they were assumed likely to be or to become state dependents. A selection of health conditions and disabilities were specified in this legislation. In 1906, the county’s second set of health laws related to immigration was introduced. What was new within this framework was the enumeration of medical diagnoses and disease labels. People with specific ailments were automatically excluded from being eligible for Canadian permanent residence.

From the beginning of the 20\textsuperscript{th} century until Canada’s third immigration legislation was passed in 1976, disease diagnosis and labelling determined a prospective immigrant’s in/admissibility. The 1976 immigration legislation abolished the inscription of specific disease categories. Instead, concern about prospective costs to the Canadian economy imposed by immigrant applicants became the explicit preoccupation of the federal government. It is here that the concept of ‘excessive demand’, a criterion against which applicant immigrants are weighed for the hypothetical, estimated public costs of caring for them, appeared. Writing of the post-1976 era, before the current immigration act was introduced, lawyer Judith Mosoff (1999) called attention to the Canadian state’s ideological practices regarding decisions about including or excluding people with disabilities.

Although the language [of the Regulations] has been updated in recent times, and the justifications for exclusion made more apparently rational, the same themes persist. The history shows that disability-based exclusions preceded the development of publicly funded health care and other important social programs in Canada [reference omitted]. Therefore, our current justification to exclude people with disabilities because they might draw too heavily on publicly funded health care or social services is really a new twist on an old policy that is based on even older stereotypes (p. 160).

With her statement, Mosoff invites us to think about what is embedded within an official text such as immigration legislation. She points out that devices and concepts inscribed in such influential frameworks infer social practices that are quite possibly communicated in successive versions. What does Canada’s current immigration legislation look like, and what are the guiding concepts situated within it that are relevant to this ethnography?

\textsuperscript{16} See my Ancestry of Canada’s HIV testing policy timeline at the beginning of this dissertation. Brian Gushulak (2010) recently published a brief overview of federal immigration health legislation and policies from pre-Confederation to the present. An illustrated timeline maps out a selection of these laws and policies. Mention of Canada’s mandatory HIV testing policy appears on page 16 of Gushulak’s report.
 Immigration legislation from 2001
In IRPA’s 99 pages and corresponding 326 pages of the Regulations, the rules by which foreign persons are to be governed and regulated in their desire to enter and remain in Canada are laid out. The documents set out detailed instructions for state control of people’s bodies before they arrive in Canada; while they are taking steps and waiting to come to Canada; and, when they are at border crossings with the United States. There are also instructions about state governance of people after they have arrived in Canada, including what procedures the state can take to have people removed.

The IRPA text stratifies people along the lines of how they seek to enter and remain in Canada. This creates legal groupings or categories of applicants, which in turn assign different procedures for state agents to do the work of processing them. This processing work is done through her or his textual representation in the form of an immigration application that each applicant works to complete. An immigration application constitutes numerous documents that vary according to various types of immigration categories listed in IRPA. Immigration lawyer Donald Galloway (1994) points out that immigration texts are fundamentally contradictory since their primary focus is the outsider, the non-citizen. The IRPA text responds differently to Canadian citizens and non-citizens, and its organization is structured by the global divisions of land into countries delimited by national borders. Galloway (1994) writes,

Immigration law has as its primary subject the stranger: the outsider who is under no obligation of allegiance to the state, who is not represented in its political processes, and whose needs and interests are, in most situations, accorded less concern than those of people who already participate in the social and political life of the community (p. 149).

In IRPA we read that there are three categories of permanent residence applicants, which are,

12(1) Family member: A foreign national may be selected as a member of the family class on the basis of their relationship as the spouse, common-law partner, child, parent or other prescribed family member of a Canadian citizen or permanent resident;

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17 “Regulations are a form of subordinate legislation that may be enacted and amended much more quickly than statues [i.e., the texts that are the various sections within the legislation]” (Ries, 2005, p. 18). IRPA and a set of immigration and refugee protection regulations came into effect in 2001. While IRPA has not been changed since, the Regulations have. For example, the Regulations were amended four times in 2010 and nine times in 2011. As stated in the Glossary, I use the Regulations valid from April 1st to June 15th, 2011. (They have since been amended. See http://laws-lois.justice.gc.ca/eng/regulations/SOR-2002-227/PITIndex.html)
12(2) *Economic immigrant:* A foreign national may be selected as a member of
the economic class on the basis of their ability to become economically
established in Canada;

12(3) *Refugee:* A foreign national, inside or outside Canada, may be selected as a
person who under this Act is a Convention refugee or as a person in similar
circumstances, taking into account Canada’s humanitarian tradition with respect
to the displaced and the persecuted.

A reading of IRPA shows that the state’s concerns about who enters and remains in
Canada are linked to the health of the country’s economic body, and the health and
safety of Canadian people. From the text we read that three important discursive
organizers of IRPA are the economy, health, and safety. It reads,

3(1)(a) To permit Canada to pursue the maximum social, cultural and economic
benefits of immigration;

3(1)(h) To protect the health and safety of Canadians and to maintain the
security of Canadian society.

The Canadian state is concerned about the risks to national security, incidence of
criminality, and averting threats that foreign citizens might present. In the IRPA section
appearing below, we see that applicants to Canada have the obligation to be truthful in
dealings with the state: in response to questions asked; in physical evidence produced;
in bodily examinations mandated by the state.

3(2)(h) To promote international justice and security by denying access to
Canadian territory to persons, including refugee claimants, who are security risks
or serious criminals.

3(16)(1) A person who makes an application must answer truthfully to all
questions put to them for the purpose of the examination and must produce a
visa and all relevant evidence and documents that the officer reasonably
requires.

The shape that the Canadian immigration medical program takes is also organized
around the discursive concepts of economy, health and safety. Table 4 indicates what
criteria structure how medical officers do their work (Minister of Justice, 2001). Section
38(1) of IRPA reads,

A foreign national is inadmissible on health grounds if their health condition,

(a) is likely to be a danger to public health;
(b) is likely to be a danger to public safety; or
(c) might reasonably be expected to cause excessive demand on health or social services.

Neither health nor safety is defined in IRPA or its subsidiary texts. A Citizenship and Immigration Canada (2010) educational document indicates that active tuberculosis and untreated syphilis are, “practically, two conditions considered to be a danger to public health” (p. 12). Conditions that pose danger to public safety are, “practically, some psychiatric conditions, and drug or alcohol addiction” (p. 12). This document also reports that, “very few cases [are] deemed inadmissible for public health or safety reasons” (p. 13). In contrast, people who are denied Canadian permanent residence because of an ‘excessive demand’ rationale “represent the vast majority of inadmissibility on health grounds. Applicants deemed inadmissible under health grounds represent less than 1% . . . of all IMAs [immigration medical assessments] done annually” (p. 13).

All people who apply for Canadian permanent residence must undergo an immigration medical examination carried out by a DMP in Canada or outside the country, and the authority for this activity and its constituent practices are located within IRPA. Citizenship and Immigration Canada agents do the work of medically assessing all people who apply for Canadian permanent residence, and this work is done with varying levels of scrutiny.

Table 4. For what is the state searching?

[A]n officer who is assessing the foreign national’s health condition shall consider (a) any reports made by a health practitioner or medical laboratory . . . and:

**Danger to public health**
31(b) the communicability of any disease that the foreign national is affected by or carries; and, (c) the impact that the disease could have on other persons living in Canada

**Danger to public safety**
33(b) the risk of a sudden incapacity or of unpredictable behaviour of the foreign national that would create a danger to the health or safety of persons living in Canada

**Excessive demand**
34(b) any condition identified by the medical examination

Both the IRPA category into which the applicant is organized by the text and her or his health or medical conditions mediate how much attention the person’s file garners by these state agents. Not all applicants will be judged eligible for Canadian permanent
residence on the basis of medical findings and evaluation. From the Regulations (SOR/2002-227) we read that,

20). An officer shall determine that a foreign national is inadmissible on health grounds if an assessment of their health condition has been made by an officer . . . and the officer concluded that the foreign national’s health condition is likely to be a danger to public health or public safety or might reasonably be expected to cause excessive demand.

Three significant changes in policy and practice
For purposes of this analysis, there are three important differences between IRPA and the previous Canadian immigration legislation dated 1976. These changes directly shape the organization of standpoint informant immigration application work. These are briefly discussed.

First, the state introduced HIV testing as a pre-condition for immigration. Since 2002, a wide range of state texts instruct and inform government agents in their work on applicants who live with HIV who apply for Canadian permanent residence. For example, the documents that appear in Table 10 (see chapter four) are either directly about HIV, or sections within these are specifically applicable to HIV and persons found to be living with HIV. This list testifies to a detailed government work apparatus specifically tailored to and organized around HIV and applicants who live with HIV.

The creation of and organization into categories of people exempted from exclusion to Canada because of their medical condition was a second significant change. The health conditions of an applicant are examined differently by the state according to the immigration category into which she or he is organized. Refugee and family class applicants will not be assessed will be excluded because of the anticipated expenses that their medical condition is expected to impose on public systems of health. Economic class applicants, on the other hand, will be.

Most standpoint informants I spoke with in this research could not normally have be denied Canadian permanent residence for hypothetical cost reasons related to their HIV-infection since most people I talked with were sponsored family members or refugee class applicants. Official reports indicate that Citizenship and Immigration Canada medical and immigration or visa officers do not exclude sponsored family members and refugees for estimated ‘excessive demand’ because IRPA,

[R]ecognizes that certain immigrant groups have compelling humanitarian and compassionate reasons to enter Canada, and thus facilitates immigration processing by exempting these groups from excessive demand assessment (Government of Canada, 2002, p. 202).
According to IRPA (s. 38), these exceptions apply to a person, who has,

(a) been determined to be a member of the family class and to be the spouse, common-law partner or child of a sponsor within the meaning of the [R]egulations [Immigration and Refugee Protection Regulations, SOR/2002-227];
(b) applied for a permanent resident visa as a Convention refugee or a person in similar circumstances;
(c) is a protected person; or
(d) is, where prescribed by the regulations, the spouse, common-law partner, child or other family member of a foreign national referred to in . . . (a) to (c).

The third and last change of significance to this analysis was the formulation of a definition of ‘excessive demand’. This provides the frame within which Citizenship and Immigration Canada medical, visa, and immigration officers do their work in deciding whether an applicant can be denied Canadian permanent residence because of her or his medical condition (Government of Canada, 2002). According to the Regulations (SOR/2002-227), the current definition of ‘excessive demand’ is,

1(a) a demand on health services or social services for which the anticipated costs would likely exceed average Canadian per capita health services and social services costs over a period of five consecutive years immediately following the most recent medical examination required by these Regulations, unless there is evidence that significant costs are likely to be incurred beyond that period, in which case the period is no more than ten consecutive years; or

(b) a demand on health services or social services that would add to existing waiting lists and would increase the rate of mortality and morbidity in Canada as a result of an inability to provide timely services to Canadian citizens or permanent residents.

The Immigration and Refugee Protection Regulations (SOR/2002-227) tell us,

The cost threshold is determined by multiplying the average Canadian per capita health and social service costs by the number of years used for the assessment window of the individual applicant. This per capita cost is published annually by the Canadian Institute for Health Information and will be used to update the cost threshold calculation (Government of Canada, 2002, p. 203).

Citizenship and Immigration Canada reports that its medical officers currently do their medical in/admissibility work with the understanding that the “average Canadian per capita health and social services costs” is $5,505 per annum (Coyte & Thavaron, 2010, p. 10). The resources that Citizenship and Immigration Canada medical officers currently use in their work are reported in Figure 3 (CIC, 2010b, p. 15).
The HIV testing policy’s official (and inferred) purpose
The “Operational Processing Instruction 2002-004: Medical Assessment of HIV Positive Applicants” document is the state’s framework for assessing the medical file of people who apply to reside in Canada who live with HIV.

Figure 3. Cost determination for required services

In this study, this text is what is referred to as Canada’s HIV testing policy (CIC, 2002; Appendices A1 & D4).\(^{18}\) Operational processing instructions are adopted by the department of Citizenship and Immigration Canada under IRPA. They are designed to inform and instruct the work of state agents called medical officers whose work consists of evaluating medical files of applicants to Canada.

Prior to April 1991, it was federal government policy that people living with HIV should not be allowed to visit Canada because they represented a threat to public health. After 1991 in Canada, the official federal policy position towards short-term visitors with HIV changed, whereby people living with HIV ceased to be considered dangerous to public health or safety by virtue of their HIV status (Canadian HIV/AIDS Legal Network, 2011a; see Klein, 2001, pp. 11-12). “... [A]symptomatic HIV-positive people entering Canada for a short term visit (less than six months) should not be denied entry or

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\(^{18}\) Two readers of this dissertation asked whether the policy number should read 2002-2004, or whether there were other instructions in the same family, perhaps labelled 2002-003 or 2002-005. I queried this point with a senior Citizenship and Immigration Canada informant who indicated that this is the correct name of this policy (personal communication, September 23, 2011). There are no other texts in this grouping.
encounter trouble at the border because of their HIV status” (W. Bartlett, 1994, in Klein, 2001, p. 11). Prior to the introduction of the mandatory HIV testing policy, activists in the Canadian HIV/AIDS Legal Network opposed to mandatory testing and exclusion of prospective immigrants living with HIV issued the following “Urgent Action Alert” as part of the public pressure and letter-writing campaign, details of which are given in chapter five (see http://www.iglhr.org/cgi-bin/iowa/article/takeaction/partners/792.html).

Persons with HIV are not a threat to public health and safety. Unlike many other infectious diseases that could threaten the Canadian public, HIV is not transmitted through casual contact. Government policies, such as mandatory screening, provide only an illusion of safety for preventing HIV, which is transmitted through very private behaviours (J. Dussault on behalf of the Canadian HIV/AIDS Legal Network, October 3, 2000; on file with author).

Indeed on the matter of state-imposed immigration HIV screening providing an “illusion” of reduced chances of contracting HIV infection in Canada, Houde et al. (2010) write of some “unintended side effects” of Canada’s immigration medical screening and the HIV screening within this (p. 35). One such side effect is suggested in the following excerpt where youth of African descent in Windsor, Ontario, perceive that Canada excludes prospective immigrants who do not have “a clean bill of health”.

Both male and female participants felt they were less vulnerable to HIV in Canada [as opposed to their country of origin] . . . Participants generally agreed that the Canadian immigration service only awards visas to migrants who have a clean bill of health (Omorodion, Gbadebo & Ishak, 2007, p. 434).

The Canadian HIV testing policy text states, “HIV infection is not considered a reason for non-admittance [to Canada] on grounds of public health” (CIC, 2002, p. 1). An applicant for Canadian permanent residence who lives with HIV will be assessed for anticipated public costs for a ten-year period because of the likelihood that she or he will need to take antiretroviral medication within the first decade of infection. Standpoint informant experiences with immigration HIV screening shed light onto the actual workings of the activities that are enacted as a result of the policy, and these are detailed in subsequent chapters.

The Canadian state has never formally articulated in writing the goals of Canada’s immigration HIV testing policy. Indeed, Figure 4 shows that Citizenship and Immigration Canada educational materials about the rationale or “principles” on which the state’s testing policy rest are confusing (CIC, 2011b, p. 6).

However, we can infer the intent of the HIV policy from close reading of the policy text, government publications, and authoritative texts such as those discussed in the previous chapter. It is problematic that public policy goals are inferred not explicit if we accept Lawrence Gostin and Jonathan Mann’s (1999) position that: to be understood and
effective, public health goals must be clear and specific. According to the two authoritative reports critiqued in chapter one, Zencovich et al. (2006) and Gushulak and Williams (2004), Canada’s mandatory HIV testing policy is ostensibly in place for disease prevention purposes. Public health authorities generally frame HIV screening, and HIV testing for immigration purposes specifically, as prudent. Citizenship and Immigration Canada researchers Douglas MacPherson, Militza Zencovich and Brian Gushulak (2006) (hyperbolically) reported an “emerging paediatric HIV epidemic” among selected migrant children tested for immigration purposes in Canada from 2002 to 2005 (p. 12). The authors invoke disease prevention as a rationale for carrying out mandatory HIV screening within the Canadian immigration medical examination.

Figure 4. Principles animating Canada’s HIV testing policy

There are, however, less restrictive practices than mandatory immigration HIV testing to pursue disease prevention goals. These include, but are not restricted to, opt-in testing where people are given the choice to be tested for HIV (Hanssens, 2007; Hoffmaster & Schrecker, 2000).

Second to the disease prevention argument for maintaining immigration HIV testing is the rationale organized around notification, reporting, and programme management (Zencovich et al., 2006). Senior Citizenship and Immigration Canada medical personnel, along with a university researcher cross-appointed to the state, postulate that Canada’s immigration HIV testing program is “unique” because it is not predicated on the exclusion of would-be immigrants living with HIV (Zencovich et al., 2006, p. 813). These author’s cite health promotion and disease prevention among the aims of Canada’s HIV testing policy. They write that the “purpose of the policy was for health promotion and counselling interventions to mitigate public health risk of HIV and for health protection
of the applicant” (Zencovich et al., 2006, p. I-28). Both the claim about the policy’s ‘uniqueness’ and its aims can be refuted from reading the policy document, considering the IRPA text, and from field results from this research. Revealingly, Brian Gushulak and Linda Williams (2004), senior medical personnel associated with Citizenship and Immigration Canada medical personnel, comment about the benefit of using the Canadian immigration medical examination for national health planning purposes “rather than only identifying conditions that could bar admission” as is currently policy, law, and practice (p. I-28).

The above-noted claims about disease prevention and health promotion as explanations for the HIV testing policy that Zencovich et al. (2006) forward must be looked at critically and problematized. Plainly said, what is not stated in the Zencovich et al. (2006) article, but what is true in policy, practice and law, is that the basis for government decision-making for rejection of an applicant with HIV is cost containment.

We also understand that Canada’s mandatory HIV testing policy and the topics of immigration and HIV are situated within larger, complex debates about economics, public health ethics, human rights, and migration, among others. Certainly, uncovering the interests that are bound up within the policy and its practices are complicated. Geographer Alan Ingram (2008) traces the presence of what he terms a contemporary “collision” between immigration and HIV and AIDS in the United Kingdom (p. 877). He examines the politics of immigration and HIV by examining what he calls the “reactionary press coverage that influenced policy formulation and judicial rulings” for a decade from 1997 in the United Kingdom (p. 875). Ingram argues that Western states have politicized HIV and immigrant and refugee applicant populations as security issues, which he finds has reduced chances for many who are “caught in the wrong place at the wrong time” (p. 875). I contend that debates and assessments of Canada’s mandatory HIV screening policy must take into account the uncomfortable tensions that HIV and the policy text raise at political and social levels, including the rhetoric related to global health and safety, population mobility, and cost containment (Bauder, 2008; MacPherson, Gushulak & Macdonald, 2006; McKay et al., 2003; National AIDS Trust, 2008; Smith & Easterlow, 2005; Stauffer, Kamat & Walker, 2002; Woodsworth, 1972; Worth, 2006).

Data on immigration and HIV in Canada
The overall number of HIV-positive applicants admitted to Canada is small relative to the population increase through immigration and the resident population living with HIV (despite exaggerated media reports suggesting the contrary, as per Kaufmann, 2008). According to the most recent national epidemiological reports, an estimated 65,000 persons were known to be living with HIV and AIDS in Canada in 2008, of whom twenty-six percent were unaware of their infection (Challcombe, 2010; Public Health Agency of Canada, 2008, 2010a, 2010b). Between 2001 and 2006, more than one million new immigrants settled in Canada whose current population is approximately 31.2 million
persons. Statistics Canada (2006) estimates that approximately one in five persons resident in Canada is foreign-born.

Most permanent residence applicants with HIV who have been admitted to Canada since the mandatory HIV testing policy came into effect are persons between the ages of twenty-six and forty-five years of age who are from Africa and the Middle East (CIC, 2010a; Falconer, 2005; Réseau des chercheures africaines, ca. 2005). In her research on the history of medical screening technologies in Canada, Sarah Wiebe (2009) found that every year “2,000 visa applicants [to Canada] are rejected on health grounds” (p. 135). Table 5 shows that since mandatory HIV screening was introduced in 2002, 4,374 persons have tested HIV-positive during immigration procedures, of which 453 persons were inadmissible to Canada based on the state’s anticipated cost of their future care (CIC, 2010a).

Table 5. HIV-positive test results in Canadian IME, Jan. 2002 to Mar. 2010

<table>
<thead>
<tr>
<th>Application category</th>
<th>Admissible</th>
<th>Inadmissible</th>
<th>Totals</th>
<th>% of all applicants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Convention refugees</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refugees</td>
<td>1,176 (30.0)</td>
<td>8</td>
<td>1,184</td>
<td>27.1</td>
</tr>
<tr>
<td>Family class</td>
<td>1,635 (41.7)</td>
<td>8</td>
<td>1,643</td>
<td>37.6</td>
</tr>
<tr>
<td>Economic class</td>
<td>799 (20.4)</td>
<td>67</td>
<td>866</td>
<td>19.8</td>
</tr>
<tr>
<td>Temporary resident</td>
<td>70 (1.8)</td>
<td>198</td>
<td>268</td>
<td>6.1</td>
</tr>
<tr>
<td>Other(^{19})</td>
<td>205 (5.2)</td>
<td>101</td>
<td>306</td>
<td>7.0</td>
</tr>
<tr>
<td>Unknown</td>
<td>31 (0.8)</td>
<td>70</td>
<td>101</td>
<td>2.3</td>
</tr>
<tr>
<td></td>
<td>5 (0.1)</td>
<td>n/a(^{20})</td>
<td>6</td>
<td>0.1</td>
</tr>
<tr>
<td>Totals</td>
<td>3,921 (100%)</td>
<td>(100%)</td>
<td>4,374</td>
<td>100</td>
</tr>
</tbody>
</table>

There were 1,050 applicants with HIV who applied for Canadian permanent residence during 2006 and 2007, of which 994 people were family or refugee applicants who could not be denied Canadian permanent residence on the basis of potential ‘excessive demand’ (CIC, 2008). Table 5 reveals that from 2002 and 2010, the percentage of admissible applicants with HIV is the economic class was approximately twenty six percent as compared with ninety-nine percent of all applicants in Convention refugee and refugee applicant categories, and ninety-two percent for family class category. 21

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\(^{19}\) “Other” includes humanitarian and compassionate applications. It also includes temporary residence applications.

\(^{20}\) Citizenship and Immigration Canada masked these data in its response to my access to information request (CIC, 2010a).

\(^{21}\) The reporting in this table might lead to confusion because the classification categories do not match those set out in IRPA’s categories in law, for example the sub-division into refugee and
The data in this table tell us that most immigrants with HIV who are granted stay in Canada are persons who cannot be excluded under the law: persons who apply as refugee or family class applicants.

Pathways to Canada
There are several ways that persons physically enter Canada: at a land border from the United States, a water crossing usually at west or east coast shorelines, or arrival by air. Immigration and customs officers of the Canadian Border Services Agency are stationed at these ports of entry and make decisions about who physically enters Canada and who does not. Standpoint informants in this study entered Canada either at land crossings or airports in Québec and Ontario. Many of these informants (though not all) who arrived at land crossings had been granted travel documents that permitted them to enter the United States from their countries of origin. Once in the United States, people reported continuing over land to the Canadian border. Other standpoint informants (though not all) who arrived by air transited through a country other than the one of their citizenship before arriving in Canada.

Persons applying for Canadian permanent residence complete either a refugee application or an immigration application (as per Figure 2). A refugee is defined as a person “who has had to flee his or her country because of a well-founded fear of persecution and has been given protection” by the Canadian state (Immigration and Refugee Board of Canada, 2006, p. 4). An immigrant is a person “who has chosen to settle in Canada and has been accepted as a permanent resident by the Government of Canada” (Immigration and Refugee Board of Canada, 2006, p. 4).22

These two types of permanent residence application forms trigger different sets of administrative and institutional processes within the Canadian government. Refugee and immigration applications carry different sorts of work for applicants that people living with HIV will engage in and sustain until the state reaches a decision about their application. Most of the standpoint informants interviewed in this study waited a considerable length of time for the state to process their application. The two types of permanent residence applications, refugee and immigration, also have applicants interacting with various government institutions and actors according to the type of application made.

Applications for Canadian permanent residence can be made both outside and inside of the country. Where a person is in Canada and files an application, including at a border crossing, this application is known as an in-land application. The paperwork for these applications is filed at Citizenship and Immigration Canada offices anywhere in Canada.

Convention refugee. There is also lack of clarity around the use of “temporary resident”, which is listed as an application category and included in “Other”.

Many of this study’s standpoint informants, though not all, filed permanent residence applications from within the country.

**Refugee person**
A person who applies to remain in Canada as a refugee will prepare many documents, work with lawyers, submit and re-submit much evidence, and present her or his case to prepare for a hearing conducted at the Immigration and Refugee Board. It was the experience of most standpoint informants in this study who applied for refugee status from within Canada that several years went by before they were granted a hearing. In Montréal and Toronto, Immigration and Refugee Board offices where refugee hearings are held are located within the same physical, highly securitized administrative spaces as the Canadian-based offices of the United Nations High Commissioner for Refugees. This is where people summoned to attend refugee hearings or interviews. To the surprise of many standpoint informants within whom I spoke, they were asked to speak on their own behalf at these proceedings (as opposed to their lawyer speaking on their behalf). If the person’s claim is accepted through this process, permanent residence can be gained. If the claim is rejected, however, the applicant will make decisions about filing a different application to remain in Canada.

In chapter five, the experiences with immigration medical screening of a standpoint informant named Alem are detailed. He was settled in Canada as a refugee through coordination of the United Nations High Commissioner for Refugees, the International Organization for Migration, and a faith-based organization in Canada. I interviewed Alem and another woman from Africa who came to Canada through these out-of-country channels. Both of these standpoint informants had Canadian permanent residence status on their arrival in Canada.

Figure 2, above, masks the complexity that people experience during their immigration to Canada. The *Map of the first thirty days in Canada for refugee applicants* at the beginning of this dissertation provides the reader with some idea about the dynamic and complex processes people engage in during their immigration to Canada. Figure 5 also speaks to an immigration application process that standpoint informants experience as confusing and complicated (No One is Illegal Vancouver, 2011). The usefulness of including Figure 5, in addition to Figure 2, is to give a visual impression of the maze-like organization of immigrating and the Canadian immigration process. This is not always captured in immigration research or well understood by people who are not immigrants to Canada. The *Map of the first thirty days in Canada for refugee applicants* also gives the reader an idea of the layers of movement and institutional interactions that a refugee applicant to Canada with HIV experiences.

**Immigrant person**
Canadian citizens or permanent residents can sponsor close family members, such as a child under eighteen years old or a spouse, to immigrate to Canada. This includes spouses and common law partners of either sex. Application in the family class is made
from inside or outside of Canada. Many standpoint informants interviewed in this study were gay men sponsored by male partners. To gain permanent residence in Canada, these informants, like others, engaged in considerable work to produce evidentiary documents attesting to the legitimacy of their conjugal relationships, homosexuality, and, in some cases, of their HIV-positive status. As with refugee applicants, immigration processing for family member applicants generally takes a long time. During this time, applicants who are both in Canada and outside the country interact variably with government institutions and agents, sustaining high levels of work.

A person who is not sponsored or otherwise affiliated through kin makes an economic class request for immigration to Canada. Applications in this category are generally made to Citizenship and Immigration Canada offices located outside of Canada. Seasonal workers and residential caregivers, students, and private sector investors are examples of economic class applicants, as per the third column in Figure 2. Applicants can gain permanent or temporary Canadian residence through application in this category. Comparing Citizenship and Immigration Canada data from 2004 to 2008, the Canadian Council for Refugees reports that a dramatic shift in policy sees Canada “bringing in more and more workers on temporary work permits, rather than as permanent residents . . . the number of people in Canada as temporary foreign workers more than doubled [during this period]” (http://ccrweb.ca/eng/media/mediakit.pdf).

**Mobility restrictions for people living with HIV**

Very few countries of the Organisation for Economic Co-operation and Development maintain restrictive immigration policies for people living with HIV. Canada, Australia and New Zealand are among the notable exceptions. Beginning in the late 1990s, Commonwealth countries such as Australia, Canada, New Zealand, and the United Kingdom reviewed their domestic immigration policies, including those related to HIV (All-Party Parliamentary Group on AIDS, 2003; Australian Federation of AIDS Organisations, 2009, 2011; Joint Committee on Human Rights of the House of Lords and House of Commons, 2007). Within a short time of each other, governments of these countries (and others worldwide, see Table 6) enacted various HIV-specific legislation and policies that included restrictions on the entry, short- and long-term residence, and immigration of people living with HIV (Amos & Wiltenburg Todrys, 2008; Somerville & Wilson, 1998; Worth, Patton & Goldstein, 2005). At the same time, effective antiretroviral medications available in many Organisation for Economic Co-operation and Development countries delayed the onset of AIDS-defining illnesses for people living with HIV infection.

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23 Data in Table 6 are estimates. Revised data are expected in the first quarter of 2012 (H. Hans-Ulrich, personal communication, December 7, 2011). This table features a slide similar to the one that appeared in a guest lecture I gave on mobility restrictions for people living with HIV (Bisaillon, 2011a). I updated the data in this slide for purposes of this dissertation.
Figure 5. The Canadian refugee application process
Expected life spans for people infected with HIV were considerably extended in settings of medicine availability such as Canada, medically transforming HIV into a chronic, albeit expensive to treat, condition in resource highest income countries.

Table 6. International mobility restrictions for people living with HIV

<table>
<thead>
<tr>
<th>Definition of restrictions</th>
<th></th>
</tr>
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<tbody>
<tr>
<td><strong>Entry:</strong> 13 countries do not allow PHA to enter</td>
<td>(Singapore, Russia, UAE)</td>
</tr>
<tr>
<td><strong>Stay:</strong> 19 countries have restrictions for PHA stays &lt; 90 days</td>
<td>(Bahamas, Iran, Suriname)</td>
</tr>
<tr>
<td><strong>Immigration:</strong> 62 countries have restrictions for PHA stays &gt; 90 days</td>
<td>(Bosnia, Canada, Egypt, NZ)</td>
</tr>
<tr>
<td><strong>Deportation:</strong> 27 countries have legislation or practices that allow expulsion of PHA</td>
<td>(Armenia, Hungary, Korea)</td>
</tr>
</tbody>
</table>


The practice of restricting the mobility of people living with HIV based on their medical condition has been repeatedly rejected in international guidelines (International AIDS Society, 2008; Joint United Nations Programme on HIV/AIDS and International Organization for Migration, 2004; Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS, 2006). On-line narratives from people living with HIV whose mobility was restricted in numerous countries, including Canada, reveal people’s personal difficulties related to the experience of health-based exceptionalism and discrimination. Eliciting descriptions about social phenomena in people’s own words provides new knowledge and opportunities to explore how narrative-centered approaches to health politics and policy can “illuminate our understanding of the social dimensions of health and illness” (Orsini & Scala, 2006, p. 125). Indeed, how the coordination of services stemming from the HIV testing policy actually works, and how this shapes the activities of persons tested, can be best and effectively known through exploring the practices and

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24 In this dissertation, the experiences of people living with HIV related to travel and residence restrictions placed on them because of their health condition are organized into (compelling) case studies. A variety of situations are presented as are the implications on people who were endeavouring to apply to remain in Australia, Canada, China, Oman, Russia, Saudi Arabia, South Korea, Taiwan, and the United States. See [http://hivtravel.org/Web/WebContentEATG/File/Case%20Studies/Personal%20Narratives%20of%20Impact%20of%20HIV-specific%20travel%20and%20residence%20restrictions.pdf](http://hivtravel.org/Web/WebContentEATG/File/Case%20Studies/Personal%20Narratives%20of%20Impact%20of%20HIV-specific%20travel%20and%20residence%20restrictions.pdf)
experiences of persons who have undergone immigration HIV testing and those people around them, including state workers who process their paperwork, with the goal of understanding the social organization of these activities and experiences.

**Drawing from the methodological literature**

I used three strategies to reference and make use of the literature in ways that were consistent with institutional ethnography. I was guided by the following quote from Campbell and Gregor (2004),

[T]he issue of knowing emerges as a contested aspect of research . . . [the researcher] must come to terms with the literature while delineating and maintaining her particular stance *vis-à-vis* discourses, authorized knowledge, and views that express a standpoint organized differently from the institutional ethnographer’s stance in the everyday world (p. 51).

I first took a position relative to the literature on immigration and HIV. The extant research on the issues has largely not been from the standpoint of people living with HIV. I used this knowledge gap as a point of entry into this research. I was most interested in, and found most relevant, research conducted from within the material circumstances of the lives of those people who submitted to mandatory HIV testing (e.g., Committee for Accessible AIDS Treatment, 2006; *Réseau des chercheures africaines*, ca. 2005; on-line narratives, note 24). As I proceeded with my own data collection, I learned more about the material conditions of people’s life and work. I became familiar with their everyday activities. I began the study from a reflexive position within the social world of standpoint informants, where I relied on their “expert knowledge as local practitioners of their everyday worlds” to form the baseline for this work (D. Smith, 2005, p. 52).

I then endeavoured to learn about the research literature on immigration and HIV in ways that explained the social production and organization of the knowledge produced. A first example of the sort of literature search activities I engaged in appeared in the preceding chapter where I explain how I evaluated the articles by Gushulak and Williams (2004) and Zencovich et al. (2006). A second example of search activities included reviewing research that brought together the subjects and the method of my project. Here I uncovered the Making Care Visible Working Group’s (2002) report, which is an investigation of the daily practices and decision-making of people living with HIV in Toronto. This study juxtaposes conventional ways of understanding how people with HIV take medication with alternate ways of knowing based on working group findings. Two of the group’s researchers explain the orientation (and contribution) of their work,

A more ‘social’ understanding of how people living with HIV/AIDS come to take medical treatment also locates their activities and experiences within institutional relations of power. This is an important step in complicating the rational decision-making frame, for it puts into view the limits of ‘choice’ of many (Mykhalovskiy & McCoy, 2002, p. 37).
The Making Care Visible (2002) project was conceptually organized around informant “health work” (p. xvii), and it was developed from a stance within researchers’ “knowledge as members of a setting” (G. Smith, 1990, p. 638). The social character of “health work” in which informants engaged, such as maintaining and building relationships with their HIV physicians and other health providers, was more complex than the theoretical explanations of these subjects — informed by discourses on treatment decision-making — projected. The study brought to light the effort informants invested to obtain their medication, and to adjust to the demands of a difficult, daily medication schedule, among other forms of work (see Bresalier, McCoy & Mykhalovskiy, 2005). Making Care Visible reoriented the treatment decision-making discourse “by calling into question the notions of individual choice that it rests on, and by displaying the links between [people living with HIV’s] decision making and broader social and political arrangements” (Mykhalovskiy, 2002, p. 45). It was from the project’s juxtaposition of different forms of knowing — material as opposed to abstract — that I first learned how to think critically about discourses that commonly circulate (or not) in practice (including my own) and in the literature.

Last, I was led by a technique that was instructive for George Smith (1990), who writes,

> Instead of starting with a review of the literature, this was left to the end of the research so that the analysis of the data could provide a structure of relevance for the reading [of the literature] rather than the other way round (p. 645).

In latter stages of my research, after I was attuned to the social and institutional features of standpoint and extra-local informant dialogue, and while I was doing textual analysis of documents that I had identified as central organizers of standpoint informant activities and experience, I returned to the literature. I could, at that time, more clearly understand the social relations organizing informant practice and talk. For example, throughout the course of fieldwork, I had become used to standpoint informants using the words ‘expensive’, ‘costly’ and ‘burdensome’ as self-referential adjectives. When I first entered the field and heard standpoint informants talking about themselves in these financial or economic terms, I did not understand that they were, in fact, employing discursively organized ideas and concepts from IRPA and its derivative documents. They were referring to the state’s work on them to assess whether applicants with certain diagnosed medical conditions would be inadmissible because of anticipated costs for treating and caring for them.
Chapter 3. Institutional ethnography as method of inquiry

In this chapter, I outline the epistemological, theoretical, and ontological underpinnings of institutional ethnography, the method used in this study to uncover features of the social organization of refugee and immigrant experience and the knowledge and ruling relations associated with mandatory immigration HIV testing. The method draws most significantly from Marxism and feminism, and Dorothy Smith’s (1977, 1981, 1990a, 1990b, 2004) interpretation of Marx’s material method and feminism’s standpoint. I also use George Smith’s (1990) political activist ethnography that extends Dorothy Smith’s sociology to generate knowledge explicitly for social justice and political organizing ends. Both of these approaches require the researcher to make epistemological and ontological shifts, and what this means is discussed. The conceptual organizers and vocabulary associated with institutional ethnography are explained, and I provide examples from this study and other research that illustrates how institutional ethnography was useful.

Anti-positivist paradigm

Institutional ethnography is a research method that offers a theorized way of conceiving of the social world with the broad aim of understanding how society works. It starts within the material events of people’s lives rather than in abstractions or theoretical explanations about these. It does this by inquiring into the features of what happens in people’s lives that are often unexamined and taken-for-granted. In this mode of inquiry, the social is defined as the coordination of people’s activities across time and place as set within patterns of social relations. This coordination is understood to happen through people’s use of texts and documents in their day-to-day activities. Dorothy Smith’s work,

[R]places the heritage of cumbersome and determinist base/superstructure divisions with a singular ontology of the social understood as actual people’s activities coordinated across time and place. Here is a way of thinking about the social as a world produced by actual people that could be researched as such and transformed (Mykhalovskiy & Church, 2006, p. 75).

The grounds for knowledge in institutional ethnography are set within an anti-positivist epistemology, the principles of which have been summarized by Guba and Lincoln (1994):

- Does not search for underlying laws or regularities in the world
- Views the world as understandable and knowable from the standpoint of the people involved in the activities studied
- Resists the standpoint of the observer
- Views science as a subjective, not objective, enterprise
- Opposes the idea that science generates objective knowledge
George Smith (1990) called institutional ethnography a “new paradigm for sociology” since the approach proposes both a method and a theorized way of conducting fieldwork and, more broadly, to seeing and conceiving of the world (pp. 630-631). On reflecting on the possibilities offered by critical social science research and the social position of the researcher within this, George Smith (1990) writes that what is required is, “a move from an objective to a reflexive [social position] where the sociologist, going beyond the seductions of solipsism, inhabits the world that she is investigating” (p. 633).

George Smith suggests that institutional ethnography’s stance to knowledge is above all reflexive, which emphasizes that people’s knowing about the world is mutually and interactively produced. The method sets out to uncover and explore the relations of power in which people’s lives are set, and research drawing from it aims to explain the lineaments of social relations that rule and regulate people’s lives through the intermediary of society’s dominant institutions. The following excerpt from Dorothy Smith’s (2006) work is useful in explaining the intent of the institutional ethnographic project.

The idea is to reorganize sociology as knowledge of society so that inquiry begins where people are and proceeds from there to discoveries that are for them, for us, of the workings of a social that extends beyond any one of us, bringing our local activities into coordination with those of others. The project is to extend people’s ordinary good knowledge of how things are put together in our everyday lives to dimensions of the social that transcend the local and are all the more powerful and significant in it for that reason. We participate in them without knowing what we are doing (p. 3).

Institutional ethnography begins within people’s day-to-day activities, experience, and knowledge. The starting place for research is within people’s material activities, actions, and practices that are empirically ‘investigatable.’

**Materialist method**

Study of the material events and socially coordinated features of people’s lives is a first example of how this study is influenced by the writings of Karl Marx and Frederick Engels, and in particular from the premises articulated in Marx’s *The German Ideology* (1846, 1970). Dorothy Smith’s development of institutional ethnography was influenced by Marx’s social and historical materialist method developed in *Theses on Feuerbach* (1846, 1970), a body of work written in response to German philosophical idealism that was a dominant current of thought in the 19th century European society.

This notion of materialism is based on sensuous human social practices. At the same time, while noting the material impact of ideas, it does not give power to ideas separated from the material social relations they are produced in, which is what philosophical idealism does (Frampton et al., 2006, p. 34).
Marx and Engels critiqued normative forms of knowing on the basis that they were overly theoretically informed, and that they elided how people experienced the events of their lives. Marx and Engels outlined a project to examine the material conditions of people’s lives, and in so doing, drew attention to how people’s activities were socially produced and connected in ways that could be opened up for investigation and empirically traced. They argued that results of such a project held the promise of yielding understandings that portrayed the actual conditions of people’s existence since they were based within actual happenings. Knowledge, according to Marx and Engels, and my position in this research, is socially produced in the material and social practices in which people engage.

Starting within people’s day-to-day activities is in purposeful contest to the stance adopted by Zencovich et al. (2006). The latter interpreted the events of the immigration medical examination and HIV testing in such a way that people’s actual experience was abstracted. Authoritative accounts conveyed an interpretation of the state’s immigration medical practices that I found to be inconsistent with the material happenings and circumstances of these medical visits. Starting from and remaining within abstracted knowing that is not connected to how people lived their lives is precisely what made the disjuncture described in chapter one possible. In this study I used theory upfront to inform how and where I looked to uncover clues about the social organization of standpoint informant experience with immigration HIV testing. I did this because I knew that an abstracted place would limit would I could say — what could be known through my descriptions and analysis — about the social organization of people’s experiences as they actually lived them stemming from immigration testing and the activities that derived from it.

A second way in which the work of Marx and Engels influenced this research was in the focus on social practices rather than speculative explanations of why and how social phenomena occur. When I interviewed standpoint informants, it came to my attention that people had various interpretations of why the state enforces mandatory HIV testing as a pre-condition for immigration. One informant explained, “They think that immigrants have a lot of diseases. So, testing is a good thing”. Some gay, married informants had understandings of state agents as homophobic. They suspected that because of this, they had to produce more documentary evidence in the applications, including about their health, than heterosexual couples. Speaking of the community-based lawyer who did not charge him for legal advice, a standpoint informant said,

He gives you a lot of time. He began to ask me about my case. He asks a lot of questions about who the lawyer is, what he has done for you, how it is going with the lawyer. He explains the political context of Canada at this time; what is behind. For example, that at this point in time, the government is not too open to gays or all this immigration in Canada.
Another informant said,

Sure we had to submit a lot of paperwork. It took me three-months of full-time effort to get things together. When our process was done, I helped heterosexual [heterosexual] friends. He was from the U.S. (United States). Compared to the narrative that we had to put together, his was short. His was two-pages. The lawyer told us we had to prove that we were a real couple. ‘Heteros’ don’t have to do that.

My analytic aim through all of this was to uncover the material features of people’s activities so that I could make sense of how these were socially organized, and how the knowledge relations therein shaped people’s practices. In this way, I was less interested in informants’ opinions or their “speculative accounts” of what happens and why (G. Smith, 1990, p. 635). This turn away from ideological or speculative accounts towards people’s social practices is what George Smith (1990), drawing from Marx and Engels, referred to as making the “ontological shift” (p. 633) (see also Mykhalovskyi & Church, 2006). I did not discount informants’ thoughts and reflections about immigration HIV testing and other immigration experiences, since these also informed, in certain ways, how their worlds were socially coordinated and constructed. But, these opinions are not construed or used as evidence or data in this study since they are simply not good accounts, in and of themselves, of how things are organized to work.\(^{25}\)

**Reflexive epistemology**

Institutional ethnography adopts and maintains a standpoint on the side and in the interests of the people for whom the research is conducted (see D. Smith, 2006). In this project, my standpoint position is aligned with immigrant and refugee applicants with HIV. This commitment to a particular perspective on the side of a distinct group of people is one way in which this study is influenced by feminism, where the experiential knowledge of people occupying places within social margins is fore grounded with the broad aims of redressing historical imbalance and oppression, and producing knowledge that reflects lived experience.

Women’s situation offers no outside to stand on or gaze at, no inside to escape to, too much urgency to wait, no place else to go, and nothing to use but the twisted tools that have been shoved down our throats. There is no Archimedean point — or, men are their own Archimedean point, which makes it not very Archimedean. If feminism is revolutionary, this is why (MacKinnon, 1989, p. 117).\(^{26}\)

While there is rarely consensus in assigning definitions to political terms, in this case feminism, “to jettison labels ‘would leave one without any signposts in a sea of chaos’”

\(^{25}\) A detailed discussion of Marx’s materialist method and contributions to institutional ethnography is in Carroll (2006).

\(^{26}\) The origin of the Archimedean metaphor is found in Jehlen (1981).
(Caine, 1997, p. 7, in Hannam, 2007, p. 3). I use the definition of feminism forwarded by June Hannam (2007), who writes that it is,

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[A] \text{ set of ideas that recognize in an explicit way that women are subordinate to men and seek to address imbalance of power between the sexes. Central to feminism is the view that women’s condition is socially constructed, and therefore open to change. At its heart is the belief that women’s voices should be heard — that they should represent themselves, put forward their own view of the world, and achieve autonomy in their lives (pp. 3-4).}
\]

In this research, I investigated people’s day-to-day events, activities, and practices, and I made these everyday sites, and the tensions that I uncovered therein, terrains of critical exploration. To do this, I foregrounded people’s social experience, working from the assumption that their knowledge about the world, and knowledge more broadly, is mutually determined and produced interactively. This reflexive position is the second way in which this research draws from feminist scholarship.

At the same time, this reflexive position also reflects an ancestry connecting institutional ethnography with ethnomethodology. Dorothy Smith explicitly drew from Harold Garfinkel’s (1967) ethnomethodology, a method that focuses on examining how people make sense of the events of their lives, and how they participate, through actions and decision-making, in producing their social worlds. Consistent with this project, Dorothy Smith’s institutional ethnography conceives of people as active and ‘skilled practitioners’ of the worlds they inhabit.27 Both ethnomethodology and institutional ethnography challenge a ‘natural’ or ‘common sense’ ontology, and the epistemological shift in these methods consists of conceiving of knowledge as reflexively rather than objectively generated. In this dissertation, informant’s everyday knowledge and experience as skilled practitioners of their day-to-day lives were the legitimate and valuable starting places for beginning to untangle social dilemmas and to understand the ruling relations that shaped their lives.

In The Conceptual Practices of Power (1990), Dorothy Smith explains that the method she developed took shape from the tensions she confronted in the 1970s and 1980s as a single mother and woman academic in Canada and the United States. Among these was the disjuncture between her knowledge of what it felt like to stand in both of these worlds, and what dominant discourses of the time had to say on the subjects. The discovery that sociology was representing her, and single women, mothers, and academics like her, in particular ways that did not coincide with the material events of their lives was a point of departure for the development of a method that produced knowledge to challenge dominant ways of knowing the social world.

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27 For a brief summary of theoretical influences on the formulation of Dorothy Smith’s thought and method, see Campbell and Manicom (1995, pp. ix to xv).
Institutional ethnography commits to starting from a position outside of normative or dominant interests and forms of knowing. These projects — this one included — inquire into and learn about the workings of society’s dominant institutions that are accepted as regulating and ruling people’s lives. This sort of inquiry regularly scrutinizes unexamined, assumed, and accepted practices and activities for what investigations can reveal about their social organization. For example, when I talked with DMPs for this research, discussions focused on tasks within the immigration medical examinations that physicians generally did not think twice about, including what forms they used and what categories were listed therein. My analysis found that routine practices organized through such forms were key coordinators of their work and of standpoint informants’ experiences.

Uncovering the relations within how taken-for-granted practices are organized, understood as being located in people’s practices, is what Dorothy Smith (2006) means when she writes, “[w]e participate in them [social relations] without knowing what we are doing”. To be clear, this position is not one of claiming truth. 28 Rather, it refers to uncovering the social relations that coordinate through and connect different places. While inquiries drawing from institutional ethnography have their starting place within people’s everyday world, analytic attention is directed at uncovering the connection between people’s local worlds and places that transcend their immediate settings. This means that the field of investigation in institutional ethnography is beyond any single physical place. In this way, the method is similar to Michael Burawoy’s extended case method (1991) and global ethnography (2000), and George Marcus’s (1998) multi-sited ethnography. These are among the most developed ethnographic methods that share certain common features with institutional ethnography.

For example, these forms of ethnography all stretch beyond the boundaries of a single location for the purpose of studying ruling relations and making explicit the social connections that join people who live, work and study in various places. Consistent with these approaches to social inquiry, I paid attention to text and expanded data gathering beyond local settings where standpoint informants live, turning ethnographic attention to the institutions within which they undertake their immigration work and interact. This is one way in which this research links with the intent of political activist ethnography developed in the work of George Smith (1990, 1995, 1998; Smith, Mykhalovskiy & Weatherbee, 2006) and those who draw from his contributions in their own research (Frampton et al., 2006; Institutional Ethnography Division of the Society for the Study of Social Problems, 2005).

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28 On the subject of truth, D. Smith (2005) writes that institutional ethnographers aim to produce accurate, faithful and truthful representations of how things work in people’s lives. “Political commitment [of the method] enforces the researcher’s responsibility to get it right” (p. 42). For earlier exploration of truth in D. Smith’s sociology, see her “Telling the truth after postmodernism” (1996b).
**Activist project of research**

The work of George Smith had a significant organizing presence in this research. His article “Political Activist as Ethnographer” (1990) was particularly influential in shaping the orientation of this project because of what it instructs about the possible aims, conduct, strategies, and application of results of critical, applied sociological investigation. His approach informed an explicitly political and engaged research strategy that came to be called political activist ethnography. Smith worked within the ontological and epistemological commitments discussed above: materialist study, turn to the concrete rather than speculative world, standpoint position, and reflexively produced, social knowledge.

George’s activist ethnography channels that curiosity and speculative energy into discovering the social world as it is being ‘put together’ in actual activities. His work formulates what I like to call an ‘ethics of empirical investigation,’ which it both privileges over abstract speculation and seeks to implant in the politics of social movements (Mykhalovskiy & Church, 2006, p. 77).

Hinted at in this statement is one way that Smith extended Dorothy Smith’s method: his project set out a course for using knowledge derived from empirically informed research to inform social justice and political work of those working on behalf of oppressed or historically marginalized people among whom he circulated and socialized. George Smith conceived of using “political confrontation as an ethnographic resource” in uncovering how ruling relations were organized (G. Smith, 1990, p. 629), suggesting that “by being located outside of and yet constantly in interaction and struggle with ruling regimes, activists can explore the social organization of power as it is revealed through the moments of confrontation” (Frampton et al., 2006, p. 35). Early on in fieldwork I detected that there were speculative accounts as to how and why immigrants were subjected to mandatory HIV screening. I was interested in findings ways to empirically investigate the organization of people’s experience so that knowledge reflecting this social organization could be communicated to standpoint informants and other audiences for their “ordinary good” use (D. Smith, 2006, p. 3).

With this in mind, I drew from George Smith’s relationship to science, knowledge production, and research output.

[George had] an understanding of science as an organization of activities that permits the making of reliable knowledge. George wanted the space to create knowledge of ruling . . . that he could offer movement activists, assured that sound decisions about political strategy could be made on its basis . . . The ethnographer is concerned with putting in place the ‘scientific basis for the political strategy of grass-roots organizing’ (G. Smith, 1990, p. 629), but using that research to develop that political strategy lies beyond his or her sphere of responsibility or competence (Mykhalovskiy & Church, 2006, p. 80).
George Smith’s standpoint was, at different times, on the side of gay adolescents and men, and people living with AIDS in Ontario throughout the 1980s. Like Dorothy Smith who mobilized her experiential knowledge as single mother and woman academic as a resource and starting point for research, Smith used his insider knowledge as a gay man living with AIDS as the launching pad into social inquiries of how the worlds of gay men, colleagues, friends, and other people living with AIDS were socially constructed. He puts forth that uncovering how things are socially organized to occur is an effective strategy for challenging and transforming what he called “politico-administrative régime[s]” (G. Smith, 1990, p. 631). In this project, as with institutional ethnography, it is the regimes that are the objects of research, and not the experiences of people. In other words, the effects of institutional arrangements are the sites that need to be opened up, scrutinized, and explicated.

George Smith’s (1990) study of the policing and criminalization of gay men is the example I use to close this examination of political activist ethnography and its influences on this research. Smith did an ethnography that examined police raids on bathhouses frequented by gay men in Toronto in the 1980s. These men were his standpoint informants. His findings revealed the social processes by which men were arrested and incarcerated. According to Smith, dominant thinking in gay and AIDS organizing milieus following the raids, and throughout the criminal investigations that followed, was that arrests and incarcerations were largely attributable to homophobia. George Smith did not dismiss homophobia as contributing to the arrests. However, from his insider and sociologist’s perspective, he had a hunch that something in addition to homophobia enabled the social coordination of arrests and incarcerations.

In his research, Smith shows that what was at the heart of the issue — what organized the men to be policed and criminalized in the ways that they were — was actually the textual work practices of policemen. The writing and recording techniques of the latter were informed by categories within Canada’s Criminal Code that were socially organized to be produced around notions of heterosexuality. These textual practices worked to the distinct disadvantage of gay men’s sexuality. In other words, it was Canadian legal relevancies, written into the Code, which shaped what policemen saw and reported. Through his study, Smith succeeds in demonstrating that something different and deeper than homophobia alone explained how gay men’s experiences in the bathhouses were recorded as happening.

What made George Smith’s findings useful for interventions work was that Smith went beyond speculative accounts offered by the gay men’s and AIDS mobilizing in Ontario of that time that suggested that homophobia, by itself, was the culprit for the criminalization of men’s sexuality. His study showed the ways in which his standpoint and extra-local informants’ knowledge was socially and reflexively organized: the former by notions of police homophobia, and the latter by the language of the Criminal Code. The results of Smith’s investigation provided activists within the Canadian AIDS organizational milieu an opportunity to use results to intervene ‘upstream’ and in the precise and particular locations that were the problems: the textual recording practices
of Toronto police officers who worked to align their descriptions of the sexual activities of men in the bathhouses with the discursively organized terms, language, and heterosexist concepts of the Criminal Code.

For me, this illustration stands as one of the best examples of political activist ethnographic research. My careful consideration of this project shaped the ways in which I approached the issues in my investigation. Smith’s bathhouse research illustrates the transformative possibilities of activist oriented research that points to levers for intervention that are empirically informed that are effective because they go beyond abstraction and speculation as to how things work.

**Deciding to use institutional ethnography**

Two discoveries led me to conceive of a study drawing from the framework offered by institutional ethnography. First, I experienced certain gaps in graduate coursework in population health. Over time, I noticed that the assigned readings and “people’s ordinary good knowledge of how things are put together in our everyday lives” (D. Smith, 2006, p. 3) were absent from the core curriculum that set out to have students explore why some people are healthy while others are not. With few exceptions, the curriculum did not have us consider the daily exerions, purposeful activities, and struggles of people as they went about living, working, studying, and so on. Rarely did I grasp a sense of the material conditions of people’s daily lives. For example, how power arrangements and the production and circulation of knowledge shaped people’s circumstances were inadequately explored in these settings. The abstraction of people’s worlds that I observed during this period was a catalyst to reinsert people back into a project of research for which I would focus doctoral efforts.

The doctoral course readings that drew from epidemiology, the staples of the population health graduate program diet, were largely within a paradigm that I would come to know as positivist. The core courses offered little opportunity to consider critical health scholarship, and when inequities were discussed, they were done in the abstract. A key issue with which I was confronted in the range of population health classrooms was that I lacked what Richard Darville (1995) termed the “organizational literacy” to understand epidemiology and the health sciences (see pp. 254-257). Darville explains that organizational competency comes from acquiring an insider language and

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29 This reference is a twist on the titles of research that investigated health inequalities and inequities. For example, Evans, Barer & Marmor (1994) and Finkler (2000). There are, of course, other references that I could name in this context.

30 I am grateful for the thoughtful teachings of Professors Geneviève Rail and Lise Dubois (Research Methods 8920, Population Health), and Professor Louise Blais (Problématique de la pratique et de la recherche dans le domaine de la santé 6500, Social Work; Practice and Research Problems in the Field of Health; my translation). The readings in these courses informed about alternate, critical approaches. Through discussions in the classrooms of these women, I was acquainted with critiques of dominant forms of population health and interventions research.
awareness of accepted cues and codes within a milieu, which can translate into a person experiencing ease when circulating in such settings.

In the absence of such background knowledge, I could not easily understand, let alone skilfully employ, the theories and abstractions that characterize the field of population health. These include logic and reach models, flowcharts, formulae, and explanations based on (hyper) rational decision-making and evidence-based approaches (see Murray & Rail, 2008; Mykhalovskiy et al., 2008 for critiques). These so-called tools that were the fundamentals of population health practitioners frustrated me because they were, to me, confusing if not completely mystifying. Generally, it was difficult to situate and reconcile the readings with the broader, stratified, social world in which I had been immersed for the ten years prior. Reflection about this led me to a second discovery.

**Ruling relations of research as praxis**

Institutional ethnography offers the contours of a critical research strategy that brings together theory and research practice. Marx (1846, 1970) describes this combination as praxis: where practice informs theory development and vice versa, which means moving from interpretation of the social world to acting within it (or changing it). “Such a critical perspective proceeds from the recognition that social life as we know it is marked by inequities that are deeply structured yet contingent features of human organization” (Carroll, 2006, p. 234). In such a framework theory and practice are relational and reflexively informed and generated.

[Praxis makes] a commitment to understand the deeper, systemic bases of the problems we face, whether social, psychological or ecological, which often means understanding the interconnections between allegedly separate issues and problems, as in the intersections of race, class and gender that constitute specific lived realities (Carroll, 2006, p. 234).

In producing reflexive knowledge about the social there is opportunity for producing an alternative to the ideologically and discursively organized accounts of how things happened for people. Such a project would acknowledge and consider the connections between knowledge, power, access, material inequality; reflecting on the “complex, stratified and historical character of social life” for how these organized standpoint informant experiences stemming from mandatory HIV screening (Carroll, 2006, p. 234).

Since there is no proscribed way to practice research using institutional ethnography, there was opportunity to make adaptations for the purposes of this study; to infuse creativity in fieldwork and analysis. I was guided by Gary Kinsman’s (2006) observation that,

Reification and fetishization are major problems in ruling discourse, and they can also limit and contain the theory and practice of social movements . . . We have to constantly resist in our research and activism giving agency and power to things (p. 135).
From the outset, I believed that there was analytic value in becoming familiar with other methods with compatible ontology and epistemology. Incorporating strategies from these research approaches could prove innovative and beneficial to the quality of analysis and findings. Nancy Taber (2010) pursued such interdisciplinary, methodological blending by grafting techniques from autoethnography and narrative research in her work that she had originally designed as an institutional ethnography. A former Canadian military employee, Taber designed a project of research where she set out to investigate and explicate the ideology “of the military careerist along with that of a military mother” (p. 7). She had intended to do textual analysis of relevant policy documents, and interview senior military personnel and servicewomen who were, like her, also mothers. However, Taber reports that representatives of the Canadian armed forces actively gate kept and succeeded in limiting her access to field sites that she had anticipated interrogating since she understood that her work posed perceived threats to the complex of state institutions. Taber explains how she readjusted her project and devised research strategies that succeeded in challenging and transcending boundaries to “address research questions that cannot be explored with traditional methods” (p. 5). She argues that such positioning is necessary and effective particularly in situations where “powerful elites . . . may rather not have their organizational policies and practices questioned” (p. 21). In reformulating her research and practicing methodological pluralism, Taber managed the “restrictions and obstructions” that dominant institutions posed to her research (p. 21).

“Targets for intervention”
Taber’s reporting of the ruling relations within her field research points to the issue that the broad social context in which health (and other) research is conducted is not without challenges for projects poised to critically investigate the social. Research strategies and findings that challenge conventional approaches chafe with the structures and modes of thinking associated with these. Not only can such approaches and their ensuing results sit uneasily with the academic disciplines within with such projects are framed, they also can be understood to be contrary to common sense or speculative understandings of how the social world works. The results of critical social science scholarship can be contested both by the academy and the social movements and organizations that findings set out to inform.

The organization of academic research and the organization of social movement priority setting create tensions to research critical of established ways of thinking and doing. For example, Kathryn Church details how the findings of her politically-oriented investigation into the ruling relations organizing work among psychiatric survivors

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31 Another example of methodological pluralism is Kinsman’s (1995, 2006) work, where he used political confrontation as an ethnographic resource to map the social relations of the policing of gay men and social movement struggles in Canada. Adapting strategies from methods with consistent ontological and epistemological commitments with institutional ethnography enabled Taber and Kinsman to construct critical social inquiries that suited their projects (and them as researchers) both ethically and politically. Both Taber and Kinsman’s work were instructive to me in my approach to and conduct of this project.
“unsettled the comfortable, taken-for-granted ways that mental health professionals view and related to their ‘client’” (see Mykhalskiy & Church, 2006, p. 79). Church explains that results of her work conflicted with normative ways of understanding work in this milieu (which contributed to her departure from it).

Critical work has an uneasy relationship to places where intellectual activity is highly applied, organized by clinical relevancies and often measured in strict output terms . . . the treatment of ruling as an object of critique rather than a client for research, and the complex research relationships with social movements rather than with corporate partners, [makes investigating the everyday world of which the institutional ethnographer is a part a complex, tension-filled enterprise] (Mykhalskiy & Church, 2006, pp. 84 & 85).

Producing research informed by the material circumstances and conditions of HIV-positive refugee and immigrant experiences presents the opportunity for results to be given to standpoint informants as explications of how their troubling, problematic and uncomfortable experiences with immigration HIV testing are socially produced. This emphasizes the point made earlier about the aims and application of activist ethnography as eschewing ideological, theoretically deterministic or speculative accounts of how things happen.

A striking example of an institutional ethnography with an activist approach similar to the aim of this study is Ellen Pence’s (1997, 2001) work from the standpoint of women survivors of domestic violence in Duluth, Minnesota. Pence’s doctoral work was an investigation of the work practices involved in reporting acts of violence against women in Duluth. The study found that women’s experience with violence in their homes was not accurately summarized in reports that documented these events. Women’s experiences were summed up in ways that did not reflect what actually happened to them through the violence. This transformation of experience happened through the coordination of people’s work practices involved in reporting: from the 911-telephone operator who entered the report into an electronic database all the way through to the adjudicator who received the accused person in court. Pence concluded that women’s experience of violence was marginalized through these “processing interchanges” (DeVault & McCoy, 2006, pp. 30-31). Although this effect was unintentional, the textually mediated social processes of available reporting systems people used were shown to account for the marginalizing of women’s experience. Pence’s research contributed to policy and programmatic changes implemented in the interest of women based on knowledge of the root causes of what was problematic for women.

In examining the method and findings of George Smith’s bath house and Ellen Pence’s domestic violence inquiries — looking at how they proceeded to uncover connections between the organization of people’s troubles and ruling relations — I saw the opportunity to respond to the ‘so what’ question that researchers should consider relative to their projects: What could be the use and application of this study results? Institutional ethnographies have identified “levers or targets for . . . intervention”, which
makes the method of interest to applied health researchers and others working in the area of population health interventions (DeVault & McCoy, 2004, p. 754). State health and social service departments in Canada have funded research and used findings from studies that employed institutional ethnography conducted from the standpoint of people living with HIV (G. Smith, Mykhalovskiy & Weatherbee, 2006). Policy makers, in addition to people living with HIV who were standpoint informants in this research, are appropriate readers of this study’s findings.

**Qualities of inquiries using institutional ethnography**

Table 7 summarizes qualities that distinguish inquiries using institutional ethnography. These qualities provide a basis for contextualizing the method’s terminology that populates this dissertation.

**Table 7. ‘How to look’ when doing institutional ethnographic research**

| Ground | explorations in the material activities and quotidian experiences of standpoint informants |
| Investigate | in detail that which is problematic, troubling, and contradictory for informants |
| Maintain | this standpoint perspective throughout the entire investigation |
| Describe | what tangibly occurs in the everyday activities of standpoint and extra-local informants, with close attention to the organization and coordination of people’s textual practices |
| Learn | about the broad, social contexts in which activities occur since these provide clues about the social organization of informants’ experiences |
| Uncover | how informants use and activate material artifacts such as texts, broadly conceived, in their daily work and efforts |
| Detect | social relations connecting activities occurring in local and extra-local sites |

This method of social inquiry investigates textually mediated processes that connect people and places in multiple sites. Second, the method instructs the researcher to conceive of and use texts and documents in ways that are unique. Texts are understood to be active constituents of social relations that provide clues about the social organization of the places and activities of which they are parts. For example, Janet Rankin (2003) analyzes a set of patient satisfaction forms that were given to her aunt as the latter was discharged from hospital. She found that the categories of questions, and possibilities for answers, were organized in such a way that answers became standardized by and aligned with hospital reform practices rather than capturing the actual experiences or ‘satisfaction’ of her aunt (and others) who had been patients. In
this study, I problematize and analyze certain texts within the *Handbook for Designated Medical Practitioners* (Minister of Public Works and Government Services Canada, 1992, 2003, 2009) to show how these serve the ideological practices of the Canadian state.

Institutional ethnography also produces analytic accounts that explicate how things are socially organized to occur. This point is what distinguishes the mode of inquiry from culturalist forms of anthropological ethnographies, which have, historically, focused on interpreting people’s cultural qualities, behavioural traits, or subjective experience. Researchers using institutional ethnography situate themselves and their projects socially and historically. For example, sociologist Gary Kinsman (1997) situated himself as both a participant in and historian of the Canadian AIDS movement. He showed how working in relation to state initiatives pulled Nova Scotia AIDS social organizing into the state’s agenda and priorities. When using institutional ethnography, the researcher takes aim at society’s institutions to uncover the social relations connecting people and their activities to places and people that are often distant from them and outside of their immediate ability to know about these connections. For example, Roxana Ng (1988) explained how job placement programmes in Ontario that intended to serve immigrant women were actually structured to function in the interests of the state. She reported on how her standpoint informants, immigrant women of colour in Toronto (of which she was one), were connected through textually mediated processes in ways that were not readily apparent. These extra-local linkages are what the researcher using this method aims to uncover and present to standpoint informants and other audiences.

**Methodological rigour**

Broadly defined, rigour is “the extent to which research accurately reflects that to which it refers” (Porter, 2007, p. 79). Concern for rigour is from positivist skepticism about the accuracy, generalizability, and credibility of research findings. While there is no universal or universally accepted approach to assessing the rigour of a qualitative inquiry, my working understanding of rigorous research is where the analytic practices that are logically consistent with an accepted, adequately described approach are employed. In this study, I made use of established techniques within institutional ethnography to collect data, analyze these, and report findings. Pawson et al. (2003) suggest criteria to assess the validity, rigour, ethics, and accessibility of research, and advance the acronym TAPUPAS (below). Asking the following questions of my research, I answer all of the questions in the affirmative, which I understand to be a measure of its rigour and quality.

- **Transparency:** Is the process of knowledge generation open to outside scrutiny?
- **Accuracy:** Are the knowledge claims derived from relevant information?

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32 Campbell and Gregor (2004) briefly elaborate on how the analytic strategies used by institutional ethnographers depart from those used by persons pursuing classical forms of ethnography (pp. 86-90).

33 It would be very useful at this time to revisit the method and results produced by Kinsman; as per the state’s significant restructuring of the funding landscape for AIDS service organizations across Canada that is underway at this writing.
Purposivity: Are the methods suitable for the purpose of the research?
Utility: Can practitioners use the findings?
Propriety: Has the research been conducted ethically and legally?
Accessibility: Is the research presented in an accessible format?
Specificity: Does the knowledge produced reach source-specific standards?

It is, however, noteworthy that rigour is not a concept explicitly addressed in the institutional ethnographic literature. Rigour does not appear in the index of the main methods text that researchers using institutional ethnography use, for example (Campbell & Gregor, 2004). Rigour is not generally a topic of discussion in the meetings of the Institutional Ethnography Working Group (described in chapter four) in which I have participated since 2009. However, it is clear that an institutional ethnography is rigorous (and successful) when the researcher clearly and convincingly shows how things are organized to happen in the material circumstances of people’s day-to-day lives; where an explication of the ruling relations that shape or coordinate people’s circumstances is produced. For the results of an institutional ethnography to be rigorous, particular theoretical and ontological commitments must be observed. These points are elaborated on in the sections that follow.

Nine methodological terms
I define and discuss the vocabulary used in institutional ethnography. I use examples from this research and other studies to show the reader how she or he can expect the concepts to be used in this dissertation.34 These explanations build on the definitions that appear in the Glossary at the beginning of this dissertation.

Social relations
These are defined as sequences of actions that shape people’s day-to-day activities and link their activities beyond their immediate setting. The organization of these sequences is interdependent (DeVault & McCoy, 2006). Social relations are simultaneously material — since they are people’s observable activities that are articulated to the activities of others — and reflexive since they are the social lineaments that connect and coordinate people’s actions that happen in concert with one another. These relations are not descriptors of what one person does, or the social relationships between friends, relatives, or family members. In institutional ethnography, and in this research, social relations denote people’s day-to-day practices and the social connections between them. “[P]eople participate in social relations, often unknowingly, as they act competently and knowledgeably to concert and coordinate their own actions with professional standards or family expectations or organizational rules” (Campbell & Gregor, 2004, p. 31).

Liza McCoy (2006) provides an easy to understand example of the somewhat complex methodological concept of social relations. She writes,

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34 Helpful glossaries exploring these terms in research using institutional ethnography appear in Frampton et al. (2006, pp. 27-38) and Dorothy Smith (2005, pp. 223-229).
You get out of bed, turn on the tap, make coffee, read the newspaper you collected from your front step — and you are participating in [social] relations (municipal water systems, international trade, the mass media) (p. 111).

Dorothy Smith (2005) also provides an instructive explanation.

Watching television, reading the newspaper, going to the grocery store, taking a child to school, taking on a mortgage for a home, walking down a city street, switching on a light, plugging in a computer — these daily acts articulate us into social relations of the order I have called ruling as well as those of the economy; what we pick up when we’re out shopping will likely have been produced by people living far away from us whom we’ll never know (p. 18; italics in original).

The conceptual heart of institutional ethnography is social relations. The researcher sets out to learn about and uncover sequences of connected and coordinated actions. Dorothy Smith (2005) notes that it is “useful, analytically, to think of social relations as temporal sequences in which the foregoing intends the subsequent, and in which the subsequent ‘realizes’ or accomplishes the social character of the preceding” (p. 228). In this study I started within refugee and immigrant accounts of their everyday practices related to mandatory HIV testing. I learned about their experiences and activities related to the immigration medical examination in which the testing is set. The analytic intent was to bring to light the details of their interactions with the state and the state agents who implement, carry out the testing, and medically assess for in/admissibility applicants found to be living with HIV. Sequences of action in this research included the standpoint informant discovering that an HIV test was mandated by the Canadian state; the person finding a DMP and submitting to the HIV testing; the person having blood drawn; the laboratory processing the blood and producing a report based on results; the DMP receiving the report and sending the person for additional diagnostic blood testing; the results of these being sent to the DMP, and so on. This is an example of a sequence of action based in the experience of standpoint informants that will be examined in the empirical chapters five to seven.

The process of explicating social relations has been compared to map-making: where social relations are schematically charted out and offered up, textually or visually, for the reader to interpret or use (D. Smith, 1990). This appears to be one of the method’s central metaphors, which is made most explicit in Campbell and Gregor’s (2004) guidebook. This resource outlines practical strategies for using institutional ethnography to pursue critical social science research.

Social organization

The interaction of social relations, “of people’s ordinary activities being concerted and coordinated purposefully”, is central to social organization (Campbell & Gregor, 2004, p. 27). The material and reflexive coordination of people’s actions that are observable and reproduced across time and place constitutes the social organization of people’s day-to-day practice. Standpoint informants in this research must present to a Canadian state
appointed doctor’s office to be mandatorily tested for HIV, tuberculosis, and syphilis; standard protocol and practices occurring in Canadian and international medical offices. This study found that within the state’s policy text or framework, and within the practices associated with testing applicants for HIV, there are very distinct, disease-specific ideas about contagion, hidden forms of disease, and moral understandings about HIV infection and AIDS. HIV as a social form is shown to occupy a unique place in government planning, programming, and practice. This exceptional social location informs and shapes the material work practices of state agents, and affects standpoint informants in ways that are problematic for them. The organization of standpoint informant experience is materially and reflexively shaped by the interaction of all of these social relations.

**Ruling relations**

These are the connections within a web of relations that organize and regulate people’s experience.35 Knowledge, culture, science, professional discourse, bureaucracy, and corporations are examples of ruling relations, and an assumption is that people are organized by, through, and as a function of these.

Ruling relations embody the concepts of power and state as used similarly in other methods and theories that share similar ontology and epistemology to institutional ethnography (Foucault, 1980; Rabinow, 2010). However, one distinction is how institutional ethnography conceives of texts or documents as active, social relations that exist between people who enact them in their doings. In contemporary societies, some aspects of ruling are accomplished through people’s use of texts that they encounter and use in their day-to-day activities. In this way, ruling relations are embedded in and part of what people do; power and state are not reified or “‘thingified’ [where] human agency and activity disappears” (Frampton et al., 2006, p. 37). The following example of class conceived as a social relation rather than a classification category usefully illustrates these points.

[Dorothy Smith extends] this critique of reification into the realm of sociology and sociological theory to describe how mainstream sociological theory lays out rules and regulations for transforming what people do together in the social world into a series of categories, concepts and things that make the social relations between people disappear, and converts them into relations between sociological categories, variables, and concepts. For instance, class in much of sociology becomes a classification scheme; a thing and not a social relation between groups of people” (in Frampton et al., 2006, p. 37).

In using texts, people become involved in activities that carry particular interests and relevancies that are often outside of their own. Research aiming to make ruling relations explicit, such as this project, explores whose interests are advanced, and how these

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35 Marie Campbell and Ann Manicom (1995) first adopt the term ‘ruling relations’. This very interesting volume presents the contributions of seventeen researchers and social reformers who use institutional ethnography.
interests manifest and play themselves out in people’s lives. Ruling relations are types of social relations that are mediated by texts, and these include, but are not limited to, print, film, television, photographs, assorted electronic media, and the Internet.  

Ruling relations can operate by replacing people’s experience with textual accounts of experience; obscuring and transforming how and what can be known. The following discussion illustrates this point. Dorothy Smith (1990a) writes about transformation of lived experience into textual reality in her analysis of the death of Virginia Woolf. She analyzes an existing published account of Woolf’s struggle with mental illness and subsequent self-inflicted death. She points out how the account in question represents Woolf’s choosing to end her life as a suicide. Smith calls our attention to the abstraction that has occurred through this account. That is, a clinical diagnostic (suicide) has come to represent Woolf’s action (killing herself). Woolf ending her life was the empirical happening, whereas suicide is the medical abstraction of the event. The point Smith makes is that textual realities transform empirical experience (see D. Smith, 2004, pp. 452-454). Abstraction occurs in people’s writing and thinking practices, as seen in this example; concepts and categories supplant social experience and obscure social relationships. The basis for Dorothy Smith’s (1990a) critique of ideological practice work such as that described in this example is in Marx and Engels (1846, 1970; see ‘cat eats mouse analogy’). She extends their thinking in this area by arguing that abstractions coordinate people’s practices, thinking, and understanding, which Smith (1990a) calls a process of ideological circularity (see pp. 93-100).

In this project, the mandatory HIV test itself embodies relations of ruling. The test is a social practice that the state frames as a necessary medical diagnostic to perform on applicants for Canadian permanent residence. Standpoint informants come to be organized by, through, and in relation to an HIV-positive result discovered through the testing of their blood for the presence of HIV antibodies. Examining how people engage with texts to explore, uncover, and critique “ruling processes” for how they objectify people’s experiences and consciousness is of analytic interest in research employing institutional ethnography (Mykhalovskiy & McCoy, 2002, p. 19).

**Texts and documents**

Institutional ethnography incorporates texts such as those listed immediately above in particular ways that do not include analyzing a text in isolation from what people do with it; texts are not recognized as discrete topics, but rather for how they enter into people’s activities. There is focus on the materiality of texts since this focus allows us to see how they are used in our day-to-day practices while at the same time connecting us through social relations to other places. An assumption is that ruling relations are enabled by the ability to produce, reproduce, and replicate texts across time and place.

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36 See DeVault and McCoy (2006, p. 33) for examples of the types of texts used in research drawing from institutional ethnography. Researchers using this method have innovatively looked at how people activate a photographic text using wedding photographs (McCoy, 1995), and how musical scores activate socially organized practices (Warren, 2001).
Texts have a “fixed and replicable character, for it is that aspect of texts — that they can be stored, transferred, copied, produced in bulk, and distributed widely, allowing them to be activated by users at different times and in different places — that allows them to play a standardizing and mediating role” (DeVault & McCoy, 2006, p. 34).

Through the reproduction of texts in people’s activities “the stability and replicability” of institutions is ensured (D. Smith, 2005, p. 45). In their day-to-day activities and through their labour, people create, use, share and transmit texts. Analytically, it is here that texts are interrogated for how they are activated in what people do with them: how people’s textual work coordinates sequences of action through time and across place. Within these documents are clues to textually mediated discourses that “frame issues, establish terms and concepts, and . . . serve as resources that people draw into their everyday work processes” (D. Smith, 2005, p. 45). The researcher examines documents “for the ways they mediate relations of ruling and organize what can be said and done”, paying attention to ideological forms of work that are carried out through texts (D. Smith, 2005, p. 45).

In this study, I talked to standpoint and extra-local informants about their work and what documents they use as part of their day-to-day practice. I paid “close attention to textual practices” as an analytic strategy during fieldwork (DeVault & McCoy, 2006, p. 34). I was attentive to what was written on the forms that informants showed me; how persons were introduced to forms and documents; what work informants did with the forms; what channels texts travelled through once informants had finished with them; and, how documents used in daily activities intersected, interacted, and depended on other texts.

I learned that all activities that informants do in relation to immigration HIV testing comes into being and are organized under the Immigration and Refugee Protection Act (S.C., 2001, c. 27) (IRPA). This was identified as the boss or governing text in this study; an official document at the top of a hierarchy of documents that is the central authorizer and organizer of people’s activities and work practices. Dorothy Smith (2010) explains the meaning of boss texts,

Boss texts . . . are authorized, through some definite institutional procedure, so that the actions they . . . authorize can be treated as acts of the institution . . . of institutionally designated individuals [Health Management Branch personnel or DMPs, for example]. The boss texts coordinate organizational . . . relations [so] how people work is controlled in conformity with the selective requirements of the boss text. [When they are written in institutional discourses, boss texts] supply categories and concepts. There are layers and layers of them (n.p.; on file with author).

The IRPA supplies the categories and concepts that are seen in layer after layer of subsidiary texts that come into being through it. The HIV testing policy framework is an
example of a text that gets its authority from IRPA. This whole family of documents organizes and coordinates standpoint informant’s experience, and enables state agents to carry out certain practices on them. This is an example of how, as DeVault and McCoy (2004) put it, “texts are like a central nervous system running through and coordinating different sites” (p. 765).

**Discourse**

This is a “systematic way of knowing something, that is grounded in expert knowledge and that circulates widely in society through language, including most importantly language vested in texts” (Mykhailovskiy, 2002, 39). Discourses are socially organized activities that circulate among people and through institutions, and they exist because people bring them into being through their social interactions. Marjorie DeVault and Liza McCoy (2006) write about the interactive relations between people, texts, discourse and ruling relations. They explain,

Discourse refers to a field of relations that include not only texts and their intertextual conversations, but the activities of people in actual sites who produce them and use them and take up the conceptual frames they circulate. This notion of discourse never loses the presence of the subject who activates the texts in any local moment of its use (p. 44).

Discursive practices coordinate people’s lives and produce and reproduce different forms of knowledge. This means that society’s dominant institutions, through which such coordination occurs, constitute interesting and relevant sites of investigation to search and learn about the subtle ways in which coordination happens.\(^{37}\) In this study, IRPA provides a conceptual frame and particular set of terms. I came to find out that cost, health, and safety — three of IRPA’s central concerns and organizers — come to bear in the day-to-day lives of standpoint and extra-local informants who regularly use IRPA terminology and borrow from concepts established in it. I investigated how people talked about each of these concerns, and I inquired into they ways in which they shaped their day-to-day experiences. Standpoint informants were aware of the high costs of their antiretroviral medicines. They spoke of wanting to quickly find paid employment in Canada so that they would not be ‘economic burdens’ on the state. From the understanding of many standpoint informants, private insurers, organized through their employer, defray medicine costs thus unburdening the government of expenditure for their treatment. The reference to economic burden and concerns for the costs to the public purse echoes the language found in IRPA, as well as a number of its subsidiary texts.

Dorothy Smith (2005) writes that discourses “come to stand over [and] against [people], overpowering their lives” (p. 41), which makes them important activities to investigate and understand. Consistent with Michel Foucault’s (1972, 1981) use of discourse,

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\(^{37}\) For an examination of how the concepts of global governance, gender mainstreaming, and governmentality are used and analyzed in a recent study that used institutional ethnography, see Campbell and Teghtsoonian (2010).
institutional ethnography centers on uncovering asymmetries of social power within social practices of language, and exposing the effects these have on people. “Discourse constrains what [people] can say or write, and what they say or write reproduces and modifies discourse” (D. Smith, 2005, p. 224). Different from Foucault’s use of discourse is the way that institutional ethnography conceives of discourse originating in and existing only because of people’s participation in particular ways and at particular times in textually mediated social relations.

**Standpoint and standpoint politic**

Taking up women’s standpoint as a place to begin locates the knower in her body, in a lived world in which both theory and practice go on; in which theory is itself a practice (D. Smith, 1999, p. 7).

Standpoint is a social position from which an institutional ethnographic investigation begins. The position is within the bodily experience of a given group of people, and the researcher inquires into the concerns and social problems of the people that occupy this stance. This particular perspective explicitly informs this study and its research design. Choosing a place from which to begin establishes a subject position and offers an alternative starting point to “the objectified subject of knowledge of social scientific discourse” (D. Smith, 2005, p. 228). A standpoint location from which to scrutinize ruling relations and uncover social organization is central to institutional ethnography (see D. Smith, 1987, pp. 181-190).

Knowledge gathered from a standpoint allows knowledge to be transformed in the interests of the people occupying this position. For example, findings from this study point to the absence of HIV test counselling when standpoint informants receive a diagnosis for HIV. I delved into and examined the state and state agents’ practices around this to understand how it is that this care does not happen. Through this study, I produced an explication of how things are organized against the possibility of counselling occurring by looking at the social and ruling relations within the immigration medical examination. By scrutinizing these social arrangements, improvements to care and other changes in the interest of immigrant applicants can be made where things go wrong or are problematic for people.

The concept of standpoint and how it is applied in institutional ethnography is effectively communicated in Dorothy Smith’s (2006) “woman’s standpoint” drawing (p. 3) (Figure 6). In this illustration, Smith draws from her experience as a woman, mother, and university instructor. We see a central character in the bottom centre of the drawing. She stands, as a participant, within a complex of social relations that organizes

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38 In institutional ethnography, what can be known from the social relations that connect people’s activities is the privileged form of knowledge. Standpoint epistemology, in contrast, favours the knowledge of one group over another. A methodological assumption in institutional ethnography is that knowledge from any standpoint is partial because people know the social world from within their particular location within it.
her experience. As a single mother, she participates in activities relating to parenting and teaching, and there are experiences stemming from these activities that are puzzling to her. She asks herself, ‘how is that that academic discourse on the well being of families led by single parents does not coincide with my experience?’

Figure 6. Dorothy Smith’s standpoint informant diagram

The woman protagonist sketched into the base of this diagram sets out to analyze the social relations that exist between single parenthood and educational institutions. This act of looking, investigating, and uncovering the lineaments of the socially organized ruling relations such as discourses on single parenthood, professional competency, and government social and economic policies on the family — all of which she is involved in as an active participant — is pictured here as the woman “looks up through [an institutional] complex from her standpoint, discovering just how it works so that she is engaged as she is” (p. 3).

Because of the effectiveness of this illustration in capturing and communicating key features of the method — what is meant by standpoint, in whose interest institutional ethnographic research is carried out, and how people come to know themselves through discursive concepts — I produced an adaptation of Smith’s illustration in ways that made it a useful visual tool during data collection. This is described in the next chapter as illustrated in Figure 8.

Standpoint binds the researcher to the knowledge of the people for whom the study is designed (see D. Smith, 1987). It requires the researcher to align with the experiences and activities of the people who occupy the research standpoint. For example, in her research on the organization of nursing work under new regimes of management, Janet Rankin took up nurse’s standpoint. She maintained their perspective while she conducted fieldwork in a variety of hospitals as an important methodological feature of her work. “[Rankin] heard what was actually happening from their [nurses’] perspective.”
She accepted their accounts as true [but not as truth]; after all they were living these experiences” (Campbell & Gregor, 2004, p. 50). Like Rankin, I maintained a position on standpoint informants’ side of knowledge relations throughout the research.

Adopting and maintaining a perspective within knowledge informed by bodily experience rather than official and so-called ‘objective’ knowledge is a political position and explicit research choice. An assumption in research using this brand of social inquiry is that starting from within the standpoint of oppressed or exploited people can reveal aspects of the social world that are invisible from other social locations (see D. Smith, 1987, 2005). This is how institutional ethnography as a research strategy is valuable. In an article on which Janet Rankin and I are in the midst of collaborating, we focus on standpoint to examine how this position shaped our respective data collection and research decisions about interviews in two separate projects using institutional ethnography (as per Appendix G6). We argue that choosing a position on the side of persons with “insider’s knowledge” of the social organization of a given experience because they have lived it is one way in which this mode of inquiry is an activist research strategy (Frampton et al., 2006, p. 32). Rankin and I refer to and explore this as the ‘politic’ of research using institutional ethnography. Knowledge built from a commitment to remain grounded in the empirically observable material circumstances of a standpoint contrasts — at times uncomfortably — with knowledge collected using numbers, measures and theories; paradigms that construct so-called ‘objective’ knowledge to understand the social world (see Gillies & Alldred, 2002; Gryndonck, 2006).

**Problematic**

A problematic is a problem arising in social relations between people and the world they inhabit. It stems from and relates to how society is organized. The concept provides the organizing frame and gives direction to research that starts from within the activities and relevancies of standpoint informants.

In institutional ethnography, a research problematic is different from a research problem as commonly understood because it is only after the researcher dialogues with informants during fieldwork that the problematic forms. For example, my motivation for designing this project was discovery of the disjuncture in knowledge that I described in chapter one. However, the point of this research was not to take issue with this disjuncture per se. A first analytic strategy was to find out details of people’s experience with immigration HIV testing — to learn “how people who live it, talk about it” (Campbell & Gregor, 2004, p. 47). Then I needed to think about what the social relations in which people are involved. Last, I needed to work to make explicit the connections between these and ruling relations in which people are implicated. To begin to do this work, I needed to learn about standpoint informant experience with immigration testing and how their HIV diagnosis gave rise to particular condition-specific experiences as per their interactions with the Canadian state and its agents.
An assumption in institutional ethnography is that listening to and learning about what is problematic for people leads to the possibility of uncovering features of their social experience that are unnoticed or taken-for-granted. This form of social inquiry reveals clues about how people are connected with broader social organization and ruling relations. Dorothy Smith (1981) writes that the problematic “organizes inquiry into the social relations lying ‘in back of’ the everyday worlds in which people’s experience is embedded” (p. 23). For example, the problematic in Rankin’s work was formulated through preliminary data collection among Canadian nurses (Rankin & Campbell, 2006). She used the problematic as a tool through which to “link nurses’ everyday work with the institutional structures that shape practice” (McGibbon, Peter & Gallop, 2010, p. 1356).

After reflecting on what I learned from the standpoint informants who participated in this study, I knew what did not work for them, and what occurrences were puzzling, difficult and troubling. From here, I could formulate the study’s research problematic; a place from which I could investigate, through additional fieldwork and engagement with extra-local informants and key texts, the ruling relations in which standpoint informants were tangled. The analytic work in this research focused on mapping out and explicating the work of state agents and the government’s work organization as these relate to standpoint informant’s experiences with the activities and practices involved in Canada’s mandatory immigration HIV testing program.

**Experience**

In projects drawing from institutional ethnography, this term is used to provide grounding in people’s social experience. Analytically, the term is used as a basis for providing clues about the coordination of people’s lives and the societies in which we live. Experience is conceived as what people know through their bodily being and social activity; or what in anthropology is known as the process of embodiment.

Experience is not understood as individual or as a form of truth. A successful institutional ethnography supersedes a single account of what informants experience because the inquiry’s purpose is to uncover details about the social links connecting people’s local, immediate world to the world of people living, working and studying elsewhere. A purpose of conceiving of experience in this way is to contrast the so-called objective forms of knowing, which are generated apart from people’s social experience with the world. Knowledge created informed by the actual, material circumstances of people’s lives “can start us in a place that is in rupture with ruling ideologies and social discourses” (Frampton et al., 2006, p. 31).

In this study, standpoint informant experience with immigration HIV testing and the practices within the immigration medical examination were the basis for exploration into the state’s practices around the operating and carrying out of mandatory HIV screening. Results show that people’s material experience with HIV testing is at odds with official, authoritative accounts of what happens to people through testing and disclosure of positive test results. This research makes visible the organization of some
features of the state’s ideological work in maintaining the appearance that people are experiencing certain practices, such as HIV test counselling, at the time they receive a diagnosis of HIV seropositivity. Standpoint informants are conceived of as the expert knowers of the events of their lives since “only the experiencer can speak of her or his experience” (D. Smith, 2006, p. 224). These informants were valued as authorities on what happened to them through Canadian immigration medical procedures.

**Work**

Research drawing from institutional ethnography uses the term ‘work’ as a metaphor to direct attention to day-to-day practices in which people engage and that their labour produces. With this understanding, work includes formal participation in the labour market, but it also encompasses all sorts of activities that people do that might not normally be construed as work. So in this mode of inquiry, the concept is defined as activities that “people do that tak[e] some effort and time, that they mean to do, that rel[y] on definite resources, and [that] is organized to coordinate in some way with the work of others” (D. Smith, 2005, p. 46). Dorothy Smith (1987) explains, “expanding the concept of work . . . requires its remaking in more ample and generous forms” (p. 165). This generous conception of work draws from feminist thought where, through an expanded idea of work, the contributions of women’s domestic labour — otherwise taken-for-granted, invisible or unacknowledged — were exposed and accounted for.

Work is both the external bodily practices that people undertake and their thinking and consciousness. In *Feeding the family: The social organization of caring as gendered work*, sociologist Marjorie DeVault (1991) makes visible the forms, quality, and quantity of the different work that women undertake to provide food for their families. DeVault points out that women make food choices at the supermarket, make decisions about most affordable prices and shop comparatively, anticipate healthy menus, coordinate meal times to suit the schedules of their husbands and children, and cook, prepare and serve food to the latter. In this way, DeVault demonstrates that there are a myriad of activities that come together in the coordination of feeding a family. Many of these practices go unseen until such as time as they are conceptualized as forms of work and accepted as central to a family’s functioning.

In this research, the activities that standpoint informants engaged in to successfully immigrate to Canada as permanent residents are conceived of as forms of work within a larger immigration application work process. This process takes a lot effort, thinking, planning, and investment in time and financial resources. This work process provided a framework for the dialogue between standpoint informants and myself. I drew from Liza McCoy (2006) who suggests thinking of work as an “empirically empty term” into which the rich and detailed descriptions of people’s day-to-day activities are added (p. 110). Generally, standpoint informants taught me about the details of their immigration application work from the point in time they arrived in Canada. Their descriptions of their day-to-day interactions with state agents in institutions of immigration and health revealed clues about the social organization of their experience, and provided hooks into the ruling relations that govern them.
In preparing to speak with informants, I was aware that using ‘work’ as a conceptual frame for dialogue had been problematic in prior research using institutional ethnography because it confused informants. The Making Care Visible Working Group (2002), whose work investigated people’s health decision-making and produced a counter narrative to dominant discourses on rational decision-making based in the empirically observable and material circumstances of people’s lives, describe how their standpoint informants, people living with HIV in Toronto, initially understood work as their formal participation (or not) in the Canadian labour force. Realizing this, the team readjusted their use of language, abandoned talking about work per se, and explained to informants that they were interested in learning from was about the sorts of things — activities, practices — that they undertook on a day-to-day basis to look after themselves; focusing on what they did to take antiretroviral medicine. Based on this Working Group’s experience using the concept ‘work’, I chose to avoid using it. Alternatively, I employed such terms as ‘activities’ (activités), ‘sorts of things’ (chooses), and ‘events’ (événements), anticipating (correctly) that informants would be more clearly understand these words in relation to their quotidian activities.
Chapter 4. Ethnographic fieldwork
In this chapter, I provide a detailed overview in three sections of the project’s data sources, collection activities, and analysis strategies. I give information about key research decisions and techniques that led me to learn about the contours and details of standpoint informant experiences and activities relating to mandatory HIV screening, which in turn provided the opportunity to uncover details about their social organization and ruling arrangements. In a last section, I examine two fieldwork challenges that I encountered, and explore what I learned from them.

Preparing for and entering the field
This study is informed by two main data sources: human and textual sources developed, organized and used by people. From fall 2009 to spring 2010 I interviewed thirty-three standpoint informants and twenty-eight extra-local informants who were for the most part located in Montréal, Ottawa, and Toronto. Three persons were at once standpoint and extra-local informants since they had both lived the experience of being immigrants with HIV, and were employed in a professional capacity with immigrant and refugees living with HIV. Most semi-structured, open-ended interviews were in person and one-on-one. Because of distance, two standpoint and four extra-local informant interviews were conducted by telephone. For example, I spoke on the telephone with a standpoint informant in Brazil and another in Alberta. I also organized two focus groups and two participant observations with standpoint and extra-local informants. I conducted standpoint interviews in Montréal before interviewing standpoint informants in Toronto. I worked in reverse for extra-local informant interviews for reasons of economy. I conducted one of these extra-local interviews in Ottawa.

Standpoint informants
Table 8 provides details about the thirty-three standpoint informants who participated in this project. These include demographic, country of citizenship, HIV and immigration statuses, gender, and other relevant information. The five inclusion criteria for standpoint informants were: having undergone mandatory HIV testing for Canadian immigration purposes; having arrived in Canada in 2002 or after; having an HIV-positive serostatus; being aged eighteen years or above; and, being conversant in English or French, or accepting to work through interpretation.

Interviews with standpoint informants were primarily conducted in English and French, with additional languages including Amharic, Cantonese, Mandarin, and Mongolian. One interview was conducted in each of these languages, and in these instances, an interpreter was used to communicate with informants. These informants could not read English or French. As such, the interpreter and I read and explained the consent form to each person. There was one other French-speaking informant who could not read French. I likewise discussed the consent form with her before we began our dialogue.
Table 8. Study’s standpoint informants

<table>
<thead>
<tr>
<th>Individual interviews</th>
<th>33 (31 in person, 2 over the telephone)</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV+ women</td>
<td>16</td>
</tr>
<tr>
<td>HIV+ men</td>
<td>13 (+ 4*)</td>
</tr>
<tr>
<td>HIV-</td>
<td>4 (3 women, 1 man, 3 in Canada on work permits, and 1 refugee applicant from within Canada)</td>
</tr>
<tr>
<td>Age</td>
<td>Between 19 and 55 years</td>
</tr>
<tr>
<td>Immigration category</td>
<td>1 skilled worker (economic); 2 refugees who received Canadian permanent residence from outside of Canada; 4 spousal (family) applicants; 20 refugee applicants who applied for refugee status from within Canada (status both accepted and pending); 2 humanitarian and compassionate applicants</td>
</tr>
<tr>
<td>City of interview</td>
<td>Montréal: 15</td>
</tr>
<tr>
<td></td>
<td>Toronto: 16</td>
</tr>
<tr>
<td>Informant citizenship (22)</td>
<td>Botswana, Brazil, Burundi (3), Cameroon, Chad, China, Congo (Brazzaville), Côte d’Ivoire (2), Egypt, Ethiopia (2), Malaysia, Mexico (4), Mongolia, Russia, Rwanda (3), St. Vincent and the Grenadines, Taiwan, United Kingdom, United States, Venezuela/Italy (dual), Zimbabwe (4)</td>
</tr>
<tr>
<td>Language of interview</td>
<td>Amharic: 1</td>
</tr>
<tr>
<td></td>
<td>Cantonese and Mandarin (used alternatively within same interview): 1</td>
</tr>
<tr>
<td></td>
<td>English: 20</td>
</tr>
<tr>
<td></td>
<td>French: 10</td>
</tr>
<tr>
<td></td>
<td>Mongolian: 1</td>
</tr>
<tr>
<td>Focus group</td>
<td>1 in Montréal (6 men, 2 of whom I had previously individually interviewed for this study)</td>
</tr>
<tr>
<td>Observations</td>
<td>2 in Montréal among persons accounted for in this table and in Table 9</td>
</tr>
</tbody>
</table>

*Four men participated in a focus group.*

Standpoint informants were citizens of twenty-two countries, with greatest regional concentrations from Africa (10) and the Americas including the Caribbean (6). Informants entered Canada under a variety of Canadian immigration application categories (as per Figure 2), including refugee, family class, temporary resident, visa...
holder, and no visa required (i.e., for persons from St. Vincent and the Grenadines, the United States, and Mexico. At the time of this research, Mexican citizens did not need a visa to enter and remain in Canada. This has since changed). I had hoped (and planned) to talk with standpoint informants from a wide variety of immigration categories. As it turned out, however, the case selection was such that the vast majority of standpoint informants with whom I met were refugee applicants to Canada. This is because the mandatory HIV testing policy successfully screens out applicants with HIV who are neither refugee nor family class applicants, as previously discussed. Individuals were at different points in their immigration application process. Two persons I talked with had had their refugee application denied and were in the midst of making a humanitarian and compassionate ground application to remain in Canada.

With a study design drawing from institutional ethnography, there is no proscribed number of informants. Instead, emphasis is placed on features of experience, diversity, and social location. It is important that informants have first hand experience with the issues or processes being studied. It is analytically useful if persons represent various diversities. For example, in this study, I recruited approximately equal numbers of women and men standpoint informants with different immigration testing experiences. Persons had applied to Canada from various places in the world, and they differed in sexual orientation. I made efforts to gather information from standpoint informants who originated from countries less well represented in Canadian HIV and AIDS research and literature. For example, I took steps to recruit people in association with organizations serving Spanish-speaking, Asian, and South Asian immigrants in Toronto. I also made efforts to recruit people with diverse sexualities among ethno cultural groups in Montréal. Since standpoint and extra-local informants interact and intersect in different ways with the mandatory HIV testing policy, data arising from these different locations were valuable.

Standpoint informant response to the study far exceeded my expectations. In addition to the thirty-three persons with whom I spoke, I was contacted by approximately thirty other people who were interested in taking part; people from countries such as Haiti, Honduras, Jamaica, Libya, Romania, Tanzania, and Uganda who were all new immigrants to Canada living with HIV. Generally, I spoke for at least fifteen minutes on the telephone with all of these people: answering questions, receiving comments, and hearing people’s immigration stories. Some of these people were ineligible to take part because they were Canadian-born, First Nations, infected with HIV after they arrived in Canada, or they had immigrated to Canada before January 2002 when the testing policy came into force. Many callers asked to be kept informed about the study results, and provided me with their contact details. I intend to email a summary of study findings to all those people who so requested.

I initially anticipated interviewing ten people in each city, as per my project proposal defended in May 2009. However, I accepted to interview more people because it came to my attention through fieldwork that a person’s immigration status as defined in the Immigration and Refugee Protection Act (S.C., 2001, c. 27) (IRPA) influences the type of
activities that she or he engages in prior to arrival in Canada and once resident in the country. I speculated (correctly) that there was analytic interest in interviewing informants who had been classified in a number of Canadian immigration categories since this difference provided unique clues about standpoint informant activities, which in turn informed about various institutional and social relations in which they were implicated through their immigration application work. I also prioritized gathering a wide variety of people’s experience with HIV testing because I anticipated that these experiences could be organized differently depending on country of origin and whether the person was medically tested in Canada or outside.

In this research, there are four individuals who are grouped as standpoint informants who meet all of the inclusion criteria except HIV-positive status. While another informant category could have been created, such as key informant, I retain the position of these individuals within the standpoint informant group for two reasons. These people provided carefully told and detailed descriptions of the events surrounding their immigration application work process and the medical examination in particular. Their HIV status notwithstanding, each of these informants had a social location that made their participation informative to this study. “I have something to say on the matter from my experience with this testing,” said one of these informants.

Second, for a variety of reasons, these people had been particularly attuned to how the Canadian state and its agents who carried out mandatory HIV screening handled the matter of testing at the time they undertook the obligatory medical examination. I learned from them that their close attention to the material circumstances of their HIV testing was because of their professional training and interest in HIV. One of these informants was a public health nurse with training in public health ethics and HIV. Another of these informants was a public health nurse with training in harm reduction. A last of these informants was a lawyer with expertise in human rights and HIV. Thus their first-hand experience with having no choice about whether to take an HIV test, and their education and professional experience with HIV, resulted in particularly self- and institutionally-aware observations. Where the activities of these four standpoint informants are referred to in this dissertation, I state so; making clear their unique place within the larger set of standpoint informants of which they are part.

*Extra-local informants*

Table 9 details characteristics of the twenty-eight extra-local informants who informed this study. The three inclusion criteria for extra-local informant participation were: having experience working with HIV-positive applicants to Canada; having working knowledge of the country’s mandatory HIV screening policy; and, being conversant in English or French, or accepting to work through interpretation. There was, however, no need for use of interpreter with these informants.

These second phase data were gathered through interviews generally conducted in English in Toronto, and French in Montréal and Ottawa. Most extra-local informants worked somewhat personally with standpoint informants in various ways and at various
points throughout their immigration application process. This group includes immigration and legal aid lawyers, HIV physicians, social workers, HIV nurses, case workers in AIDS service organizations, and temporary shelter personnel. At further distance from standpoint informants are a set of extra-local informants who come into contact with many standpoint informants early on in their immigration trajectory. This group includes a Canadian Border Services Agency employee, three DMPs, a Toronto Public Health senior medical officer, and two public health nurses. The two extra-local informants who did not have direct, personal interactions with standpoint informants including a Citizenship and Immigration Canada employee and a former senior government medical advisor.

Table 9. Study’s extra-local informants

<table>
<thead>
<tr>
<th>Extra-local interviews*</th>
<th>28 (24 in person, 4 over the telephone)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Between 30 and 65 years</td>
</tr>
<tr>
<td>Sex</td>
<td>8 women and 20 men</td>
</tr>
<tr>
<td>City of interview</td>
<td>Montréal: 3</td>
</tr>
<tr>
<td></td>
<td>Toronto: 20</td>
</tr>
<tr>
<td></td>
<td>Ottawa: 1</td>
</tr>
<tr>
<td>Language of interview</td>
<td>English: 26</td>
</tr>
<tr>
<td></td>
<td>French: 2</td>
</tr>
<tr>
<td>Focus group</td>
<td>1 in Toronto (3 shelter staff; 2 men, 1 woman)</td>
</tr>
</tbody>
</table>

*Three individuals, citizens of Colombia, Hungary and Zimbabwe, were at the same time standpoint and extra-local informants because they had both lived the experience of being immigrants with HIV, and they were working in a professional capacity with immigrant and refugees living with HIV. These three people have been counted once as extra-local informants.
It was my intention to interview additional federal government employees of Citizenship and Immigration Canada associated with the maintenance of the HIV testing policy, as well as medical, visa and immigration officers employed by the government since they are involved in decision-making about whether applicant persons with HIV are accepted or denied for reasons of medical inadmissibility. Very unfortunately, gaining access to these persons proved difficult because of a variety of vetting techniques with which I had to contend. These included delayed or no return communication from my request for an interview, or inaccessible or difficult to locate contact information for the most suitable federal employee.

Designated Medical Practitioners in Montréal and Toronto generally were unresponsive to my written invitation to take part in this study. For example, after several telephone calls and faxes sent to the office of a Toronto-based DMP, I finally succeeded in speaking with the physician. In our brief telephone exchange, he informed me that he could not participate because all of his medical screening work was “property of Citizenship and Immigration Canada”. In the Handbook for Designated Medical Practitioners (Minister of Public Works and Government Services Canada, 2003, 2009), doctors are told repeatedly that they are not to discuss an applicant’s immigration application with them. They are also instructed not to interact with the media about matters related to their immigration medical work (Minister of Public Works and Government Services Canada, 2009, p. 6-2). There is, however, no mention of prohibitions about speaking with researchers or other publics.39

I had anticipated interviewing fewer persons who work somewhat personally and directly with immigrant and refugee persons living with HIV. As I proceeded through fieldwork and my understandings grew, however, I learned about interactions between standpoint informants and a range of persons who were new to me that I anticipated would beneficially inform this study. In the end, I integrated more extra-local informants into the project for reasons similar to those discussed in relation to more than planned for standpoint informants.

**Working with texts during fieldwork**
Consistent with institutional ethnography’s particular relationship to and interrogation of texts, I accorded prominence to locating documents relevant to the HIV testing policy in the lead up to fieldwork. These included IRPA, the Regulations, the HIV testing policy, the Handbook for Designated Medical Practitioners (pictured below; editions 2003 and 2009, respectively), blank medical forms that DMPs fill out and submit to the government on behalf of standpoint informants, provincial government medical surveillance forms, among others. I learned that there were numerous texts that the Canadian government has created in relation to HIV and AIDS. A sample of these

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39 A former Citizenship and Immigration Canada senior medical advisor, who was an extra-local informant in this study, told me that he was not surprised that DMPs generally did not respond to my telephone calls or fax transmissions. He confirmed that a change to the Handbook for Designated Medical Practitioners from the 2003 and 2009 editions was that DMPs were instructed not to talk to the “press”.

128
appears in Table 10, and I return to some of these documents in later chapters. I reviewed these official, publicly available (albeit difficult to locate in some case) documents relating to the mandatory HIV screening policy. The goal in this textual review was to build understandings about the work processes in which the texts are located as they are brought into being and used in people’s work practices.

I continued to search for and review relevant documents during and following immersion in the field. I anticipated discovering previously unknown (to me) documents, forms, references, websites, and other resources that standpoint and extra-local informants use in their daily practices. This turned out to be the case. For example, during the first standpoint interview with Mariam in Montréal I learned about government-issued refugee applicant identification documents and the refugee application package — a central part of which is the Personal Information Form that details the refugee applicant’s story and need for seeking protection. For the refugee applicant to Canada, the latter text provides details about the circumstances of the person’s reasons for leaving her or his country. Woven into the narrative are the reasons, or grounds, for seeking protection from the Canadian state. Through this form, the person’s story is transformed into a request or claim to the Canadian government. This is a key form in many standpoint informants’ application work process. Mariam carefully explained to me how and when she uses these documents. The details she supplied provided me with clues about the work that she carried out in relation to numerous other persons and institutions.
Table 10. Official texts guiding state agents’ work on immigrants with HIV

<table>
<thead>
<tr>
<th>Year</th>
<th>Title</th>
<th>Details</th>
</tr>
</thead>
</table>
| 2002 | “Operations Memorandum” by CIC’s Medical Services Branch, January 15 | “Announcement of routine HIV testing in immigration medical examination, and guidelines for medical, visa and immigration offices. Canada Gazette, June 14  
- Medical officers are referred to use current costing provided by the Canadian Institute for Health information.  
“Operational Processing Instruction 2002-004, Medical Assessment of HIV Positive Applicants” by Medical Services Branch, July  
- Instructions to medical officers on how to screen applicants with HIV for inadmissibility to Canada. |
| 2003 | “Operational Instructions, RIM 083, New Policy for Automatic Partner Notification of Family and -Dependent Refugee Class Applicants who test Positive for HIV” | - Procedures giving the state authority, through visa officers acting overseas, to inform a Canadian citizen or permanent resident of the HIV status of her or his spouse where this person is overseas and where HIV is detected through the immigration medical examination. Applies only to persons outside of Canada. CIC does not have an equivalent policy relating to spouses who test HIV-positive who are in Canada. |
| 2005 | “Memorandum” by the Medical Services Branch, July 15                 | - Guidelines to medical officers for how to assess temporary residence applicants who are HIV-positive. |
| 2008 | “Operations Bulletin 063, Assessing Excessive Demand on Social Services” by CIC’s Health Management Branch, September 24 | - Instructions designed to inform medical officers to consider all available evidence presented by an immigrant applicant before making a decision of inadmissibility because of excessive demands on social services in Canada. Issued following the Supreme Court decision in Hillewitz v. M.C.I. and de Jong and the Federal Court of Appeal decision in M.C.I. v. Colaco. |
| 2009 | “Handbook for Designated Medical Practitioners” by CIC’s Health Management Branch | - Reference manual that includes medical report and HIV post-test counselling forms that DMPs are to use for the immigration medical examination. |
| 2011 | “IR3 Medical Manual” by CIC, February 25                             | - Tool for CIC visa and immigration officers in their work of assessing applicants against public health and safety criteria.  
“Overseas Processing 15 Medical Procedures” by CIC, February 25  
- Chapter issuing procedures to medical officers about how to conduct their work of assessing and processing the DMPs medical report on an applicant person. This includes how to communicate with HIV-positive applicants via a “Health follow-up handout for HIV infection” form. The chapter includes a template for a document to be sent to applicants who are assessed medically inadmissible (i.e., ‘procedural fairness letter’). |

Note: This is a selection of texts rather than an exhaustive listing of available texts relating to HIV.
In interviews with state employees, a number of texts that came to be important parts in my analysis came to my attention. It was during interviews with three DMPs in Montréal and Toronto that I first learned about the Handbook for Designated Medical Practitioners (Minister of Public Works and Government Services Canada, 1992, 2003, 2009). During these interviews, physicians and I discussed this Handbook and its contents for how it shaped their work practices. I set out to carefully review the contents of the three successive editions of the manuals to which I had access. In these Handbooks for Designated Medical Practitioners, I found complete sets of blank medical forms that I learned constitute an applicant’s official medical file. DMPs complete the forms through the immigration medical examination, sending them on to Citizenship and Immigration Canada for review and decision making about an applicant.

The Handbooks for Designated Medical Practitioners (Minister of Public Works and Government Services Canada, 1992, 2003, 2009) reveal useful information about features of physician work with applicants living with HIV. I would later use these forms in my analysis. For example, DMPs explained to me how forms are filled out and where standpoint informant medical charts travel after they have finished with them. I was introduced to PowerPoint presentations that my Citizenship and Immigration Canada informant uses in her work involving public education and presentations on the mandatory HIV testing policy and the state’s medical in/admissibility determination process to which I return in future chapters (Appendices B2 & B3). This state informant and I discussed the slides during our interview. I wanted to know how she used them in her work. In these three examples, the texts that I learned about were part of informants’ working tools and materials, and these provided topics of conversation and entry points for dialogue in future interviews that I conducted.

Recruiting standpoint informants
The study was advertised in the same ways and through similar channels in Toronto and Montréal. As per University of Ottawa’s late August 2009 ethics approval, I indirectly recruited HIV-positive informants (Appendix C1). This promotion involved virtual and physical work on my behalf. I first used social media to circulate the one-page recruitment notice and letter of introduction in both English and French (Appendix B4). For example, Toronto People Living with AIDS Foundation included the summary in one of its e-bulletins, which HIV-positive members receive monthly. The appearance of the study in this e-bulletin garnered a significant number of responses from both eligible and non-eligible potential informants who most commonly contacted me by telephone to inquire about details of the study. In mid-September 2009, a Latin American man I later interviewed wrote,

I read about your study in the ‘PWA [Toronto People Living with AIDS Foundation] Weekly Programs Update’. I am interested to participate in your study. I am applying for permanent resident in Canada sponsored by a family member and I recently took the medical exams for the process. I think I can give you and your study my feedback and experience with the medical exams and with what I lived.
Second, executive directors and senior staff in AIDS service organizations in Ontario and Québec agreed to post the study materials on their organizations’ bulletin boards for client viewing. Conversations with these persons sometimes led to unexpected opportunities. For example, after discussing this study, a research director at an AIDS service organization in Toronto offered me complimentary interview space in which I later interviewed a half dozen standpoint informants. This was suitable to standpoint informants and me since the location was familiar and conveniently located.

In and around the greater Montréal area, including Laval and the Laurentians, I posted study advertisements in AIDS service organizations and public HIV clinics where there were no particular permissions required or restrictions relating to such postings. I also arranged to have the study advertisement and summary disseminated through the AIDS Committee of Ottawa and the Bureau régional d’action sida Outaouais in an effort to talk with standpoint informants in the Ottawa-Gatineau area. In contrast to Toronto where most standpoint informants learned of my research through virtual means, people in Montréal learned of the work from postings on bulletin boards and by word-of-mouth. No informants in Québec contacted me as a result of postings on virtual sites including Fréquence VIH; the Québec branch of the Association canadienne des infirmières et infirmers en sidologie (Canadian Association of Nurses in AIDS Care) (Appendices B5 & B6); le Portail VIH/Sida du Québec; or various immigration-related list serves with local to international readerships. One person read the recruitment notice at Concordia University’s Québec Public Interest Research Group office. Of standpoint informants interviewed, I knew four women from my prior and ongoing personal involvement in the Montréal AIDS organizational milieu.

Despite concerted efforts to locate people living with HIV outside of Canada whose immigration applications had been denied, this population was not part of the study. I took a number of steps to try to locate applicants whose permanent residence application had been denied. The Canadian HIV/AIDS Legal Network distributed the study’s summary via its international list serve. I also broadcast the call through the Canadian Council for Refugees national listserv. I communicated with Toronto-based lawyers in private and public practice with expertise in HIV and immigration who have significant numbers of HIV-positive clients (some of whom I knew had had their application for Canadian permanent residence denied for reasons of estimated cost). I was interested in having lawyers speak with their clients about this study so that these people could decide whether to participate. Last, I spoke to standpoint informants about my wish to recruit people whose applications had been denied for reasons of medical inadmissibility. In turn, these people communicated with persons in their Diaspora networks who were asked to email or telephone me if they were interested in taking part. These three avenues of exploration were not fruitful in linking me with applicants with HIV whose application for permanent residence had been denied for reasons of medical inadmissibility.
Recruiting extra-local informants
Though some recruitment of extra-local informants occurred through word-of-mouth, I had approval to directly approach these informants. To this end, I placed cold and follow-up telephone calls relying on contacts in my personal and professional networks and results from the exploratory groundwork for this study, described in chapter two. I sent faxes and wrote emails to the extra-local informants appearing in Appendix B1. In Montréal, I sought out an invitation to attend the psychosocial rounds at an HIV clinic where I presented my project to approximately ten staff persons. The intent was to garner interest in the research and recruit staff persons. From this encounter, a nurse with extensive personal and professional experience with HIV-positive immigrant and refugee people contacted me via email, and I later interviewed him.

During the extra-local recruitment phase, I was surprised to learn that the medical world functions primarily on documents transmitted by fax technology. I was initially puzzled at this old-fashioned adherence to hardcopy transmission, which meant more — and more challenging — work for me in my efforts to reach doctors, and DMPs in particular. This mode of communication came to my attention when I needed to get research documents such as recruitment notices and letters of introduction to these informants prior to interviews (as per Appendix B4).

These letters of introduction and consent forms were difficult to circulate expediently and directly because of the fax mode of transmission. Most physicians were unaccustomed to circulating documents via email, which I had planned to use as my primary mode of introduction. I communicated directly by email with a few HIV physicians. I communicated by fax with two DMPs, and through a receptionist with the third. Administrative assistants were skilled at prioritizing documents for physician attention, and since my research represented another form of work for the doctors, having the DMP learn about my research was not always an especially high priority. As fieldwork progressed and I became more attentive to the multiple sources of data, my initial response to these inconveniences became more finely attuned to the social organization of how things were happening in these medical settings. I recognized that my extra-local informants’ documentary practices offered valuable clues into the social organization of their workplaces.

Immersing in the field
The techniques I used to collect data in this project were fairly consistent with those used in other qualitative methods, including forms of classical ethnography where participant observation, focus groups, and interviews are routinely used to generate data; with emphasis on collecting thick, rich data in these interactions. Most often the researcher journals, takes observational field notes, and uses transcripts of audio recorded data. In addition to these forms of collection, the particular emphasis on texts in institutional ethnography required that I identify, locate, and discuss texts and other documentary material with informants. Discussion about how people used texts in their day-to-day work became a topic of dialogue.
There are interview strategies available to researchers drawing from institutional ethnography that assist researchers in their efforts to use texts during interviews. Since I had never participated in interviews that discussed texts, I made use of techniques suggested by DeVault and McCoy (2004) and Campbell and Gregor (2004). In particular, they recommend using dialogue in ways that have researcher and informant stay focused on material happenings. From a starting from place within people’s actual activities and practices, the authors suggest that conversation about empirically observable features of people’s lives can be built around specific events as they are talked about in the order in which they occur.

For example, I asked standpoint informants to start at the beginning of their immigration story, telling me about what happened when they reached the Canadian border with the United States. People began to talk about the activities involved at the border, and I was careful to interrupt and ask for clarification if, in their descriptions, I did not ‘see’ (or could not piece together) their movement through time. I was interested in hearing about the minutiae of what people’s activities entailed so that I could build a chronological storyline. This stopping and starting of people’s storytelling to check my understanding was a useful strategy since the fine details of what we do in our day-to-day practice can go unnoticed and be taken-for-granted. These details are often key to research drawing from institutional ethnography, making it ever more important to make sure that they do not get glossed over, which can happen in circumstances of everyday conversation. Campbell and Gregor (2004) suggest that the researcher must be “attentive and avoid the ordinary conversational etiquette where people assist each other in making meaning” (p. 77) . . . [since] “informants have to say it. Those are data in institutional ethnography” (M. Campbell; my notes on her teleconference lecture, September 7, 2009).

In this research, attentiveness of this kind was ever more important because I was aware that standpoint informants are accustomed to storytelling about details of their immigration process and health status. Some people begin telling oral stories to state agents working at the Canadian border. People tell oral and written stories to lawyers who represent them. They continue telling stories to social workers at HIV clinics through whom their access to social services is arranged, and so on. I knew about all these occasions for people to tell their ‘stories’, and thus I was intent on getting behind and beneath usual forms of narrating to get at different information. I consciously wanted to access different information from the ‘scripts’ people were used to telling institutional actors. Part of how I did this, usually with success, was explaining to people that the study was focused on social relations, ruling arrangements, and material events. I engaged in dialogue about these with the helpful of several useful devices.

While interview questions are not developed in advance of fieldwork using institutional ethnography, given that the problematic and lines of questioning develop progressively during fieldwork, I found it helpful to create and have on hand a chart that displays the method’s theoretical underpinnings and conceptual framework within which interviews in institutional ethnography proceed. These are outlined in Table 11. It was instructive
to reflect on the loosely framed principles therein before and during fieldwork. This table served as a reminder of the analytic focus that I had to maintain to collect good quality institutional ethnographic data: dialogue and observations squarely centered on the material activities of an informant’s everyday experience. The tool was similarly useful when I scrutinized, contemplated, and worked with the data I had collected. In Appendix B7 I provide an example of questions and topics that I talked about with both standpoint and extra-local informants. These questions were framed with guidance from the orienting cues in Table 11.

Phase One
This study occurred in two sequential phases. The first phase spanned from September 2009 to January 2010. During this time, standpoint informants consented to talking with me for one-on-one sessions that were between sixty to one hundred and fifty minutes in duration (Appendix B8). When an informant contacted me by telephone or email to inquire about the study, I was often asked about my motivation for designing an interview-based study dealing with the topics of immigration and HIV. I generally mentioned personal and professional interest in the topics of immigration, HIV, and social and health policy work. I responded openly to questions. The following passage is from my field notes in date of October 5, 2009. It is an example of the opening sentences that I said to informants on the telephone.

I am investigating the mandatory HIV testing policy. I am examining it from the perspective of those who are screened for immigration purposes. I set the policy within the context of government decision-making about immigrants, and particularly those who are found to be living with HIV. What activities do people do as a result of a positive diagnosis at immigration? This is what I am curious about. This is what I am interested in talking and knowing more about; based on your experience and expertise. There are comparatively few immigrants to Canada with the knowledge of what happens through mandatory HIV screening for someone who tests positive. You are one of them. I value and need your knowledge to do this review and carry out this research successfully.

One southern African-born woman, whom I would come to interview, told me that she was not in the habit of responding to research advertisements. Her interest was piqued because of the topics listed in the study advertisement that she saw in the waiting room of the Immunodeficiency Treatment Centre at the Montréal General Hospital. Over the telephone and via email, she explained that she had had difficult immigration experiences over a period of five years. It was through mandatory immigration screening that she discovered her HIV-positive status. This woman agreed to take part in my project after a lengthy telephone call and several email exchanges that probed my safeguards for protecting her identity, the methods, and planned outcomes. (I emerged feeling as though I had undergone a rigorous job interview.) The informant stated that it was her interest to help others, where possible, in avoiding the confusion and frustration that she had experienced with her Canadian immigration application process, and the immigration medical screening in particular. She told me that she was
intrigued by the method of inquiry that she thought held the potential to generate results ‘useful’ for policy work.

As a matter of course, I issued a letter of introduction to interested and eligible standpoint informants after our first communication (Appendix B4). The letter invited the person to contact me if she or he wished to take part. Most people renewed contact with me, and from there we planned for a convenient time and place to meet. When arranging interviews over the telephone, I requested that informants bring with them the texts and documents that they had used in their Canadian immigration application procedures. Whilst some informants produced documents, others did not know what I meant by the request, and still others were puzzled.

Anna, whose immigration application work experiences related to the immigration medical examination are detailed in chapter seven, had already destroyed all of her health and immigration paperwork to prevent her HIV status from being discovered by anyone who might happen upon her documents. This was also the case with several other informants. When this occurred, we worked to recall details of people’s paperwork. As I gained experience with interviews and learned about informant work and how this intersected with the state’s activities relating to HIV screening, I built my knowledge into the interviews to fill gaps such as the absence of physical artefacts.

Most often texts and documents that standpoint informants brought to interviews consisted of official government documents, correspondence, training course material, certificates, completed forms, and references to websites. With one informant, I sat at the computer where she toured me through her Citizenship and Immigration Canada portal, which she accesses via a client identification number. Standpoint informants track the status and evolution of their immigration application through this service. Therein, updates are issued as inputted by federal employees. The majority of standpoint interviews were conducted in informal, home-like settings. In Toronto, I conducted some of these interviews in rooms at AIDS service organizations or in space within a community sexual health clinic if informants did not have stable housing or they shared living quarters. I remunerated all standpoint informants $25.00 for talking with me about their health-related immigration experiences.

All interviews were generally framed within the dialogical tradition in institutional ethnography of “talking to people” (DeVault & McCoy, 2004, p. 756). During the first several interviews with standpoint informants, I worked to generate broad accounts of standpoint informant work and the problems they encountered related to Canadian immigration HIV testing. The assumption that life has a socially organized character that can be empirically explored and researched loosely structured interview dialogue. A particular tone and interest were set early in interviews, and these qualities opened up and oriented dialogue in certain ways (as per Table 11 & Appendix B7). Personal settings such as homes or very quiet spaces after hours in AIDS service organizations were conducive to hearing, learning from, and talking about the details of standpoint informant’s immigration application work. Exchanges in these milieus were routinely
<table>
<thead>
<tr>
<th>Analytic concept</th>
<th>Analytic intent</th>
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<tr>
<td>Research occurs from a particular standpoint rooted in the everyday actions of</td>
<td><strong>Uncover</strong> what issues, troubles and concerns are of priority to standpoint</td>
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<td>standpoint informants. This perspective is maintained throughout an inquiry to</td>
<td>informants</td>
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<tr>
<td>scrutinize the work and organization of institutions</td>
<td></td>
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<tr>
<td>Researcher “thinks organizationally” to investigate work practices and processes</td>
<td><strong>Orient</strong> interviews toward aspects of social organization that coordinate</td>
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<td>in organizational, bureaucratic, and professional sites (D. Smith, 2006, p.</td>
<td>standpoint informant activities (social relations)</td>
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<td>24)</td>
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<tr>
<td>Inquiry is material, empirical, and based in what actually happens in people’s</td>
<td><strong>Listen</strong> to “stories” of what practices, actions and activities informants</td>
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<td>daily lives</td>
<td>engage in (T. Diamond in DeVault &amp; McCoy, 2004, p. 756)</td>
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<td>Problematic is discovered, progressively, through the researcher’s immersion in</td>
<td><strong>Unearth</strong> contradictions in informant’s taken-for-granted understandings of</td>
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<td>the field</td>
<td>how things happen. To discover ruptures where occurrences in the standpoint</td>
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<td></td>
<td>location are translated into official versions (often through texts). These are</td>
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<td></td>
<td>possibly at odds with what informants know or what is observed</td>
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<td>Investigation is focused on picking out organizational features that operate</td>
<td><strong>Identify</strong> the implicit and explicit social relations that inform and shape</td>
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<td>across and through multiple sites, looking at how these are empirically linked</td>
<td>informant everyday activities</td>
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<td>to each other through textual mediation</td>
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<tr>
<td>Inquiry is especially attentive to textual and documentary practices in their</td>
<td><strong>Uncover</strong> ways in which texts and documents organize what informants say and</td>
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<tr>
<td>varied forms</td>
<td>do in practice (discursive organization)</td>
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<tr>
<td>Investigation is interested in how the informant’s social location informs</td>
<td><strong>Open</strong> up windows on the practices and actions of organizations and institutions</td>
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<tr>
<td>her or his knowing and what can be said from this position</td>
<td>because these will provide clues about social organization and ruling relations</td>
</tr>
<tr>
<td>Researcher develops incremental understandings from informants and texts. She</td>
<td><strong>Learn</strong> which texts and documents people use in their daily activities, and</td>
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<tr>
<td>or he follows up on ‘threads’ in the data from one interview or observational</td>
<td>how they activate these. Informants will talk to the researcher about the work</td>
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<tr>
<td>setting to the next</td>
<td>practices of others, so that the researcher will identify extra-local informants</td>
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<td></td>
<td>to interview or physical sites to observe in later stages of research</td>
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longer than anticipated. The privacy of domestic surroundings, the informal comfort and ‘safe space’ these afforded, allowed for silences, detailed descriptions, and clarification. Standpoint interviews also provided adequate time for the informant and I to scrutinize, ponder, and discuss their immigration application documents.

**Phase Two**
The second phase of research took place most intensively from January to May 2010. I did one final interview with a Citizenship and Immigration Canada informant after this period. Extra-local informants consented to participate in individual interview sessions that were most often sixty minutes in length (Appendix B8), making interviews in this phase shorter than those in the first phase. Informants were sent a letter of introduction and interested persons replied with their availability to meet me for an interview. With the exception of two extra-local informants whom I interviewed in my home, and four others whom I interviewed over the telephone, all of these informants were interviewed in their places of work in Montréal and Toronto. The texts and documents referred to and discussed in extra-local informant interviews were commonly computerized case notes, correspondence, standardized government forms, educational pamphlets, presentation notes, data management strategies, blank medical forms, and the *Handbook for Designated Medical Practitioners* (Minister of Public Works and Government Services Canada, 2009).

**Moving locations**
The tandem research phases were marked by such physical shifts as my travel from Montréal to Toronto and back again, and the personal to institutional interview sites referred to above. Institutional ethnographers often interview standpoint informants first and then move into extra-local informant professional workplaces. This is what I did in this study. The aim of sequential fieldwork phases where extra-local informants are interviewed after standpoint informants is to explore with the former the puzzles, concerns and questions that emerged from interviews with the latter. Extra-local informants filled in gaps in my understanding based on information I gathered about features of their work practices and day-to-day activities. For example, through textual analysis and conversations with state employed informants, I was able to piece together the sequences of how the medical file of an HIV-positive applicant moves through different hands and across various locations within the organization of the Citizenship and Immigration Canada bureaucracy.

McCoy and DeVault (2004) suggest that each interview is “oriented to sequences of interconnected activities” that “build up an understanding of the coordination of activity in multiple sites” (p. 757). The assorted personal files that standpoint informants brought to interviews, along with their knowledge about how these documents worked, allowed me to identify and direct myself to relevant service providers, government bodies and personnel, and other resource people who play key roles in the HIV testing and permanent residence application processes. Defining the application process and all the activities it generates as a ‘work’ process, discussed in the previous chapter, provided a framework for dialogue with informants.
Summarizing data collection activities as I am doing here for the reader accurately portrays how I engaged in fieldwork, and explains why I made the research decisions I did. The overview nevertheless neatly and hermetically conceals the reality that fieldwork was a deal more organic, and far less linear, than I am able to convey. Capturing in words the fluidity and fullness of the field research — where phases overlapped and were at times perplexing and disorderly — is difficult. Data collection, including textual review, was a dynamic, engaging and iterative experience. This confirms that “[f]ieldwork and empirical inquiry present a ‘lived dilemma rather than simply the neat achievement presented in [a] written report’ (Yates, 1995, p. 23 in Weinberg, 2002, p. 79). As I explained in chapter two, I moved back and forth from the literature to the field; from audio recordings and transcripts to texts; from city to city; and, from private to public space. Sometimes these actions and my thinking about them bumped up against each other in ways that opened up interesting and unexpected fieldwork experiences.

For example, after I had transcribed a good number of interviews, I thought that there were certain shortcomings in the data and, by extension, my understanding of and appreciation for standpoint informant experience with refugee hearings at the Immigration and Refugee Board of Canada. For one thing, I had never attended a hearing, so I did not have first-hand experience of the very formal government procedure that was central to the immigration application work process of refugee applicants. I only learned later in the process that while these hearings are not open to the public per se, the refugee applicant is authorized to invite a personal friend, for example, to attend. Agreement or permissions for a personal friend to attend must be organized, most commonly through arrangement with the person’s lawyer, in advance of the official procedure.

What I identified as shortcomings led me to develop alternative strategies and venues for data gathering. In late fall 2009 and spring 2010 I initiated opportunities for observational fieldwork among standpoint informants in Montréal. This consisted of three clusters of activities: leading a focus group with Spanish-speaking immigrant men living with HIV; shadowing a woman and her lawyer as they prepared her for her refugee adjudication hearing at the Immigration and Refugee Board; and, accompanying a woman and her lawyer to her interview or hearing at the Refugee Board. I used my contacts among health and legal practitioners, as well as standpoint informants, to

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40 I also learned, but only a short time ago, that written transcripts of these proceedings are produced. The refugee applicant can request a copy. What also came to my attention rather late in this research is the existence of the Canadian Legal Information Institute’s public database that “make[s] Canadian law accessible for free on the Internet” (see http://canlii.ca/en/index.php). A selection of Immigration and Refugee Board of Canada decisions are listed therein. A “full text” keyword search for “HIV” yielded 72 hits on August 7, 2011, and 87 hits on January 2, 2012. See http://canlii.ca/elisearch.do?language=en&searchTitle=Canada+%28federal%29+Immigration+and+Refugee+Board+of+Canada&sortOrder=relevance&searchPage=elisearch#courtSearch.vm&t=csr&jurisdiction=ca&text=hiv&id=&startDate=&endDate).
organize these observations. This fieldwork had not been part of my original research design, and the University of Ottawa granted two amendments to the study’s ethics approval to accommodate this fieldwork (Appendices C2 & C3).

There are limitations with interview-based research since the settings are orchestrated to happen as they do. Since the emphasis in institutional ethnography is learning about what people do in their daily lives, observations of people actually going about their workdays adds to what can be known about the social and ruling relations that permeate a setting. This issue speaks to sociologist Timothy Diamond’s (1992) advice to researchers drawing from institutional ethnography. He comments “in insisting on bodies being there, [we are sensitized] to bodies as part of the data . . . It’s not about just words, but how the words live in embodied experience” (Diamond, 1999 in DeVault & McCoy, 2004, p. 758). Diamond’s point is that considerations of what people’s bodies do physically are key sources of data since they provide a basis for unpacking the social and ruling relations within people’s experience. These observations and interactional work provided me with emergent data that meant that interviews unfolded more knowingly in later stages of fieldwork.

**Capturing data**

I audio recorded and transcribed informant interviews. I made audio field notes immediately following each interview. These notes consisted of verbally recording my own observations and clues on which to follow up in future interviews. This was a pragmatic strategy that complemented my written notes and helped me to manage fatigue following particularly lengthy interviews. For extra-local informants, where the interviews were generally shorter, I also made written notes and dictated audio recordings to produce the thick, rich description typical of ethnographies.

There were three memorable experiences where informants expressed resistance to being voice recorded that are usefully mentioned here. As I began an interview with one DMP, he told me that he would give me a hand signal to let me know when to turn off the recording device so that he could make points “off the record”. We agreed that when he showed me the universal ‘time out’ hand gesture, I would turn off the recorder. Naturally, I obliged him in his request, and we twice spoke with the device switched off. I told him that he was the only informant to specify that there would be “off the record” conversation, to which he responded that he was surprised. A standpoint informant who initially accepted to meet with me later rescinded since she did not want to have the interview voice recorded because of her unresolved immigration status in Canada. Last, a former Citizenship and Immigration Canada senior medical advisor informant declined to be recorded for concern of being misquoted. He wrote,

> The method behind my resistance to taped interviews is [a] tendency that I have seen used where for a follow up or an unanswered question the interviewer goes back to the tape to see if things fit. There may be context issues that while

140
appearing to fit with the follow up may not. I prefer to be re-interviewed for any follow-ups.

During fieldwork, I benefited from membership and participation in several “epistemic communities” (Yanow, 2009, p. 276). These were also sources of data in the form of feedback to preliminary results and fieldwork findings. I participated in the Institutional Ethnography Working Group facilitated via teleconference by Janet Rankin of the University of Calgary. I made two presentations about fieldwork experiences, observations and findings to members who provided helpful critique (mid-January 2010; May 28, 2010). Likewise, presentations I gave at the McGill Qualitative Health Research Group meetings (March 11, 2009; September 30, 2009) and at the Canadian HIV/AIDS Legal Network Second Annual Symposium on HIV, the Law and Human Rights on June 11, 2010 were events through which I received helpful feedback from attendees (Bisaillon, 2010b; Appendix G4). On the heels of the latter presentation, which roughly coincided with the end of phase two of field work, I attended an intensive, week-long training in institutional ethnography. This training course was led by Dorothy Smith, and took place at the Ontario Institute for Studies in Education of the University of Toronto. The session provided me with a chance to discuss emerging findings from this study with fellow classmates, and to commence analytic work with the considerable amount of data that I had collected.

**Working with the data**
There were three intertwined phases involved in the analysis of the data collected for this study. I began by reading the data, then moved to marking up the data, and finally with writing about the data. Analysis was an iterative process that began in the first interview, and continued throughout the writing of this dissertation. In conveying what my analytic work consisted of, I share the experiences that sociologist Eric Mykhailovskiy notes when he writes, “(d)escribing interviews as a set of questions doesn’t get at the actual work involved. For me, analytic thinking begins in the interview. It’s like an analytic rehearsal. I’m checking my understanding as it develops; I offer it up to the informant for confirmation or correction” (in DeVault & McCoy, 2006, p. 23). In this section, I explain and detail the analytic work that I carried out in the study’s three phases of data analysis.

**Reading and deliberating phase**
I read transcripts, listened to audio files, and scrutinized collected texts, official, standpoint, and my own field notes most intensively from June 2010 to January 2011 (though review and reflection on these continues into this writing). Frequent revision of data was done with the assumption that there are discoveries and rediscoveries to be made through successive readings of these (see D. Smith, 2005). The goal of analysis was to present cogent and convincing arguments centered on analyzing what happens in examined settings. I combed the data in the pursuit of: identifying and examining taken-for-granted practices; considering contradictions or tensions these posed for informants; and, identifying clues about the social organization of these contradictions.
Practices that are taken-for-granted go unnoticed and are not necessarily associated with ‘work’ despite that these are effortful activities in which people routinely engage. These activities are analytically valuable precisely because they provide clues into the subtle and often unaccounted for features of the social and ruling relations within a setting. In this study, an early finding was that for standpoint informants, the state’s immigration decision-making process by which they are deemed medically admissible or inadmissible are enigmas to them; a source of not only bewilderment, but of tension.

Standpoint informants engage in many activities to understand and correctly proceed through the state’s immigration application channels. In this research I uncovered that an important figure in the lives of most standpoint informants to whom I spoke is a lawyer. The lawyer with whom the applicant works is a figure who often acts as an intermediary between the state, the law, and the standpoint informant. ‘Lawyering work’ is a huge form of work for standpoint informants, and I have reported on some details of this work (Bisaillon, 2010b; Appendix G4). There is much (much) more that can and should be said about the coordination of standpoint informant experience from their perspective at the intersection of the organization of knowledge practices of lawyers, the legal aid systems in Ontario and Québec, the federal Immigration and Refugee Board of Canada, and how standpoint informants engage with their legal counsellors in the context of their immigration application work.

For example, people work to find a lawyer to represent them through immigration procedures or to file paperwork; refugee applicants think about how to write their Personal Information Form that summarizes their story about their need for fleeing their country and for seeking protection in Canada; applicant persons move from location to location to register, obtain and authenticate their legal aid certificate through which their lawyer will be remunerated (and that is a condition of them working with the lawyer for those persons who are publicly subsidized); they make appointments to see lawyers and then conduct Internet searches on their behalf so that the lawyer will be knowledgeable about the social conditions in the country from which they are seeking refuge, among other work forms. While I collected much (much) data about these social relations and expected to report on these in this dissertation, they are not part of this analysis that instead focuses on the social organization of people’s experiences with the immigration medical examination. It is my intention to turn attention to the features of standpoint informant ‘lawyering work’, building on a focus on legal policy issues. Of particular interest is how the central organizing presence of the law or legal governance generates specific sets of institutional practices, and how legal advice and forms of knowledge play a mediating role between the law and people’s everyday practices. How are people informed? What concepts do they draw on? Research with this focus is under examined in the social science literature, if at all.41

41 In fact, I have begun this writing. Richard Ericson and Patricia Baranek’s (1982) inquiry into the social and ruling relations within the Canadian criminal system from the point of view of accused persons has been a particularly salient frame of reference in this regard.
Informants spoke of issues and problems arising in descriptions of their day-to-day activities. I read the data in search of clues to connect informant activities to social processes. These connections are the pieces of a larger puzzle that I aimed to know more about. In following informant experience of confusion about the circumstances about medical determination of eligibility or admissibility, and by tracing the coordination of people’s activities and circulation of texts in these activities, I began to see how things worked. It is here that analytic mapping was a helpful technique because spatial relations and the passage of time could be explored differently than through note taking and writing. For example, from standpoint informants’ stories I began to chart people’s movement through various institutional complexes such as those organized with immigration health, domestic health and social services. I also pieced together people’s interactions with texts.

Earliest iterations of my analytic mapping appear in Appendix D2. From left to right on page one, I charted the movement of the standpoint informant as she or he moved from the Canadian border through stages of her or his immigration process. I paid close attention to the place that HIV occupied within this. On page two, I recorded some of the discourses on which people drew in the narratives they told (e.g., HIV testing, truth telling, the law, disability, political and bureaucratic organizations of health care). Among the greatest benefits of these schematic exercises were that they recorded my evolving understanding of the research problematic and its connection to broader institutional relations. The considerable effort it took to accurately reproduce and represent the maps reminded me that they were informed by the appreciable efforts people made to immigrate to Canada while managing HIV infection. The consolidation of my mapping work from this stage is represented in the map that appears at the beginning of the dissertation as the *Map of the first thirty days in Canada for refugee applicants.*

*Marking up and sorting phase*
To organize textual data such as transcripts and field notes I colour-coded these during successive readings. I used the computer colour tool to highlight and assign one colour for each of the following five categories: work, talk, texts, people, and institutions (Figure 7). I was attentive to these categories as I read transcripts and other materials. I paid careful attention to and took note of the following: what people were doing and what interactions with others looked like (work); what language and terms people used in their descriptions (talk); what documents informants brought to the interviews, or those that were revealed in their talk (texts); what actors informants interacted with directly or indirectly (people); and, what institutions were referenced or inferred (institutions).
Figure 7. Colour-coding interview transcripts

I then created indexed Word files that I organized and named according to these five categories. Table 12 shows how I proceeded to further subdivide and name these based on topics in the data as they appeared in people’s descriptions of their activities, and is also coloured with the same codes as Figure 7. I copied and pasted informant statements about features of social organization into the files and sub files. In the right hand column of Table 12 there are samples of informant statements copied and pasted from transcripts. Through these marking and sorting activities, cumulative details about the social and ruling relations in which standpoint informant experience were a part began to appear. I explored and began to write about these.
<table>
<thead>
<tr>
<th>Category</th>
<th>Topic file</th>
<th>Informants’ statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work</td>
<td>Appointments, waiting, employment, Internet searches, completing forms</td>
<td>And then I was referred to different organizations and I <strong>had to look around to find a lawyer</strong>. . . And nobody wanted to take that case basically for some reason. They said, okay Hungary, HIV, you’re not going to win. You will now be deported. <strong>And when I went for the organizations</strong> I was referred to Mr. E. [as my lawyer].</td>
</tr>
<tr>
<td>Talk</td>
<td>Concealing, telling the truth, medical inadmissibility, burden to the health care system, cost, sexual orientation</td>
<td>In that appointment I remember the doctor <strong>started to ask me questions</strong>. With the first question he made me I knew I was HIV positive. He asked me if I had unprotected sex or if I used needles. I said I was homosexual married with a man. He asked me if I had unprotected sex with other men in Canada. I felt like he was trying to investigate about me and I was confused. I said yes with one or two only. He was very cold and he kept asking me <strong>questions about my sexual behavior</strong>. For example he asked me about the <strong>number of partners</strong> I had. I felt accused and surprised even though I knew I was positive. Finally, he told me, ‘You are HIV positive’.</td>
</tr>
<tr>
<td>Texts</td>
<td>Personal Information Form, Interim Federal Health Insurance card, IRPA</td>
<td>And also we collect <strong>human rights documents</strong> from <strong>Amnesty International documents</strong>, current situation in the country and so basically human rights violations, sexual orientation or if it’s related to HIV/AIDS. So, we put together a <strong>nice big, big package</strong> so it gives a big clear picture to the [Immigration and Refugee] Board Members. So it might make it a little bit easier to make the decisions, but sometimes it’s not.</td>
</tr>
<tr>
<td>People</td>
<td>Lawyer, DMP, social worker, family members, case worker, HIV physician</td>
<td>The <strong>DMP</strong> sent me to another doctor. He did not tell me anything about immigration; whether a denial based on my HIV status. I did not ask him direct questions about immigration. He just told me that he will send my file and everything to [Citizenship and Immigration Canada in] <strong>Ottawa</strong>.</td>
</tr>
<tr>
<td>Institution</td>
<td>Canadian border, clinic, Citizenship and Immigration Canada, Immigration and Refugee Board, AIDS service organization, legal aid services</td>
<td>The <strong>blood tests</strong> came showing I tested positive. His desk was full of papers and envelopes. He told me I could fill a form that was for <strong>Public Health</strong>. That Public Health was going to call me. That they knew that I was HIV-positive.</td>
</tr>
</tbody>
</table>
In reviewing collected materials, I was carefully thinking about what was organizing people’s talk. For example, IRPA is a frequent reference in many interviews with standpoint and extra-local informants. The reference might be indirect, and most often is (because people generally do not know the IRPA’s name or consciously think much about it). Nevertheless, IRPA is an organizer of how standpoint informants speak about their everyday practices and themselves. One informant said, “I am an economic burden to Canada because the management of my HIV costs the state a lot of money.” In addition to IRPA, we find within this statement traces of socially created and organized entities such as the mandatory HIV policy, organization of health care, the pharmaceutical industry, IRPA and the Regulations, the market, among others.

In conjunction with this colour coding and marking up of transcripts, I continued to produce analytic maps. The maps in Appendix D3 illustrate a thinking exercise where I examined the sequences of action connecting several sites (listed as A, B, C and D on page 1), starting with the DMPs office where standpoint informants are diagnosed with HIV (A). On the next pages I follow the standpoint informant’s medical file through these sites, noting talk, texts, work and people implicated along the way. In doing this, I reflexively explored and analyzed social organization and relations involved in the file’s movement and the processing. I mad use of other research that has explored the social in this way. On the last page of this exercise, for example, I retrace George Smith’s (1990) sketch showing the actions and ideological practices through which men in Toronto bathhouses were arrested in the early 1980s. Smith’s analysis, and my visual interpretation of it, explains that policemen’s textual practices were socially organized by the language of the Canadian Criminal Code through the ideological circle work identified by Marx and Engels (1846, 1970) and extended by Dorothy Smith (1990a), as discussed in the previous chapter.

**Reflecting on fieldwork and challenges**

Fieldwork in Montréal, Ottawa, and Toronto was not without its challenges. As I explained in the last chapter, standpoint is a key ontological and theoretical position, and it marks the starting place for research drawing from institutional ethnography. It bound and grounded me in the experiential knowledge of standpoint informants. As I would come to find out, this social position shapes data collection, pragmatic decisions about interviews and observational work, and the tenor of interviews. I also came to find out that there is to date no attention in the institutional ethnographic literature to how a standpoint politic shapes interview and observational research.\(^\text{42}\) I discuss and

\(^\text{42}\) In August 2010 at the Society for the Study of Social Problems Annual Conference in Atlanta, Georgia, I presented the first draft of an article entitled “Dialogue differences in disability: Interviews with primary and secondary informants” articulated around four challenges that I experienced in my interview fieldwork (i.e., geography, talk, distance, and time). This provided the base from which Janet Rankin and I began a collaboration on an article in which we address the influence of the politics of standpoint on interviews using institutional ethnography. At this writing, Rankin and I are currently preparing our article entitled “Politics and pragmatics in
illustrate how I navigated the politics of a standpoint position during both of this study’s research phases.

**Interviews and the social features that shape them**

The politics and stance of the study’s standpoint position were central organizing features for the lines of inquiry during interviews. These gave rise to certain differences between interviews with standpoint and extra-local informants, and I discuss three of these.

**Politics of standpoint**

The two groups of informants are positioned differently within the relations of knowledge about immigration HIV testing. By this I mean that standpoint informants know from their experiential standpoint how things happened for them during this process. Extra-local informants know about HIV testing through their understandings, which are interpretations that are “written up” in textually coordinated forms of knowledge (Darville, 1995, p. 254). For example, what a refugee or immigrant person with HIV knows about the time it takes to prepare, track, and successfully file an immigration application from start to finish is significantly different from how a state official understands this time and the effort that it takes to undertake this work. This is because the knowledge of the state official is both at arms’ length from the experience of actually doing this work and because interpretations are mediated by representations of time as they are “written up” in reports on wait times and bureaucratic steps in the application process. For example, on (normally very long) wait times that immigrant applicants endure, a newspaper recently reported that “There are now more than 1 million applicants waiting to be processed around the world . . . According to the current processing delays at the Nairobi visa office — 31 months — Nasteha may have to wait until August 2013 . . .” (Solyom, 2011). What the rather flatly and tersely written article does not reveal is what this waiting work actually looks and feels like for people confronted with such seemingly infinite waiting.

Extra-local informants’ textually organized knowledge sometimes contrasted with what I had learned about standpoint informants’ experiential knowledge. When this occurred, I worked hard to contextualize for extra-local informants how my claims were different from their understandings: that they were organized within different forms of knowledge and set within different ruling relations. My points were not always well understood.

For example, in my presentation of preliminary findings from this research at the Canadian HIV/AIDS Legal Network Symposium in June 2010, referenced above, I made several points about standpoint informant’s experiences with mandatory HIV testing as set within their larger immigration application work process. Reported findings were

health research and fieldwork using institutional ethnography” for peer review submission (see Appendix G5).
based within the material circumstances of people’s lives and within my analysis of several official texts such as forms within the *Handbook for Designated Medical Practitioners* (Minister of Public Works and Government Services Canada, 2003, 2009) and several pages found within the Citizenship and Immigration Canada website. The points I made during this talk reported critically, and in some cases unfavourably, about how the organization of several components of the state’s testing program impacts negatively on standpoint informants. After the presentation I had a discussion with a senior medical advisor from Citizenship and Immigration Canada who challenged my findings. What was analytically valuable in this exchange was that it underscored her position within knowledge claims that were divorced from how things happen in the material conditions of the lives of immigrants discovered to be living with HIV. Her knowledge was an objectified form of knowing that relied on “textually based realities” that, in this case, relied on knowledge of standpoint informants as communicated to her through DMPs, medical officers, and other state employees (D. Smith, 2005, p. 227).

**Physical milieus**

The physical settings in which standpoint and extra-local informant interviews took place were significantly different. The settings in which extra-local interviews took place provided clues into the social organization of these sites and the textual work practices that people undertook there. Extra-local informants who participated in this research were predominantly professional employees. Interviews were conducted in such places as staff lunchrooms at HIV clinics; offices in hospitals, immigration and legal aid clinics; board or meeting rooms in government buildings and law practices; office space in refugee shelters; and, securitized office space within Citizenship and Immigration Canada office complexes. Interviews with extra-local informants were designed to be informal in the way that standpoint informant interviews had been. As it turned out, however, a more planned, formal approach to organizing interviews proved necessary.

When arranging and conducting extra-local informant interviews I frequently waited in the same waiting rooms as standpoint informants I had talked with. I sat on the standpoint informant’s side of people’s desks. The work I engaged in to secure these interviews matched some of the descriptions that standpoint informants had provided on the matter. Where appointments with professionals I had planned to meet were delayed or cut short, I negotiated new scheduling with receptionists and office administrators, which was some of the work that standpoint informants had talked to me about having to do. The materiality of this positioning within some of the same ruling relations that organized standpoint informant activities was particularly noticeable in the offices of social workers, HIV specialists, and immigration doctors. In these sites, I realized I needed to learn how to conduct myself in the highly secured, formalized, and regimented settings that included the waiting and examining rooms of hospitals and immigration hearing rooms within state office buildings.

After some time and experience in the field, I began to recognize that waiting in reception areas, being invited into lunchrooms, being toured around a federal office,
being introduced to senior staff and decision-makers, and being ushered into professional office spaces provided opportunities to pay careful ethnographic attention to what was happening in all of these locations. I took note of what the receptionist was doing; of where the public health pamphlets were situated; and of what the memos posted on hospital lunchroom bulletin boards instructed. There was something to be learned about how all of these sites — and the people within them — were socially organized to function. Through such serendipitous observations, I realized that I was encountering some features of extra-local informants socially organized work practices.

**Time keeping**

A last fieldwork finding that set apart standpoint and extra-local informant interviews was what I term the pragmatics of professional time. These pragmatics shaped interviews in ways that were sometimes frustrating, and they also revealed features about the social organization of institutional workplaces and the extra-local informants with whom I met.

Within the pressures of scheduling among professionals, time took on a character and urgency that was common among many extra-local informant interviews. One HIV physician I interviewed glanced at his watch every few minutes during our interview. A standpoint informant who was a patient of this doctor had remarked on a similar experience saying, “Something that made me uncomfortable was that the doctor was looking at his watch while he was dealing with me”. Perhaps because of this exigency related to time, extra-local informants seemed to me to be less consistently engaged in interviews than standpoint informants. Since time pressed down considerably on interviews with extra-local informants, I had to navigate these interviews differently than those that took place with standpoint informants. For one thing, I was more conscious of carefully choosing lines of questioning with extra-local informants because the time I anticipated being able to spend with them was quite hemmed. Several times, scheduled one-hour interviews were disappointingly reduced because the professionals had to respond to the demands of their work and (arguably over booked) daily appointments.

Despite frustrations stemming from interviews that were difficult to arrange or appointments that were unexpectedly cut short, I understood that I needed to pay close ethnographic attention to how extra-local informants spoke about their busy schedules. Although these features of their work initially seemed unrelated to my research, I thought that within the competing demands of extra-local informant work — research, clinical practice, teaching, administration, community involvement, advocacy — there might be clues that would lead to other important sources of data. What I came to comprehend was that I was experiencing the tightly coordinated and choreographed character of conducting research among professionals whose self-descriptions as ‘busy’ were officious and distinctly unlike the standpoint informants’ busy lives; found to be as full and charged with commitments, albeit different ones, and differently organized inside relations of appointments and waiting. A challenge that emerged in my fieldwork
was to learn how this ‘busy-ness’ was constructed, and to learn how this concept worked at the interface of the waiting work in which my standpoint informants engaged.\(^{43}\)

For example, I was surprised when, facing early challenges associated with recruiting DMPs, a physician acquaintance advised me to offer these government contractors financial incentive in exchange for their participation. He noted that my project competed with medical programs of research in terms of demands on their time, and that paying doctors might be incentive for them to get involved. I was surprised that student research was compared with non-student led programs of research. Perhaps naively, I also did not anticipate that stably employed, and, I assumed, well-paid health professionals, would require monetary compensation as acknowledgement for their participation, and particularly from a student. In my first ethics application, I was clear that I would only remunerate standpoint informants.

I also realized that negotiating the logistics such as date, time, place, and length of the interview was an integral part of the research process for which I needed to plan and accommodate when endeavouring to interview extra-local informants. This frequently involved working with receptionists who were highly skilled at mediating the waiting work into which I found myself drawn. On the whole, extra-local data collection required more patience, persistence, diplomacy, and diligent follow-up than standpoint data collection.

**Ideological versus material talk**

A key challenge in fieldwork using institutional ethnography is succeeding in getting behind and moving beyond general, speculative, and ideological accounts of how things happen, as I explained in the previous chapter. This sort of talk can permeate interviews and focus groups. In this way, I paid attention to the junctures in conversations with standpoint and extra-local informants that carried institutional language. For example, when I met with the first of three DMPs interviewed for this research, the physician referred, very generally, to an applicant’s ‘medical file’. This has within it a great many practices and discursively organized categories that are institutionally organized, and I wanted (and needed) to learn about these from DMPs.

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\(^{43}\) Like analysis of standpoint informant ‘lawyering work’ that I anticipate producing from this study at a future point (see last paragraph of p. 142 and footnote 41, above), I would also like to delve into the matter of the social organization of time and scheduling among urban professionals since I did not fully do this for purposes of inclusion in this dissertation. I was flabbergasted at this ubiquitous and pervasive feature of extra-informant existence that was certainly a factor in how I was able to conduct fieldwork, and with whom I was able to talk. I remain puzzled at how it is comes to be that professionals appear to be (and talk about being) so very swamped in the Canadian cities in which I conducted fieldwork. A proxy for another socially organized experience associated with late modernity such as stress or anxiety (as per Young, 1993, 1995)?
Over time, I refined my interviewing skills and developed techniques to promote the collection of data that emerged from the material circumstances of informants’ practices. An assumption is that informants’ talk is inevitably organized by their location inside ruling relations and the abstract forms of knowledge that such relations generate. Informant’s knowledge is in this way shaped by their everyday knowledge and by conceptual understandings that might or might not match the material events in their lives; informants’ discursively organized knowledge structures their interpretations. During interviews, when informants moved to abstract talk, I paid close attention since these were useful glimpses into the discursive organization of their thinking and decision-making. At the same time, and as I have said, these accounts were not evidence in the same way that people’s activities and practices were because in and of themselves, they do not explain how things work.

As in other qualitative methods, it is easy to veer off the intended interview dialogue course, straying from topics that are potentially of the most analytic interest. Given that a tenet of institutional ethnography is that data are those bits of information that are material and empirically traceable, it was very important that most data I gathered consist of descriptions of people’s material practices, actions, and activities. Some standpoint informants I interviewed drifted towards talking about personal feelings, which I quite expected given that we were talking about highly personal, private matters; implicitly or explicitly involving a health condition with which informants, and me, had varying levels of comfort, not to mention a complex relationship with.

This being said, I nevertheless recognized the risk of being drawn off course and the challenges associated with staying focused on material happenings. This is another instance and example of how, when, and where I used Table 11 as a practical resource. It lists eight orienting concepts of interviews drawing from institutional ethnography and outlines the corresponding purpose of each orienting feature. The information in this table was helpful throughout my entire research process because it reminded me of the analytic intent and focus that I wanted to maintain.

**Interview guide and pictorial**

Despite knowing that empirical data were what I was seeking, I was not always successful in eliciting them. When this occurred in the interviews and focus groups that I conducted, I worked to bring dialogue back to empirical descriptions.

To do this, I developed two devices, the first of which was an interview guide referred to earlier in this chapter that built from the template for which I had received ethics approval (Appendix B7). In this project, this technique proved especially useful in the conduct of the extra-local interviews with professionals and administrators. These extra-local informants often requested an interview guide that I sent to informants prior to meeting with them. Designing an interview guide that emphasized informants’ work activities was an effective way of demonstrating to extra-local informants that interviews would focus on their job activities. Discussing the finer, seemingly mundane
details of their day-to-day work processes seemed acceptable to most extra-local informants with whom I met.

A second helpful device that I created to support fruitful interviews was the pictorial representation of the project seen in Figure 8. This illustrates the research’s theoretical and subject orientation, which I adapted from Dorothy Smith’s (2006) drawing that is illustrated in Figure 6. The visual tool complemented the written descriptions of the study that appeared in the letters of introduction and consent forms. The pictorial depicts the standpoint of HIV-positive immigrant and refugee applicants to Canada. It locates the discursive intersections of the numerous “institutional fields” that circulate in relation to people living with HIV in Canada — in which they are participants — and the ruling relations that extend them into various sites (McCoy, 2006, p. 113).

An example of how I deployed the illustration was when I arranged an interview with a caseworker in an AIDS service organization serving non-White persons. Initially, this informant was reluctant to take part. Endeavouring to set up the interview was not straightforward, and I did careful follow-up. During a subsequent personal conversation, the informant explained that she was hesitant to participate because, speaking on behalf of what she called “her” community (non-White persons living with HIV accessing services through her employer), she thought that members had been amply researched. The informant expressed scepticism about my motivation for conducting research among people of colour living with HIV given that I am White and, she presumed, not living with HIV. She questioned my knowledge about the issues faced by people living with HIV, and queried me about how I proposed to apply study findings. The caseworker was concerned that the findings could possibly have negative implications on communities of recent immigrant and refugee people of colour living with HIV in Canada.

The watershed moment in securing this informant’s participation was when I showed her Figure 8 (actually, an earlier, hand drawn iteration of the figure that appears here). Using this illustration, we discussed the project, including the method, in detail. She grew more open to this study when she seemed to understand its potential practical usefulness and focus on social and ruling relations. This understanding provided her with the means to make sense of the work on her own terms, which she understood through ‘participatory action’ and ‘community-based research’ frameworks. In doing this, this informant relied on discursive understandings and interpretations of these forms of social inquiry (despite the fact that my research falls within neither framework, a point I made clear). The visual helped this informant make sense of my research on her terms, and presumably shaped her decision to take part in this study.

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44 This issue of ‘research fatigue’, as a by-product of intensive scrutiny of people living with AIDS since the early 1980s, is discussed in Paula Treichler (1999). She chronicles and characterizes the AIDS epidemic as one “of [semantic and cultural] significance . . . that has produced a parallel epidemic of meanings, definitions, and attributions” (p. 1).
In preparing Figure 8, I used some of the normative discourses in Canada as these relate to immigration, HIV, health care service delivery, and economic organization. I knew how to do this because I had learned about the discursive properties of each of these discourses within research, advocacy, and academic communities. My knowledge and “organizational literacy” it informed supported the success of extra-local informant interviews (Darville, 2005, pp. 254-257). I sometimes used these normative discourses as a tactic to engage informants before and during interviews. For example, when the AIDS service organization caseworker referred to above asked what I knew about issues facing non-White immigrant and refugee persons living with HIV in Canada, I used concepts such as ‘vulnerability’, ‘anti-oppression’, ‘anti-colonial’, ‘anti-racist’ frameworks, ‘stigmatization’, and ‘discrimination’. In doing this, I consciously positioned immigration, HIV and Canada’s mandatory HIV screening policy in discursive research,
advocacy and academic traditions that were familiar to this particular informant (and other informants, as I would come to find out).

The schematic above also created a way to discuss this research in a largely non-textual language that was understandable to informants with various levels of literacy and education. It provided a way for extra-local informants to see how the findings of a project using institutional ethnography are intended to provide details about the social organization of activities and experiences that aim to support people in developing new understandings of the organizations in which they work; building empirically derived evidence to support decision makers to develop functional and constructive strategies that can address issues that matter in people’s lives.

*Exploring my institutional capture*

As I have explained, a theoretical assumption that underlies this research is that the regulation of our lives is accomplished through discursively organized and textually medicated ruling relations that take shape through our participation in them. Since these relations insert themselves into and shape the project of research and the researcher’s thinking, part of the challenge in carrying out a project framed within institutional ethnography is to think about one’s “institutional capture” relative to our own participation in and use of normative positions and dominant discourses (D. Smith, 2005, p. 225).

This methodological term is defined as a process where researcher or informant are drawn into the sets of relations that organize day-to-day activities, which include both the material and thinking practices. When we use terms and ideas frequently and with familiarity, we tend not to step outside of the lens through which they assist us in seeing and knowing the world that we live in. For example, in his investigation into the day-to-day work practices of colleagues, psychiatrist and anthropologist Robert Barrett (1996) reflects critically on his position within a mental health institution in Australia in which he was also an employee. He writes,

> [M]y familiarity with the world of the psychiatric hospital and its language often made it difficult for me to perceive the taken-for-granted assumptions on which that world was built. It was only with the assistance of my anthropologist colleagues, who continually insisted that I maintain a sense of curiosity about what I normally regarded as self-evident, that I was to make use of my cultural competence in an analytic way (p. xvii).

In this study, I worked to develop awareness about my relationship to and position within normative discourses on immigration and HIV. For example, once I learned from standpoint informants that many experienced the same sorts of problems during their immigration medical examination, that is, experiences related to the absence of post HIV test counselling, I realized that I needed to do some thinking about the matter of pre- and post-test counselling for HIV.
I brought into the project understandings that this sort of care to people undergoing an HIV test or receiving an HIV-positive diagnosis is an internationally accepted and recommended form of standard care. If my own experiences with HIV testing were any indication of what was happening to immigrants to Canada with HIV through medical screening, it was quite possible that no counselling at all was being offered; regardless of whether persons knew their status before the immigration medical examination or not.

Findings from this study indicate that standpoint informants generally do not receive HIV counselling, an issue explored in subsequent chapters. As I write, I continue to contemplate the issue of HIV counselling as it appears (or not) in the material circumstances of the immigration medical examination. From another sweep and review of collected data, I see that the issue about what value standpoint informants think pre- and post-test counselling would add to their experience of their diagnosis remains somewhat opaque. What are people expecting? What are people missing when they do not receive counselling from the DMP who reveals their HIV infection? Partial answers to these questions are discussed in the next chapters, and the social relations within these are explicated based on what I was able to learn from extra-local informant work and my review of a variety of official texts issued by the Canadian state.

Following a presentation that I gave in Montréal in March 2009 where I outlined my research plans prior to commencing fieldwork, a lawyer and former HIV activist who was in attendance asked me if I was setting out to know whether HIV test counselling was actually occurring for immigrants in the immigration medical examination. She reminded me that in introducing mandatory immigration HIV screening, the federal government pledged that counselling would be a central component to the services delivered to applicants for permanent residence. She also reminded me that the state’s position on this was in large part a function of the civil society activism around opposing the introduction of mandatory testing and educating government about international standards and norms of care for people who undergo an HIV test.

It occurred to me, belatedly, that the lawyer’s questioning was an opportunity to think critically about the origins of the emphasis on counselling. Were I to begin this study today, I would trace the concept of counselling backward into extra-local relations so as to be lead in different directions, and to get a better understanding of the origins of the term for its rhetorical value. Where did the language come from? What is its one-sided message? How does it speak to people? On reflection, it seems likely that Canadian immigration medical policy advisors were introduced to the notion of counselling from the civil society lobbyists who worked to oppose blanket testing and exclusion of HIV-positive immigrants in the last years of the 1990s. In response to this pressure, the state took up the idea in its work, committing to ensure that counselling was provided to all prospective immigrants. In the last decade, Citizenship and Immigration Canada has produced a wide range of materials relating to immigration HIV testing counselling. It has gone to much effort to give the impression that this from of service is actually
happening, as if to appease civil society watchdogs, when results of this study indicate that counseling does not happen. Herein is a paradox: the lobbyists’ insistence on counselling as a standard of good care provides the Canadian state, all of these years later, with a vocabulary to carry out the ideological work of insisting that counselling practices occur. Counselling as a rhetorical device is used against the intended purposes of lobbyists, is at odds with good clinical reasoning of DMPs, and is against the best interests of immigrant applicants living with HIV.

There would have been analytic relevance and value in probing the matter of counselling both more and more deeply explicitly with all informants. This would have garnered useful clues into the social organization of their engagement with the discourse of HIV test counselling. However, it was distinctly not a lack of “curiosity”, to cite Barrett, above, that kept me from exploring the topic in greater depth with standpoint informants. Rather, when standpoint informants and I discussed counselling and their experiences with the DMPs more generally, we did so from within the frame of some of the same understandings, concerned as we were about the well being of immigrants and other people living with HIV. We had some similar understandings about what good care of people consists of. The lack of a more probing and profound discussion about the organization and deployment of this particular word and issue means that opportunities were missed to “perceive the taken-for-granted assumptions on which [our] world was built”, as Barrett writes.
Chapter 5. Hunting out the human immunodeficiency virus

The purpose of this chapter is to describe the conditions through which standpoint informants came to learn about their HIV-positive status, which occurs in various countries, including Canada, and through different sorts of testing circumstances. The analytic interest is uncovering how the knowledge of their HIV status entered into the process of their immigration to Canada and with what consequences.

The argument I make is that HIV testing in the context of immigration ushers in a set of institutional practices of assessment for immigration purposes that would not otherwise happen, since HIV testing of Canadian citizens and permanent residents is generally voluntary, perhaps anonymous, and within specific public health relations such as partner notification. I disrupt taken-for-granted assumptions about medical testing technologies such as the HIV, CD4 and viral load tests by arguing that these technologies and the practices to which they give rise embody and organize social relations that stretch beyond the clinical or medical encounter. I then describe the organization of knowledge practices of state and civil society actors in the lead up to the introduction of the HIV testing policy in 2002, where particular forms of knowledge were mobilized by each: epidemiological risk knowledges advanced by the state were investigated and challenged by civil society actors that structured a counterdiscourse drawing on human rights and legal discourses, ethical and moral reasoning, and other types of expertise.

HIV in the setting of immigration is shown to be a strong institutional marker around which there are particular forms of state surveillance directed at immigrants; a point more fully developed in chapter six that is structured around examination of the state’s work apparatus organized around medical in/admissibility and HIV. In this chapter I show that immigrants with HIV are drawn into an institutional terrain organized around the public biosocial identities associated with living with HIV in Canada. Their participation in the knowledge practices of AIDS service organizations sees people socialized and politicized in particular ways after their arrival in Canada. Within this, we see that Canadian law, and the work of lawyers, occupies a strong organizing presence in people’s lives.

“What’s in an HIV antibody test?”

There are three tests that play significant roles in determining whether a prospective immigrant with HIV will be admitted to Canada. These are the HIV antibody test, the cluster of differentiation antigen 4 (CD4), and the viral load tests. After defining each of these from a biomedical perspective, I turn to exploring them in nuanced ways, bringing attention to some of their social and political meanings. These tests play important roles in the social organization of everyday activities in which HIV-positive applicants to Canada engage. The intention of this section is to “go beyond and disrupt the coherence of conventional understandings” about these medical technologies as organizers of people’s experiences (Mykhalovskiy, 2002, p. 43).

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45 This subtitle is a twist on the title of an article written by Clatts, Dean & Tortu (1991).
The HIV test acts *as if* it is a simple indicator of the presence of absence of virus, but . . . the binary logic that this claim depends upon, the logic of either positivity or negativity, can be read as the simplification of an ambiguous field in the interests of a notion of the public health (Waldby, 1996, p. 126).

At the normative level of interpretation, the HIV, CD4 and viral load tests are names of medical diagnostic tools that enable the work of physicians as they monitor people living with HIV in clinical settings. The HIV test aims to detect the presence, or absence, of a blood borne, incurable pathology. The test diagnoses the presence of antibodies that an HIV infected person’s body produces in protective response to the virus. The HIV test does not look for disease, rather, it finds out how the immune system has rallied to protect itself. “(T)eesting works as the first component in an individual diagnosis for the person screened. It either provides reassurance that no hidden pathology exists”, or reveals the presence of HIV infection (Waldby, 1996, p. 116).

In 1981, the first person in North America was identified to be suffering from a diverse group of opportunistic infections related to what would come to be identified as AIDS.46 Between this date and 1985 when the HIV test was approved by the United States Food and Drug Association and began to be regularly used as a diagnostic tool in North America, it was not possible to determine with certainty whether a person was living with AIDS. The HIV test was initially developed to screen donated blood, and later it was adapted for the purposes of testing the blood of individual people. The test began to be used as a key technology in HIV prevention efforts in Canada at around this same time. Table 13 provides historical context to the epidemic and testing technology as they developed in the first ten years.

Prior to 1985, infected people and those who cared for them, as well as physicians, epidemiologists, and researchers generally read and interpreted a range of symptoms that appeared on the body’s outside (e.g., a skin cancer known as Kaposi’s sarcoma) and inside (e.g., a fungus known as *pneumocystis carinii* pneumonia or PCP) to gauge whether a person was sick. “The existence of an antibody test allowed AIDS science to make its first step away from reliance on the interpretation of visible symptoms and into the interior of the AIDS body” (R. Ariss, 1992, in Waldby, 1996, p. 116).47

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46 For a “reference tool for the many political, scientific, cultural, and community developments that have occurred over the history of the epidemic”, see the Kaiser Foundation’s Global HIV/AIDS Timeline at http://www.kff.org/hivaidstimeline/hivtimeline.cfm

47 Lock and Nguyen (2010) write that the invention of the stethoscope in the early 19th century was one of the first technologies to “permit indirect access to the interior of the body, rendering the patient’s subjective account of malaise secondary to the ‘truth’ of science” (p. 69).
Table 13. AIDS and HIV in the 1980's

1981: Referred to as the start of the HIV/AIDS epidemic in North America. It is, however, believed that HIV had been present for many years. First documented cases of *pneumocystis carinii* pneumonia (PCP) and Kaposi’s sarcoma reported by the US Centres for Disease Control (CDC) in groups of young gay men in San Francisco and New York.

1982: CDC coins the term Acquired Immune Deficiency Syndrome (AIDS) to define an illness striking gay men, people who use injection drug, people of Haitian descent, and haemophiliacs.

1983: Virus responsible for AIDS is discovered by Luc Montagnier of the Pasteur Institute in Paris. The virus is later named the Human Immunodeficiency Virus. In this year, AIDS is identified as being transmitted via heterosexual sexual intercourse.

1985: United States approves the first HIV antibody screening test (ELISA) to test donated blood. The Western Blot, a more specific test, is approved in 1987.

1986: CD4 tests are introduced as part of standard tests for people with HIV in North America.

In Canada, CD4 and viral load tests are most often administered in combination on a person living with HIV. Each of these is briefly explained. Everyone has CD4 cells, and the CD4 diagnostic test is a reflection of a person’s immune system strength at the cellular level. The CD4 test done on a person living with HIV looks into the percent of person’s cells infected with HIV. A CD4 count fluctuates over time, and as the person’s infection advances, the count decreases. An HIV specialist, and indeed the person living with HIV, carefully observes and tracks the CD4 count over time. Results of the CD4 test guide the doctor in recommending when the infected person should start antiretroviral treatment, which, for most people infected with HIV, will involve a lifetime regimen of pill taking and involvement with the pharmaceutical industry. This measure is considered a more accurate medical indicator of HIV progression than viral load results (M. Bailey, personal communication, May 26, 2011). The CD4 test is increasingly (though not yet universally) available throughout the world as antiretroviral treatment is being ‘rolled out’ worldwide. In sub-Saharan Africa there “are large areas where CD4 and [viral load] testing capacity is limited or unavailable, and small, but growing, pockets where capacity [for CD4 and viral load testing] is available” (Taiwo & Murphy, 2008, S11).48

48 The “HIV and AIDS Treatment in Practice” (HATIP) newsletter and on-line resources of NAM (National AIDS Manual) for resource-limited settings provides current HIV treatment information in such environments. See http://www.aidsmap.com/hatip
The viral load test is a measure of the quantity of HIV in a person’s blood. Measurements have become increasingly more sensitive over the years. An HIV physician will use these test results to examine and monitor the effectiveness of antiretroviral treatment in a person taking medication; whether the person’s body is accepting treatment and fighting infection. The goal of drug treatment is to suppress HIV infection to such a point that it becomes and remains undetectable by the viral load screen. In Canada, when a person is diagnosed with HIV, the tandem tests of CD4 count and viral load tests are generally administered for the purpose of collecting a ‘baseline’ set of numbers on the state of a person’s infection.

Viral load tests have been widely used since approximately 1996. At this time, effective drug therapy for HIV infection became available to North Americans. Trials for the drugs that would be approved for use in 1996 began four years earlier, and generally only people participating in pharmaceutical research would have had their viral load counts taken during this period. For a time, the viral load test was considered the best indicator of the advance of HIV infection, however, this is no longer the case. Worldwide, viral load tests are currently much less commonly available for and practiced on people living with HIV than CD4 tests. This is because unlike for Canadians, second line therapy for a person whose body does not respond well to first line drug treatment is not widely available throughout the world. In other words, most people in the world who live with HIV have very limited medicine choices. If for whatever reason the bodies of these women and men do not tolerate and accept the antiretroviral medicine that is available to them where they live, their infections will not be controlled, and they will die in the absence of alternative treatment.

In Canada, people living with HIV are generally asked to see their HIV physician three or four times per year. About two weeks before these visits, a person visits her or his HIV clinic and gives blood from which CD4 and viral load test results are produced. The doctor interprets these results with the view of suggesting when the person should begin antiretroviral treatment. The trend over time, as observed in successive medical guidelines published by the United States Centers for Disease Control, has been to suggest that people with HIV start taking medication earlier and earlier in the lifecycle of their infection or disease (United States Department of Health and Human Services, 2011). This recommendation plays itself out in the practices of HIV physicians and the work that people living with HIV do to be able to structure their lives to take

49 Some people with HIV have a low viral load even in the absence of medication. These people form a small minority of people living with HIV (an estimated one to five percent). Accompanied with other criteria, this state is called a natural controller or non-progressor status (see http://aidsmap.com/HIV-non-progressor-status-established-soon-after-infection/page/1432975/).

50 The viral load test was not found to be an accurate indicator of the development of an infection, particularly for a “concrete minority of women” whose viral load tended to remain steady while their CD4 count dropped (M. Bailey, personal communication, June 20, 2011).
antiretroviral medications, and this has a distinctly social character (Making Care Visible Working Group, 2002). This social character brings into view, quite sharply, the pharmaceutical industry and a biomedical apparatus.

The HIV test is more than a diagnostic laboratory tool. The test is simultaneously activated as a set of practices that involve and join people living with HIV, physicians, laboratory technicians, nurses, and other clinical health personnel over time and across place. Michel Foucault (1980) developed the idea of technologies of sex reaching into people’s private lives and dominating them. These technologies include disease detection tests and devices that are used as forms of social control over people that are exercised through a constellation of institutions in contemporary society organized around the administration of their health (or, rather, their diagnoses or disease). From this perspective, the HIV, CD4 and viral load tests are examples of technologies that carry social and political significance beyond the medical. They have within them particular social relations, to which I now turn.

*No test, no virus? HIV test and the body politic*

Catherine Waldby (1996) examines the HIV test as a “technology of the body politic [in] the double sense of the word” (p. 112). The test is a medical instrument that positions HIV infection within a person’s body, but it is also “the central technology in the biomedical mapping of the virus’s presence in the body politic” (p. 113). Screening populations for disease brings people to the attention of medical authorities and authorizes more, and more extensive, types of tests to be carried out on them; characteristic of the social process of ‘medicalization’, where a person’s health is made medical and through which medicine is an institution of social control (Bouchard & Cohen, 1994; Conrad, 1992; see Lock & Nguyen, 2010, pp. 67-71; Zola, 1972). The CD4 and viral load tests are examples of precision tests that are enabled by the HIV test because they follow the discovery of HIV infection, and they are gateways to a course of medical intervention. If there is no test, and no subsequent diagnosis, does a health condition exist? The question (and answer) raises more than ontological or philosophical concerns.

Medical science is a social construct that directs our attention to health conditions and diagnoses in particular ways. In explaining his understanding of the ‘politics of health,’ Didier Fassin (2005) impresses that these occur in the relational activities of people under particular historical conditions; ruling relations governing social constructions of health and sickness. In countries where HIV/AIDS incidence and prevalence are under reported, such as China and parts of the Muslim world, should we think that HIV does not affect people? Retrospectively, Cindy Patton (1989) writes, “The narrative, AIDS, needed HIV and its test — HIV does not exist outside the test — in order to legitimate the social repression of AIDS as a medical, rather than a political phenomenon” (p. 33). Waldby (1996), in response to Patton, writes,
It is this mutual implication which belies the test’s status in the popular imagination as simply a technical means of identifying an existing pathological condition... the creation of a serological test has the effect of actively redefining the conceptualization of a disease entity, refining it and orienting it in a certain direction based on the limitations of the test (p. 127).

The detection of HIV brings into social view a pathology that is otherwise hidden in the most discrete and hard-to-reach parts of a person’s body. For this reason, as dissertation findings illustrate, the “HIV test carries a particularly heavy diagnostic weight, producing the only evidence that infection has taken place” (Waldby, 1996, p. 113). This speaks to the infection’s complexity in cellular, medical, social and political realms. HIV infection can conceal itself inside the body’s healthy cells and mimic these, which can obscure and elude the presence of HIV.51 The infection’s skill in this regard led Paula Treichler (1999) likens the virus to a “James Bond... 007... of secret agents” that enters the body (p. 31). This association conjures up images of subterfuge, risk, and subversion. “The invisibility of disease is always a problem for biomedicine, hence the emphasis it places on the importance of the diagnostic gaze and the array of scopic technologies dedicated to overcoming the body’s opacity” (Waldby, 1996, p. 117).

Immigrant and refugee people with HIV who were interviewed for this study reported coming under suspicion from people in the institutions within which their lives in Canada come to be organized. As revealed in standpoint informants’ stories, and through the analysis in forthcoming chapters, reticence toward them is shown at border crossings as they enter the country; at the time their HIV-positive status is disclosed to them by a DMP; and, during refugee adjudication interview and hearings at the Immigration and Refugee Board. I argue that even though an immigrant person’s HIV infection has been exposed to her or him (and the government) through a mandatory HIV test, a procedure that Patton (1990) referred to as a coercive technology of confession, the properties of HIV listed above compound the suspicious gaze that can be turned to the immigrant person with HIV because of her or his association with HIV infection.

People who test HIV positive are marked with “the truth of their infection” (Waldby, 1996, pp. 138-139), but the presence of HIV within the body doesn’t generally mark it with distinguishing traces on the person’s outer, social skin. This absence of visible signs is because the infection can have a latency period that can span up to a decade; variable according to a person’s social circumstances. During this time, a person with HIV can go about her or his life asymptomatic of any sickness. And yet, infection of white blood cells “presents the same problem for the immune system as the infected person presents to epidemiology and public health strategies. In the absence of visible signs of

51 The nomenclature of HIV and AIDS also obscures that there is a high degree of biological variability within these designations, and that they are composed of a number of diseases. This is said to contribute to why an effective vaccine has not been found.
infection both infected cell and infected person can spread infection unhindered” (Waldby, 1996, p. 118).

It is precisely here — in the absence of visible signs of infection — that HIV and people with HIV have, through time, been conceptualized as threats to the health of populations whereby social categories and hierarchies of hypothetical risk/transmission/infectivity/sexuality have been devised to apply to them (see Clatts, Dean & Tortu, 1991). And the “demand for risk assessment is far more rigorous for certain groups than it is for others, depending on what position their self-identified categories occupy in the hierarchy of infectiousness determined by epidemiology” (Waldby, 1996, p. 114). In this dissertation I show that the HIV test achieves a form of permanent mark of social identification on immigrant people with HIV: these occur in textual form in the work practices of government personnel, where a circulating paper trail on them begins from the moment the Canadian government discovers them to be living with HIV. The test “compels a less literal and more acceptable form of identification [than tattooing and card carrying], more acceptable because it is a form of identification general to first world political culture” (Waldby, 1996, p. 120).

The positive results of an HIV test bring people in Canada (and elsewhere) into the permanent and ongoing-through-time view of public institutions. Through these, people with HIV will be managed, referred, and monitored for the duration of their lives. Writing during a period in time where Canada was developing its epidemiologically informed procedures to change medical screening procedures directed at prospective immigrants to Canada, Waldby (1996) wrote that the HIV test “acts as a diagnostic technology for clinical medicine, a surveillance technology for epidemiology, and a disciplining technology for the medico/social management of the infected” (p. 114). A refugee applicant from Africa name Elimane talked about his experiences with health surveillance. He was both resistant to and accepting of being tracked by the state.

I received a letter [from Citizenship and Immigration Canada] that said that I was still under surveillance for HIV and TB [tuberculosis]. I was telling her that I understand why I am under surveillance for HIV. All the communicable, reportable diseases, including HIV, are ‘surveilled’. I see my doctor every three months; give my blood, so I know that I am being watched for HIV. I accept this. Actually, I am proud of my doctor . . . My HIV is progressing slowly.

I have been a permanent resident since April 2009. Yet, I still get letters about my TB. Every month I have to call the nurse at Public Health to tell her that I am fine. We have a permanent file at public health. We are like prisoners; jail people. We are regular visitors there. If the nurse changes, it will be frustrating and we will have to go through all the process again; explaining that there are people from Africa who, because of the type of vaccines given when young, will always be reactive.
There are examples of such coordination in the work practices surrounding the HIV-positive diagnosis of an immigrant living with HIV of people working within medical, epidemiological and public health systems in Canada. In most Canadian provinces, an immigrant person who tests positive for HIV through federal immigration screening will have her or his status communicated to provincial health authorities in the province in which the person settles. Reporting practices differ from jurisdiction to jurisdiction. Through fieldwork for this study, I learned that in Ontario, the person’s name is linked to a positive result within a provincial database since the DMP practicing in Ontario fills out provincial forms enabling the transfer of this medical information. From there, public health is notified, and a nurse will be assigned to get in contact with the immigrant so as to deliver messaging about disease transmission and discuss behaviour and lifestyle choices. Mamadou, a family class applicant, talked about his meeting with a public health nurse within a week of being diagnosed HIV-positive by a DMP.

The nurse called me to invite me to either see me or to talk on the phone. We met at a public place, on the same day as her call. We met and spent two hours together. They want to make sure that you understand that you should not spread the virus and that you must take precautions. It is my understanding that these are the main messages that they want to deliver. We talked about everything. My husband was with me at the beginning because of where we’re from. I mean, in [country name] there is a high level of corruption. You cannot easily trust people. I joked, ‘this is Canada; they are not going to put us into jail!’ The goal of the session was to communicate that I must tell people that I am positive before having sex with them, even when the sex is protected. She told me that there are cases in the courts. You can go to jail and they can prosecute you.

In Québec, by contrast, there is no comparable nominal tracking system. No standpoint informants residing in Québec reported having been summoned to meet with public health authorities; nor had they heard of anyone who had been. It is through this sort of sequence of action that the immigrant living with HIV enters into the “economies of such institutions, which seek to make the invisible developments of their infection visible in a regular and measurable way, that can be communicated between institutions” (Waldby, 1996, p. 124).

**What is involved in testing positive for the Canadian state?**

When I have presented findings from this study, I have been struck that native-born Canadians generally know little about the details of the immigration experiences of foreign-born residents and citizens, including medical screening procedures (Bisaillon, 2010b, 2011b). To bridge this gap, I include the immigration testing experiences of two people, Alem and Susanne, who were standpoint informants. The intention in doing this is to give the reader the opportunity to be anchored in features of people’s everyday activities as these relate to the imposition of HIV screening as a pre-condition of immigration to Canada. In chapter seven, a detailed examination of standpoint
informant immigration application work process, with focus on the activities within and
relating to HIV diagnosis during the immigration medical examination, are explicated for
the social and ruling relations found therein.

The events of people’s lives, and the immigration application work of Alem and Susanne
are part of larger social and political arrangements. This is confirmed as we hear and
read the presence of the government, state agents, the economy, legislation,
technology, and ideological concepts in the following vignettes.

Alem Tareke Yacob
Alem and I met on a fall afternoon at a legal aid clinic. He was in the midst of working
with a lawyer to file documents to have his wife come to Canada. Alem came to Canada
as a sponsored refugee, and he was granted Canadian permanent residence while he
was outside of the country. For the most part, people working in a variety of Canadian
and international institutions filed immigration paperwork on Alem’s behalf. Alem’s
story provides insight into his experiences with state initiated HIV testing in a context
where punitive practices towards people known to be living with HIV operate. Finally,
Alem draws attention to his thoughts on some tensions presented by Canada’s HIV
testing policy.

“Some doctors tell you, and some doctors do not tell you about the HIV test”
“I know my HIV status because I learned it through Canadian immigration procedures,”
began Alem in response to my lead question that queried his immigration story and how
HIV was handled through the process. Alem had been in Canada two and a half years by
the time we met. He began by telling me that he had been a refugee in several camps in
Sudan. “I had an official UN [United Nations] High Commissioner for Refugees identity
card that stated my refugee status, which is very important when living in Sudan. I had
genuine documents to show the reasons for my refugee claim.”

“I was born in Eritrea where I was politically active against the government. This led me
to leave the country.” Alem’s brother had already immigrated to Canada as a church-
sponsored refugee, and his wife and children were resettled with him. In 2002, Alem’s
brother asked the church to consider sponsoring his sibling. This represented the
beginning of his immigration application to Canada. He was sent immigration papers
from the Canadian government that he filled out and sent to Canadian government
centre in northern Africa. “After waiting a long time, I had an interview with an
immigration consultant agency called the International Organization for Migration. That
was in 2005.”

“After that,” Alem continued, “I waited a long time before receiving an official
immigration document at my place of residence. This stated that I needed to go for a
health examination. I went by myself to the doctor as I was asked.” He brought this
piece of government correspondence to a specific medical office in Khartoum, as he was
instructed, and “the doctor did urine, blood, whatever they took. There are specific
doctors [DMPs] who work with Canadian Immigration. They know each other.” The
doctor was not Sudanese-born. She was a doctor employed by the Canadian
government to do this kind of work. She had no connection with the Sudanese
government, and she did not inform the national government of his HIV-positive test
results. The Canadian government paid for her services, though later, once in Canada,
Alem said, “I reimbursed for airfare and medical expenses in the amount of $2,000.”
There was no written indication on the forms that he was given in the doctor’s office
that he would be tested for HIV. “The doctor told me this verbally. Some doctors tell
you, and some doctors do not tell you about the HIV test. I only had to fast for the
examination.”

“If I were not a sponsored person, I would still have to live with HIV”
Alem was asked to return to the doctor’s office several days later and he did. During this
visit he was informed that he was HIV-positive. “The doctor asked me if I knew prior to
the test that I was HIV-positive. I did not. That was the first time. It was a confusing
time. I was wondering how it happened.” Alem did not have much time with the DMP.
She told him about medications. He understood that he would only get medications
once in Canada. She did not do further testing such as CD4 count or viral load. “The
doctor told me that I was still allowed to go to Canada, but that I had to know that I was
positive. She told me to take care of others and myself; not to transfer HIV to other
people.” He was surprised that he could still go to Canada. “In Sudan, there are no
‘legal’ AIDS service organizations. There are no referral organizations. It is hidden. That
is why the doctor does not refer you anywhere . . . People know that living with HIV in
Sudan is very serious and dangerous because you can be deported if you are not
Sudanese. That is why people do not volunteer to do the HIV test.”

Between the time I was tested and the time I came to Canada one year passed. I
did not have medication in that time. At that time, the only thing that keeps me
out of stress and a normal person, in a good way, is that I can come to Canada.
The doctor told me that I have a chance to come to Canada even if I am positive.
I was happy for that because I know that I will get medication, work, and I can
help myself. That hope helps me to be out of stress.

In the DMPs office, Alem had to sign a document “that indicates that you know that you
are HIV-positive. You must sign this.” Alem did not get a copy of this document or his
medical report. He understood that this document must be sent to the Canadian
government along with his medical report.

I was not nervous to sign because the doctor had already assured me that I could
come to Canada . . . I do not know how it happens for others. I do not know why
the doctor told me that I could come to Canada. If I were not a sponsored
person, I would still have to live with HIV. I do not know if I would have been
able to come here if I were living with HIV and not a sponsored person.
Alem understands that at this point, his file was sent to a “medical worker” in Canadian Immigration. From there it made its way to a visa office in the Canadian province where he would immigrate. “The doctor did not tell me this. I later found out when I received government correspondence about my visa to Canada.” Alem received a visa to Canada after one year of waiting. He had no idea why it took so long. However, he speculated that maybe it was because of the medication that he would have to take once in Canada. Shortly after receiving the visa, he received a two-page document from the International Organization for Migration. One page confirmed that he was HIV-positive. The letter advised that soon after his arrival in Canada, he must meet a doctor. The second page was a list of doctors with their addresses. “That was the only paper about my HIV status. On your travel document, there is no mention of HIV.”

“They consider HIV to be different than other diseases”
I asked Alem about his understanding of why the Canadian government tests for HIV through immigration medical screening. He responded,

I think that the Canadian government changed their policy about HIV because they expect immigrants will be carriers of HIV when they arrive, and that they will infect people who already live in Canada. They consider HIV to be different than other diseases; thinking that it can be easily spread to other people. Maybe they changed their policy because they found that the number of people living with HIV had increased.

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Susanne Kunene
I met Susanne in her apartment where we talked for two hours. She had arrived in Canada in mid-2002 and applied for state protection as a refugee applicant. Susanne was not aware whether or not she had been tested for HIV during her first immigration medical examination eight or so years before. (Though indeed she would have been screened for HIV since she arrived after January 2002.) The processing of her application took three years, and it was during a second immigration medical examination that her HIV status came to the attention of the Canadian government. By this time, Susanne already knew her status because she had taken herself for HIV testing at a local clinic. She suggested that she was likely infected with HIV in Canada because she had not left the country since her arrival in 2002. She provides careful detail about efforts she made, and challenges she faced, to gain permanent residence from her social location as an immigrant living with HIV. Susanne’s immigration application work process reveals quite different social and institutional relations than those identified in Alem’s story.

“Here, I believe that all the systems and networks are connected”
I was born in southern Africa and I arrived in Canada in 2002. I waited about two years for the refugee hearing. It took a very long time. I did not leave the country during that time. If you leave, you will not be allowed to come back in. In the
end, my refugee claim and subsequent appeal were both declined by Citizenship and Immigration Canada.

From my lawyer I learned that there was another way to stay in Canada. I applied for permanent residence status by filing a humanitarian and compassionate claim. ‘Please, we are all humans; consider me that I am a good person. I work, I pay my taxes, I do not have a criminal record’. Many of the documents that were submitted for this application were the same as the refugee application. I collected documents from my church and workplace. I submitted tax returns. The lawyer said that the government needs to know that you are not a strain to the social welfare . . . that you socialize with the citizens of Canada.

After eight months of waiting, I received a letter from Citizenship and Immigration Canada stating that I was accepted in principle. This means that the government has accepted the grounds and reasons on which you applied for stay. The letter also stated that acceptance was conditional on a criminal check and health grounds.

By this time, I had discovered my HIV-positive status through self-initiated testing. During that wait time, I wasn’t very, very comfortable. I was not sure what was going to happen. Friends and peers were saying that you do not get permanent residence if you are HIV-positive. However, I was excited and thought that I was okay because the provincial government had been providing me with antiretroviral medication since I discovered my infection. Here, I believe that all the systems and networks are connected . . . I know that they are different departments or divisions, but I think that they are all connected. The federal government knew, or so I thought, that I was HIV-positive when they issued me acceptance in principle . . . To me, it meant that the government accepted me with my HIV-positive status.

“Maybe he is fed up with immigrants coming in with HIV”
At this point, I was advised that I needed to go for a medical examination. I saw the same immigration doctor as I had for my refugee claim. I saw him three times in all, and this was the second encounter. I told him that I was HIV-positive, and that I was undergoing medical screening for the purposes of a permanent residence application. He said, ‘No, no, no.’ He told me that ‘if you are HIV-positive, Citizenship and Immigration Canada will not accept you’. He is a professional, and I did not expect that. He was unkind the three times I saw him. He hardly talked to me.

The third and last time I saw the immigration doctor was after he called me to see me. He had me sign a document that stated that he counselled me for HIV. He did not give me counselling. I asked him why I should sign it. Most of these
places don’t tell you things unless you ask them. I generally did not ask questions. I feel that with HIV, there is so much prejudice, and there are some things that you can ask, and some things that you cannot. There is power. I could have refused, because he did not counsel me. I didn’t care. I signed it. I did not get a copy of the consent form that he made me sign. He likely didn’t counsel me because I told him that I had an HIV specialist. I don’t know. Maybe he is fed up with immigrants coming in with HIV.

“Time was running out for me”

Then I received a second letter from Citizenship and Immigration Canada saying that my permanent residence application might be declined because of my HIV-positive status. Right away I called Ottawa and my lawyer to understand and discuss. It was impossible to reach anyone in Ottawa. This is when I told my lawyer about my health status. I was really, really frustrated. I was told that I needed to send additional medical information to Ottawa in thirty days or a decision would be made about my application based on my health. This meant that I would be declined. It was at that time that I realized that my lawyer did not have much information about HIV and immigration. He did not know how to go about it.

I decided that the letter meant that I needed to provide the government with biomedical information about myself. I went to see my HIV specialist. He said he would help me by writing a letter providing details about my CD4 count and viral load. This is what we thought Citizenship and Immigration Canada was looking for. He seemed somewhat familiar that HIV seems to be a problem with immigration. The doctor knew more than the lawyer. I sent this doctor’s letter to Citizenship and Immigration Canada. A short time later, I received their response. They instructed me that the information that we provided was not the information they sought. They did not, however, say what they wanted. They said that the chances were high that my permanent residence application would be denied.

My resource people at this point were the clinic doctor and social worker. They were nice, but not too well informed about immigration and HIV. The social worker at the HIV clinic referred me a state-sponsored refugee agency. The caseworker there was more familiar with cases where people were new arrivals as opposed to persons who had been in Canada longer. She had no information about my particular situation and could not help me with my problem. I was really troubled. My immigration processes had been a battle. I thought that things had started to open up with the first letter. Time was running out for me.

I received a third letter from Citizenship and Immigration Canada. I had been declined for permanent residence because of my health. I immediately called the Citizenship and Immigration Canada office in [city name]. I knew to contact this
immigration officer because his name was on the letter that I received. He told me, ‘Yeah that is how it is. Now your only option is to sign a temporary residence permit to say that you will stay in the country for three years. You will not get deported during this time. Then you can re-apply after three years. When you re-apply, you start from scratch. When you do that, they will not consider your medical condition’. He urged me to take the permit. He said he would write me a letter to set an appointment to sign the paperwork. I would not be eligible to leave the country for another three years. I would not have seen my family in nearly a decade [had I signed the form].

“You are not supposed to offer better interest rates”

For one month, nothing happened. The immigration officer did not get in touch. I have no idea why. Immigration is so slow. For something small, it could take six months. It could take ten months. The wait is something normal. I went to see the HIV clinic social worker. She called an organization that serves refugees and made an appointment for me. I went and met with a lawyer. I spent a lot of time with the lawyer; telling him my story. After hearing the story, the lawyer told me that my chances were good. He had just done a similar case with a person with HIV treated at the same clinic. It went well. He said that I had a ninety-nine percent chance of success if he proceeds in a certain way. He knew of a clause that ninety-five percent of lawyers do not know about . . . ‘As long as they accepted you in principle, and now, as long as they are declining you because of your health, you are good. Give it a good six months’, he said . . . He wrote the government a letter. That was the first time in I don’t know how many months that I saw a bit of hope.

The lawyer explained the chain of action for the file: that it would go from him, to the Citizenship and Immigration Canada office in [city name], and to Ottawa for assessment and decision. I called the local Citizenship and Immigration Canada officer and he confirmed that he received the lawyer’s letter. He said, ‘I will do my part’. What I found strange is that he offered me the temporary permit option knowing that there was something else that I could do. He knew the clause! I think that he is not allowed to initiate this to me. I think that he is not allowed to give better information. It is like if you work in a bank, you can receive information from clients, but you are not supposed to offer better interest rates.

As it turned out, when Ottawa asked me to send them additional medical information, I did not send in the correct information because their written request was vague. If you are not a lawyer, you know nothing. You would have presented the same thing as we did. What they really wanted was a particular type of document from a lawyer. The lawyer’s letter needed to reference a certain Citizenship and Immigration Canada document, which is the “Operational Bulletin 21” from 2006 that explains that a person can request exception from
inadmissibility in context of humanitarian and compassionate application. All the government wants you to do is ask for an exemption!

“God used him by not giving me that interview”
A lot of people do not know that there is this allowance for exception. After we submitted this, I got a letter stating that I got approved. I was accepted in principle two years before I was finally accepted for permanent residence. If I had not submitted this document, my case would have been closed. Do you understand? When I went to the local Citizenship and Immigration Canada to pick up the documents for my permanent residence, I made a point of meeting the immigration officer who had sent my file to Ottawa for assessment. God used him by not giving me that interview where I would have signed the temporary permit. That would have changed the course of my life entirely.

Every once in a while, the agent told me that Citizenship and Immigration Canada Health Management Branch might ask for a medical examination at some point; they will write to you. She advised me not to decline that. Just go and do whatever they ask you. It is random. It is something normal. For the sake of statistics, governments should do the HIV test to see if it is immigrants who are bringing in more HIV. What I do not agree with is treating people differently once they are in Canada and found to be HIV-positive.

* * *

“Why is the government spotlighting HIV, anyway?”
From the local world and bodily experiences of Alem and Susanne, the remaining sections of this chapter transport the reader into the circumstances of the Canadian state’s legislating and decision-making as these relate to applicants for permanent residence who live with HIV.

I interviewed a standpoint informant from Brazil who applied to Canada as a temporary worker. ‘Anita’ was pursuing higher education in Canada, and had prior degrees in health ethics. She was one of the four standpoint informants who were not living with HIV, as I explained in chapter four. She had also been active in HIV work in Brazil, with a focus on civil activism and public health education. At her immigration medical examination, Anita realized that if she wanted to come to Canada, she had no choice but to accept HIV screening as imposed by the Canadian government: Brazilian nationals are among those that Canada designates it must subject to HIV testing, among other health screens, if they want to be eligible for a Canadian visa, since Brazil is on Canada’s
designated country list.\footnote{See footnote 15 (p. 77) for details about countries Canada designates. Citizens from certain countries undergo particular forms of medical screening as a pre-condition of applying to Canada.} Anita was very surprised to learn that Canada screens and sorts according to the HIV status of prospective immigrant people.

I am surprised that HIV is mandatorily tested for. It is strange. I always think about Canada as a very first world country; respect for human rights. It is a big discussion. In Brazil, it is a big discussion. For example, by law, nobody can be obliged to do an HIV test. So, the doctor can give you information; explain why it is important to do this test. But, you have the choice to do it or not. Nobody says you have to do it.

I had to sign a waiver indicating informed consent. I had no choice but to do an HIV test. If not, I would not have been given a visa. From a legal point of view, everything is correct because I agreed and signed a document. But, in reality, I did not have a choice but to submit to a test because I wanted to come to Canada. No HIV test, no visa. So I had to do it.

After arriving in Canada, Anita related that she was further shocked to discover that her fellow students from Germany, Norway, and the United Kingdom were not similarly obliged to undergo HIV testing as a pre-condition for securing a visa. Anita shared with me that she and her Brazilian compatriots had had discussions on this very topic; the unequal, if not inequitable, application of a Canadian public policy devised for and applied to certain immigrants.

Amongst ourselves, not publicly, we Brazilians agreed that had they had HIV, they likely would not have been given visas. We were all uncomfortable with this situation: that the HIV test is only for nationals of some countries and not others. Why not everybody? If everybody needed to be tested, you can understand. But, it is not for everybody. We were uncomfortable with the fact that the Canadian HIV policy did not apply for work visa applications for nationals of all countries. We started to say jokes like, ‘HIV from Germany is very welcome in Canada. HIV from UK, well, very nice! And HIV from Brazil? No, we don’t want Brazilian HIV.’ It [the policy and practice of HIV testing] is meaningless!

I understand a TB test because there is high prevalence in Brazil and it is eradicated in Canada. The epidemiological data substantiates the needs for this. About HIV, it makes no sense. [I think the thinking is that] Brazil is not part of the first world countries. So, okay we needed to ask them [for an HIV test]. If they are poor, they may be sick. My feelings were not good. I did not get good feelings from this [experience].
Anita asked me, “Why is the government spotlighting HIV, anyway?” Her question raised an important issue and hinted at tensions buried within it. Below are historical events that endeavour to answer Anita’s question and explore the ‘how’ of the state’s decision-making process about HIV immigration screening of applicants for Canadian permanent residence.

“Informed and rigorous debate”
Since 2002, all persons who apply for permanent residence to Canada and some categories of temporary residence are screened for HIV as a feature of Canada’s immigration process (Government of Canada, 2002). Tuberculosis and syphilis are the two other conditions for which applicants are mandatorily screened (Citizenship & Immigration Canada, 2002). There was no blanket immigration HIV testing in Canada before January 2002. Instead, physicians were previously guided by a list of health “indicators”, and HIV testing was not “routine” (Klein, 2001, p. 12). Anecdotal reports from medical doctor colleagues indicate that the addition of HIV into the Canadian immigration medical examination was the first and only change to the diagnostic procedures in approximately fifty years.\(^5\)

Unlike persons who test positive for HIV, persons found to have tuberculosis or syphilis who apply for Canadian permanent residence from outside of the country must seek treatment before being admissible. People with these conditions who apply from within Canada must also be treated and provide the government with written proof that tuberculosis has been rendered inactive and that syphilis has been ‘passed’ (or ‘cleared’).

The decision to integrate HIV testing as a mandatory, routine part of all immigration medical examination was made by Citizenship and Immigration Canada with technical input from Health Canada employees. As part of a full review of Canadian immigration law and policy that spanned from 1998 to 2002, Citizenship and Immigration Canada commissioned Health Canada to provide advice on “which medical screening procedures are required to protect public health” (Citizenship & Immigration Canada, 1998, in Klein, 2001, p. 2). The Ancestry of Canada’s HIV Testing Policy timeline at the beginning of this dissertation situates the federal government’s review of immigration and health legislation within a broad social and historical timeline.

In fall 2000, Health Canada recommended that Citizenship and Immigration Canada automatically exclude HIV-positive applicants based on health status, including refugees and refugee applicants who were otherwise protected under international law (Thompson, 2000). When the Minister of Citizenship and Immigration Canada made its recommendation public, the Canadian HIV/AIDS Legal Network, the country’s leading organization related to HIV and AIDS, the law, and human rights, along with the Canadian Human Rights Commission, strongly opposed mandatory testing and blanket

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\(^5\) I queried this point with a senior Citizenship and Immigration Canada informant. The person checked with colleagues and informed me that there was no information to prove or disprove this (personal communication, March 1, 2011).
exclusion of all prospective immigrants found to be living with HIV (T. de Bruyn, personal communication, April 11, 2008; R. Jürgens, personal communication, March 27, 2008; Klein, 2001). At the 2002 International AIDS Conference, members of the Canadian HIV/AIDS Legal Network lobby shared their strategies for resisting the federal government’s proposal of testing and categorically excluding all prospective immigrants with HIV from immigrating to Canada. They write,

Within hours, we [employees of the Canadian HIV/AIDS Legal Network] responded to this announcement. We started a letter writing campaign to the Ministers of Health and Immigration; [we] created a special section on HIV/AIDS and immigration on our website; [we] published an ethical analysis of the issues related to mandatory testing and exclusion of prospective immigrants; [we] gave numerous interviews to Canadian media and wrote several letters to the editor of Canadian newspapers; and[,] we published and widely distributed an 80-page report with a thorough analysis of the legal and policy issues raised by HIV/AIDS in the context of immigration. The report’s analysis and recommendations have been used very widely, including by the Ministerial Council on HIV/AIDS, a body that advises the Minister of Health on HIV/AIDS-related issues (Haig, Klein & Jürgens, 2002).54

Over the course of eight months from the time Citizenship and Immigration Canada announced the recommendation about categorical exclusion of HIV-positive applicants, the Canadian HIV/AIDS Legal Network assumed leadership of a national civil society mobilization against the imposition of testing and exclusion based on HIV status. The Canadian HIV/AIDS Legal Network framed its efforts within the logic of an “informed and rigorous discussion” on immigration and HIV, and its employees commissioned research that set out to produce a counter narrative or juxtaposition to the state’s official decision-making (Klein, 2001, p. 3). These projects included Barry Hoffmaster and Ted Schrecker’s (2000) ethical and moral analysis and Alana Klein’s (2001) investigation of the legal grounding of mandatory HIV testing for immigration and exclusion based on health status, both published by the Canadian HIV/AIDS Legal Network (below). This organization and its researchers considered how and by whom state evidence was produced. They also called into question key ideas and some of the normative assumptions nested within the expressed state’s need for mandatory HIV testing and exclusion of HIV-positive persons.

Klein (2001) reported that the federal government framed mandatory HIV testing and blanket exclusion of those testing HIV-positive as the optimal strategy to protect the public health and safety of Canadians; the “lowest health risk course of action [and] the preferred option” (D. Dodge 2000 [Deputy Minister, Health Canada], in Klein, 2001, p.2).

54 An example of a letter that was used in this advocacy campaign is still posted in the “Take Action” section of the International Gay and Lesbian Human Rights Commission website. See http://www.iglhrc.org/cgi-bin/iowa/article/takeaction/partners/792.html
The federal government’s decision-making about this was based on recommendations formulated by “technical working group” consultations where group members convened in discussions about the (then) newest, most “modern” medical screening technologies and risk assessment procedures associated with HIV and AIDS and other infectious diseases (Angus Reid Group, 1999; Kirkpatrick & Frankel-Howard, n.d., p. 5).

Klein (2001) brings more detail and considerable nuance to the state’s decision-making process in this regard, including the sort of evidence that was considered by working group members, and how this evidence was presented. Klein draws attention to the point that working group members were not presented with a viable status quo scenario: where there would be no changes to the medical screening technologies deployed on prospective immigrants at the time of the immigration medical examination. In other words, discussions proceeded from the assumed need for the Canadian state to impose mandatory HIV screening of immigrant applicants as the “lowest health risk option” (Kirkpatrick & Frankel-Howard, n.d., p. 17).

Health Canada organized a process through which its ‘experts’ were assigned with reviewing available evidence on the issue of immigration medical testing protocols and procedures. This process came to be known as the Montebello Process, named after the Québec conference centre at which meetings took place. Federal government actors reviewed the public health risks that would hypothetically be associated with several diseases, with a view of making recommendations for changes to the immigration medical screening protocols to Citizenship and Immigration Canada. The process was “designed based on epidemiological science and decision tree methodology”, and the “scientific assessment” estimated probabilities for disease spread throughout the
resident Canadian population (Kirkpatrick & Frankel-Howard, n.d., pp. 5-6). Attendees were for the most part trained in medicine and epidemiology and employed by or affiliated with Citizenship and Immigration Canada and Health Canada. The supposition of physicians and epidemiologists present was that HIV-positive immigrants would spread HIV infection to at least one resident Canadian (Angus Reid Group, 1999; Kirkpatrick & Frankel-Howard, n.d.; Klein, 2001).

According to media reports, Dr. Ronald St. John, a Health Canada scientist, said that the ‘Montebello Process’ calculated that, on average, ‘a migrant with an infectious disease like HIV transmits the condition to at least one Canadian resident’. He added that Health Canada did not know how many HIV-positive immigrants enter Canada, but that ‘the estimate is one in 1,000’; that Health Canada ‘estimated that each annual group of immigrants and refugees coming to Canada would generate thirty-seven HIV infections if they were not screened’; and that ‘screening reduces that probability’ . . . The assumptions underlying the statement that immigrant and refugees ‘generate’ 37 HIV infections are simply false [because] HIV is one hundred percent preventable (Canadian HIV/AIDS Legal Network, email communication, October 3, 2000; on file with author).

In a review of available documents and textual materials associated with the Montebello Process and the state’s broader decision-making regarding immigration screening protocols for infectious diseases available, I found no evidence to suggest that attendees at the Montebello Process made meaningful use of research evidence other than medical and epidemiological to inform their choices.\textsuperscript{55} For example, though there had been two focus groups held in each Calgary, Montréal, and Toronto to “assess Canadians’ views on Health Canada’s possible option for the screening of migrants for HIV/AIDS” in view of delivering recommendations to Citizenship and Immigration Canada, it is unclear how and if the people convened at Montebello made use of these data (Angus Reid Group, 1999, p. 3).

There is likewise no paper trail to suggest that legal, public health ethics or human rights scholarship or guidelines available at the time were used. In the case of the latter, such texts were especially designed to assist states in responding to HIV and AIDS from within a rights-based framework. Examples include the Siracusa Principles (United Nations Commission on Human Rights, 1984) and the International Guidelines on HIV/AIDS and Human Rights (Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS, 2006). To be clear, the concerns of those convened for the consultation were first about expected costs to public health

\textsuperscript{55} Materials I reviewed include: a nineteen-slide presentation to the Ministerial Council on HIV/AIDS authored by Citizenship and Immigration Canada employees (Kirkpatrick & Frankel-Howard, n.d.); and, a nineteen-page consultant’s report on results from focus group research guaging the general public’s “views with regard to current and potential policies for the screening of migrants” (Angus Reid Group, 1999, p. 3).
systems of treatment for people living with HIV, and second about the health of Canadians (C. Clark, 2000, in Klein, 2001, p. 2).

Then employees of the Canadian HIV/AIDS Legal Network wrote,

Our efforts were successful. In June 2001, Health Canada changed its initial advice to CIC [Citizenship and Immigration Canada], saying that HIV-positive immigrants and refugees should not be considered a threat to public health and need not be excluded from coming to Canada on that ground. CIC will proceed with mandatory testing, but nobody with HIV will be automatically excluded (Haig, Klein & Jürgens, 2002).

At the same time, Citizenship and Immigration Canada announced that there would be certain people exempt from being denied the opportunity of permanent residence for reasons related to their health status, whether HIV or another condition. These people included family members and refugee applicants. A last important feature of the state’s public commitment in the processing of applicants with HIV for the purposes of this analysis is Citizenship and Immigration Canada’s stated commitment to ensuring that DMPs would deliver pre- and post-test HIV counselling to all applicants as part of the immigration medical examination. This commitment was largely a result of the educational work about HIV and counselling delivered by the Canadian HIV/AIDS Legal Network to federal employees at the time.

Hoffmaster and Schrecker (2000) and Klein (2001) analyzed numerous problems related to mandatory immigration HIV testing and exclusion based on health and anticipated cost of care for people living with HIV. The left hand column of Table 14, below, lists six of these concerns (Bisaillon, 2010c). The table’s centre column briefly explains these in more detail. From the right hand column where this study’s informants’ experiences with each of the six concerns are listed, we see that the issues remain of concern for people. As the fieldwork for this study progressed, it became more and more evident that the issue of whether and how applicants were receiving pre- and post-test HIV counselling pursuant to the state’s commitment as listed in Table 14 could be mapped out in the material, day-to-day activities of DMPs and standpoint informants. As will be examined in later chapters, this point was troublesome to standpoint informants who, time and again, talked to me about the issue of HIV test counselling and the immigration medical examination. The last row of Table 14 lists concerns about the “exceptional status of HIV”. What this looked like based in the material circumstances of people’s activities similarly came into view through this research.

**Institutional discourses: Canadian AIDS organizational milieu**

Present in the talk and work of all standpoint informants, and most extra-local informants, was the existence of an institutional field that I call the Canadian AIDS organizational milieu.
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<th>Tension</th>
<th>Elaboration</th>
<th>Informant experience</th>
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<td>More harm than good associated with mandatory HIV screening</td>
<td>HIV and AIDS are stigmatized conditions. Settings worldwide in which persons are tested for HIV are highly variable because of social conditions.</td>
<td>“Where testing is carried out in overseas offices, counselling is consistent with the standards of that country. If it is not offered, then it is not offered.”</td>
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<tr>
<td>Whether and how pre- and post-HIV test counselling occurs in practice</td>
<td>Counselling is internationally recognized as integral to responsible health practice in relation to HIV screening.</td>
<td>“Interesting that the WHO [World Health Organization; where I was tested] did not obey its own recommendations about counselling [in the context of my test]. It has a staff that seems unaware of WHO guidelines on counselling [because I prompted them to talk to me about HIV].”</td>
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<td>Health-based denial of immigration application</td>
<td>Methodologies and international policies exist to evaluate the human rights consequences of public health interventions. Mandatory testing is framed as inconsistent with these, as is testing for the sole purpose of immigration.</td>
<td>“I explained to the [immigration] doctor [outside of Canada] that I was applying to immigrate to Canada [and that I had HIV]. He said, ‘why are they making you do blood work and waste your money? I do not know anybody who was HIV-positive who immigrated to Canada.’”</td>
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<td>Legality of mandatory testing for the sole purpose of possible immigration</td>
<td>Involuntary HIV testing is permissible in rare circumstances in Canada. Mandatory testing remains an exception under Canadian law.</td>
<td>“I signed a waiver indicating informed consent. I had no choice but to do an HIV test. If not, I would not have been granted a visa. From a legal point of view, everything is correct because I agreed and signed a document. But, in reality, I did not have a choice but to submit to a test because I wanted to come to Canada. No HIV test, no visa. So I had to do it.”</td>
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<td>Exclusively negative assessment of an applicant to Canada neglects to project positive contributions</td>
<td>Government agencies are experienced in considering qualitative evidence, but potential contributions of an applicant are not currently calculated into the cost-benefit analysis that is made of applications.</td>
<td>In the absence of a review of adjudication guidelines and policies used by CIC [in reviewing visa applications], “current policy results in immigration denial on medical inadmissibility grounds and the consequent loss to Canadian society of some gifted individuals” [Coyte &amp;</td>
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Table 14. Tensions, contradictions, experiences with immigration HIV testing
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<td>Applied to HIV and AIDS since the 1990’s, where public health responses to and funding for AIDS programming are criticized by public health authorities as being differentially treated at the expense of other conditions. Applied colloquially where people living with HIV are treated differently as related to health status.</td>
<td>“I think of all the immigrants who go through the immigration process to the end, just like me; who are intelligent; with good experience, but who would get blocked because of their numbers [CD4 count and viral load]. I did not know that these could determine my fate. If I had had a low CD4 count and high viral load, I would not be sitting here [in Canada].”</td>
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After numerous interviews with standpoint informants, it was obvious that this organizational field came to be a central organizer within their immigration application work process. Standpoint informants are quickly initiated into and participate in this environment. A refugee applicant named Berhanu exclaimed,

I was shocked when I got to Canada! I did not know how big AIDS was. We do not have this of information in [home city]. We just see it on TV. Like how many people are infected. How many doctors, pharmaceuticals. It was both a cultural and a civilization shock.

The Canadian AIDS organizational milieu is a form of civil society organizing that is articulated around a felt need for health condition specific service to people living with HIV and AIDS. This need has been transmitted orally and textually through successive generations of people living with HIV and those who work alongside them or on their behalves. Currently involved in this milieu are people of all backgrounds and ages, with notable involvement of mostly (though not exclusively) men who have been living with HIV for more than twenty-five years. The latter are colloquially referred to as ‘long-term survivors’.

Of course, the presence of death and dead bodies populate the worldwide narrative provided by AIDS and its string of opportunistic infections. Jasmin, a standpoint informant who applied to Canada as a refugee applicant, attended the annual general meeting of an AIDS service organization. Jasmin talked about being moved by the minute of silence that people present observed as part of the formal opening of the meeting. The silence was to commemorate the members who had died during the year. My own participation at such events confirms that this is also more generally initiated as an important symbolic act and ritual aimed at remembering people all over the world who have died from AIDS related illnesses.

The historical roots of this organizational milieu originate within the well documented forms of exceptional social and institutional responses to AIDS and people living with
AIDS in the 1980s, and the social mobilizing that infected and affected people, along with allied health practitioners, subsequently or in parallel engaged in to achieve various ends (Epstein, 1991, 1996; Mykhalovskiy & Rosengarten, 2009). These included lobbying to have monies allocated for research into the medical explanations for AIDS; pressuring governments to provide funds for care and medicines for people living with AIDS; and, organizing around inequitable treatment in policy, law, and practice of AIDS and bearers of its associated conditions. As a reflection and continuation of this historical orientation for activism, originating as it did from people’s locations of social difference, exclusion and marginality, the spirit that animates and inhabits the Canadian AIDS organizational milieu is that the provision of specialized structures for and services to people living with HIV is necessary.

During an interview with a lawyer with expertise in immigration law, whose clientele is composed of immigrants and refugees living with HIV (among other people with HIV), I was provided with some details about his work and commitments.

**L:** Is it necessary to have a legal clinic specialized in serving people living with HIV?

**I:** We are funded through legal aid, and we operate as legal aid clinic with a specialty in HIV. This work can be seen as part of a political commitment and culture of support for people living with HIV. This social engagement and activism is shaped by social responses to AIDS and HIV. You should look at the website for better details.

**L:** What about your work?

**I:** Well, my entire work is related to the HIV testing policy, obviously. So, all of my clients are living with HIV and because I’m the immigration lawyer, I mean I suppose that maybe nine out of ten of them would have gone through the current policy as it stands with mandatory testing linked to medical inadmissibility and all those things. Some of my clients immigrated prior to the starting of the mandatory testing, so they didn’t directly experience it, but now they’re maybe sponsoring family members who are now living with HIV.

The HIV test done to people at immigration is not just a test. It has long-term effects for immigrants, and their family members, in many respects. The aim of my work is to enable people living with HIV to immigrate or bring their families to Canada. A large part of my daily duties consist of giving legal advice to clients and other lawyers, and managing the cases of long-term clients.

**L:** What is the need for an immigration division within your legal clinic?

**I:** About five years ago, the clinic noticed that more and more people were coming in for immigration-related legal advice. In response, it found funding to
hire me. It is important to give people clear, factual information about immigration to Canada. It is a confusing process, made even more so for people living with HIV. I think that this clinic provides a comfort to people because the clients will not have to wonder if their lawyer is okay with their HIV status.

I: What precise knowledge is needed to advise clients on immigration and HIV?

I: More than knowledge of the law itself or familiarity working through people’s legal problems, it is necessary to have awareness; consider the social character of HIV. There are issues of discrimination. People with HIV might access social services in particular ways that people without HIV or another disability might not. How and which types of social services people draw on mean different things for the different immigration application categories. This affects the types of decisions that Immigration and Refugee Board agents can make about an applicant with HIV.

The AIDS organizational milieu in Canada is populated by a variety of organizations, and at this writing, there are seven such organizations at the national level. The purpose, character, and number of these have changed through time, which is partly marked by the transition of HIV to a chronic health condition due to the availability of high quality and effective medicines to slow the progress of HIV infection in people in Canada.

Organizations have divided themselves up according to interest and expertise, and within these divisions are further subdivisions. For example, there are AIDS organizations active in the fields of pharmaceutical treatment, medicines research, information dissemination, disability, the law, legal reform, and policy. Some groups are organized to provide direct service to people living with HIV (e.g., food and furniture banks, support groups), while others serve watchdog and coalition functions. Still other organizations are structured around racial (Black, Asian, South Asian), Aboriginal, Official Language, and social (e.g., women, youth, immigrant, lesbian, gay, bisexual, transgender) group affiliation. Provincial or regional umbrella AIDS organizations exist across Canada. These aim to bring together AIDS service organizations by way of membership, solidarity or shared purpose, and collective action. As explained in chapter two, I made contact with Ontario and Québec umbrella organizations in exploratory groundwork for this study.

Standpoint informants choose to frequent and participate in some or none of these organizations. Anaïs, who came to Canada as a refugee applicant, explained her thinking about not getting involved with an AIDS service organization. She makes it clear to me that she will participate in this study on her terms. Rightly, Anaïs also situates my work

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56 As noted in chapter one, this number might well shrink and/or organizations might be forced into organizational partnerships depending on the future of federal government funding for AIDS work, which will come into focus during 2012.
within the larger institutional field of HIV research, which she treats as associated if not
symbiotic. From my field notes,

Anaïs contacted me after seeing the study’s notice posted on an HIV clinic
bulletin board. She emailed me. Then we talked on the ‘phone. Anaïs was
investigating the project (and me), and her potential role in it. She was straight
with me: she dislikes the idea of taking part in research and studies. Anaïs was
really concerned about her privacy. She does not get involved in AIDS service
organizations because she self-describes as private. Anaïs is concerned with not
implicating government workers or lawyers in a negative way. These people
helped her to immigrate. Anaïs does not want to be linked back to them.

The HIV testing technology that intends the ‘serosorting’ of people into HIV-positive or
HIV-negative categories can be seen as one enabler of the Canadian AIDS organizational
milieu. That there are people living with HIV at all is knowledge that can only be derived
from a medical diagnostic, whether this is performed as a mandatory feature of
Canada’s immigration program or initiated through a person’s free will. The HIV test is a
ruling relation as understood within the frame of institutional ethnography: textually
organized social connections within institutional complexes that produce “specialized
systems of concepts, theories, categories, technical language” (D. Smith, 1996a, p. 47).
The medical discovery of HIV antibodies and a person’s subsequent knowledge of their
infection propel her or him into new social locations and forms of institutional
organization. Whether applicants to Canada are located in the country or outside at the
time of applying for permanent residence, people come to be represented and
understood and indeed governed through their participation in numerous categories:
disease, transmission, infectivity, immigration, and sexuality, among others. People
might simultaneously be classified into several categories. In government ranking
systems, for example, a gay, Black male immigrant with HIV is at once conceived of as a
sexual, transmission, risk, racial or ethnic, and immigration category. All of this work of
categorizing is enabled by and accomplished through the results of the HIV antibody
test.

Second, a positive result enables a person’s eligibility and entrance into the social world
of the Canadian AIDS organizational milieu. William, a family class applicant, talked
about seeing a lawyer shortly after he was diagnosed with HIV through Canadian
immigration. William and his husband Frank heard that there were special legal services
organized for people living with HIV.

Since my partner is working, we could not apply for legal services through the
[HIV legal] clinic because of revenue. I think that the cut off for access to service
at [clinic name] is annual income of $17K. My partner was earning $50K, I think.
First we saw a woman lawyer, perhaps a trainee, who then referred us to the
immigration and HIV lawyer. He accepted to see us for one session; to give us
some tips. We explained our story and outlined our concerns in depth.
Shlomo, a refugee applicant from the Middle East, talked about how he came into contact with public health authorities, a local AIDS service organization, HIV legal services, and, educational events coordinated through the work practices of the latter three.

I phoned [name] who is a manager and identified myself as a person who needed services. He volunteered to come to my house. He came and showed me things: confidentiality, responsibility [specifically for people living with HIV]. We signed a consent form, like the one you asked me sign before this interview. Later on he introduced me to a caseworker. She helped me greatly, for example, attending some conferences. She was the one to introduce me to [legal clinic name] and the workers there. At these conferences I met other PHA [people living with HIV] and we discussed about how to live life; how to defeat things that come against us. There were young and old people. It is interesting to discuss with similar people. How can you take your drugs; how to handle side effects; how to have good contact with your doctor. I am lucky. I get good advice from social workers and other people. Like about what vegetables and other foods to eat.

The AIDS organizational milieu in Canada is a strong purveyor of information and education to standpoint informants. Subjects for which standpoint informants reportedly receive training include immigration and HIV, the law, and research approaches among people living with HIV. One person who called me on the telephone expressing interest in being interviewed at the same time queried my “knowledge transfer and exchange strategy”, as he called it. In plain language, he was asking me how I anticipated communicating research findings to people. He explained that he had been trained by an AIDS service organization as a peer educator in HIV research. Based on what he learned in this training, he explained, he knew what the various components of research among people living with HIV in Canada should consist of, and ‘knowledge exchange’ was part of this.

A refugee applicant named Pierre, who was also trained through the same organization, talked about how ‘empowered’ he had become since coming to Canada and participating in AIDS service organization seminars and conferences.

I live downtown. I am here at ACT [AIDS Committee of Toronto] everyday, as well as at Black Cap [AIDS service organization]. That is how I know everybody by name. I do a lot of volunteering. [Names of the three AIDS service organizations to which he belongs, and a research group for which he sits on the advisory committee]. I know that I have to ‘empower’ myself.

I asked him,

\textit{L: What does ‘empower’ mean to you, exactly?}
I: The [Pierre] that you see today is not the same of three years ago. I am active. I did not know the word PHA [person living with HIV] before three years ago. 

*Empowered* because I want to know about sex, criminalization, immigration; about starting a life; about treatment [informant emphasis]. I will not get Canadian [labour force] experience unless I get involved in community.

Through their work with people who are new to Canada, organizations that specialize in providing services to immigrants living with HIV provide a context for a standpoint informant to learn, see, and understand her or himself as ‘being HIV-positive’ in Canada. Standpoint informants talked about learning about the rule of law in Canada and their civil rights and responsibilities as people living with HIV. In this way, we can see that people are rapidly politicized and socialized into a certain frame, within which these AIDS service organizations, and others that serve different clienteles, operate. The subset ‘being an HIV-positive immigrant or refugee’ is a particular social position that standpoint informants occupy, that other clients of AIDS service organizations who are Canadian-born, for example, do not occupy. Percy, who came to Canada as a refugee applicant, said,

[Name of an employee of an AIDS service organization] invited me to the PHA [person living with HIV] capacity building summit. This is done for new immigrants who are PHA. This was to teach us about our rights and how Immigration handles our cases. They showed us a chart. Such as those who take medication, and those who do not. How much they cost the government. We did not know this information before, but we were knowledgeable after the training.

There is no single or universal way that standpoint informants experience their new social location as immigrants and people living with HIV. There are, however, social and ruling relations that coordinate people’s activities through time and across distance beyond a single person’s account. These are in part discursively shaped by people’s involvement in the complex of social and institutional relations that constitute the Canadian AIDS organizational milieu, and people’s participation in the discourses formulated within the milieu reproduces it.

**Chapter 6: The state’s immigration medical in/admissibility work**

The purpose of this chapter is to describe the state’s medical in/admissibility work within the Canadian immigration system as a textually mediated work organization. The *Immigration and Refugee Protection Act* (S.C., 2001, c. 27) (IRPA) coordinates the successive work practices of people who participate in this complex, including immigrants with HIV, DMPs and medical officers, among other state employees. The analytic interest is examining the textual coordination that IRPA achieves by providing a language, setting discursive concepts, and establishing institutional relevancies through which people carry out their immigration work.
The argument I make in this chapter is that people’s work happens in ways that favour an administrative, cost-oriented form of reasoning. The organizing logic of the immigrant application process as a cost relation means that people’s work practices happen in such a way that emphasis is placed on certain forms of authority, notions of contagion, reasoning, visibility, action, surveillance, and bodily inspection. Such emphasis in turn forecloses other possibilities for seeing and knowing. I draw on the notion of intertextuality as it is developed in institutional ethnography to explore how the concepts of safety, health and cost in IRPA shape and are projected into people’s immigration work practices. I examine the HIV testing policy as a window into people’s practices by engaging with its assembly, problematic assumptions, and the forms of knowledge that are written into it to consider how language is projected into the text-reader conversation.

Public policy is intended to affect people, and the HIV testing policy ushers in work practices that filter out particular categories of people living with HIV. Through the examination of some parts of the policy text and the work it intends, I show that there are various exclusions, interfaces, stratifications and inequities related to geography, health status and lapsed data that have consequences for standpoint informants. I draw attention to the fact that immigrants with HIV come to integrate IRPA’s concepts of safety, cost and health into their own conceptual language and decision-making practices, a point that I closely explore and carefully explicate in chapter seven.

*Institutional discourses: Immigration and Refugee Protection Act*

The IRPA discourses around the economy, health, and safety shapes how standpoint informants see and talk about themselves; a point explored in the next chapter. The discursive lens provided by these IRPA organizers also provides the direction for state agents’ work on standpoint informants. For example, the work of Citizenship and Immigration Canada officials on the file of an applicant person living with HIV is organized around the concept of medical inadmissibility, which intends the exclusion of certain persons. All of this work comes under the auspices and authority of IRPA that provides “theories, rules, principles or laws that control how [people’s] actualities are selectively attended to in constructing textual realities” (D. Smith, 2010; on file with author).

The IRPA text is the senior regulatory document that coordinates the activities and practices of standpoint and extra-local informants. This position at the top of a hierarchy of other texts that are produced under and authorized by it makes it a ‘boss’ or governing text. The significance of drawing attention to how IRPA organizes subsidiary texts is because it is the purveyor of categories that were found to the key organizers of informant’s immigration application work. For example, the eight official texts listed in Table 10 (chapter four) are all part of IRPA’s genealogical tree. In institutional ethnography, this sort of relationship between texts is referred to as intertextuality. In drawing attention to texts in a same family, the analytic interest is to consider their influence on each other and the ways in which people use them.
[T]hat texts do not stand alone; their sense is not independent of other texts . . . the interdependence of institutional texts [is organized to happen] in a hierarchy: higher level texts establish the frames and concepts that control and shape lower level texts (D. Smith, 2005, p. 226).

This point about connections and relationships between texts is illustrated in Figure 9. In this map we see that IRPA is the senior text that organizes texts that are enacted under it. Likewise, people’s work with these documents is authorized by this text. The textual tools that people make use of, and the variety of documents that they create through their labour, shown in the eight circles in this figure, all come into being under IRPA. In this chapter, I examine IRPA and the HIV testing policy text.

The understanding that texts create and authorize particular concepts also means that these texts are vacuous until people fill them with meaning. “Linguists have drawn attention to how some words don’t seem to refer to anything; seems like they’re waiting for something to make their sense. Linguists call them shells” (D. Smith, 2010; on file with author). This in-filling work is achieved in people’s labour, which is done in particular places, circumstances, and over time.

A shell doesn’t identify an everyday [recognizable] object or person. [People’s a]ctualities have to be worked up in language, not to describe, but to fit. That’s the work of inscription, the writing . . . of some reality [in] documentary form (D. Smith, 2010; on file with author).

Categories, terms, and concepts come alive because they are given meaning through people’s practices. Through these work processes, standpoint informant actualities are converted into “textual realities [and] become institutionally actionable” (D. Smith, 2010; on file with author). What and whose accounts disappear through these transformations? How are standpoint informants’ experiences described and made to fit within the ideas laid out in IRPA and its derivative texts?

The economy as a discursive organizer
The health of the country’s economy is among the primary concerns of the Canadian immigration program, as articulated in IRPA’s text. Specifically, the text reveals that the state’s preoccupation is in knowing, or rather anticipating, how much the applicant for permanent residence might cost publicly funded systems in Canada. The state agent’s assessment work of applicants who have been diagnosed with a medical condition that the government determines to be of concern does not include an estimation of the person’s possible contributions to Canadian society, only potential costs to the state.

For standpoint informants, immigrating to Canada is not an inexpensive undertaking.
People spoke of the layers of fees that they are responsible for paying either up front, before arriving in Canada, or once they are in the country. Disbursing monies is a critical activity within their immigration application work process. Recall Alem’s statement in the previous chapter about reimbursing the state soon after his establishment in Canada.

Alem said, “I reimbursed for airfare and medical expenses in the amount of $2,000”. A refugee applicant named Martine explained,

J’ai ensuite pris des démarches pour demander la résidence permanente. Il fallait payer 550 $ pour moi-même et les enfants 150 $ par enfant. En tout, j’ai payé environ 2 250 $. La famille est toujours en attente.

People report that it is easy to find information about what fees they have to pay to apply to immigrate to Canada. Reimbursement schedules are also reportedly easy to find within the government website. In contrast, standpoint informants report that Citizenship and Immigration Canada’s site offers little useful information about immigration and HIV; an intersection of subjects that becomes of acute relevance once a person is diagnosed with HIV through immigration procedures. Finding information about where in the state’s processing of their immigration applications process their file is located, knowing how it is advancing through the necessary steps, for example, is likewise problematic for standpoint informants. A family class applicant lamented,

Everything here takes a while! It seems to take two weeks for everything. Everything just takes so much time. I have no idea what they are doing with my application at this point. There is so much waiting! It is always the same situation: I have no status, I have nothing; I am in a limbo. I cannot apply for anything. During the time I was visitor or temporary resident, I was unable to work. Wait, wait, and wait. For months! The first lawyer told us that it would be like this: that it would take months to process all the papers related to the processing of the immigration application. Nothing explains the wait other than ‘this is the wait time’.
Figure 9. Textual hierarchy organized by IRPA

Immigration and Refugee Protection Act and Regulations

- Operational Instructions
- DMP manual
- HIV policy
- IR3 instruction
- Immigration application
- Medical diagnostic, expert reports
- Medical assessment report
- Visa decision letter
There is limited information available on the on-line system. I am just looking and looking on-line. The lawyer says that they look with a magnifying glass at each file.

My own work searching Citizenship and Immigration Canada’s site for what sort of information is available to the public on immigration and HIV confirms that there is nothing particularly useable. I had learned from standpoint informants that the state’s web resources do not clearly articulate its position on HIV, and this was confirmed in my own search efforts.

Standpoint informants know that as people living with HIV, they will likely participate in treatment regimens provided by the pharmaceutical industry at some point in their lives. They will come to use and depend on medicines for their survival, and in the absence of particular medicines, they will die from AIDS-related illnesses. The analytical work of two standpoint informants about the eventuality of taking medicines is rather anxiously cast within a temporal frame. They explain,

I am not yet on medication [because my immune system is strong and my HIV infection is not too advanced], but it is only a matter of time before I go onto medication.

Just yesterday I was thinking how my life changed when they told me I am HIV-positive. I wonder how my life would be now if I was not positive. I am still not taking the medicines because I am okay for now, but I know time is running and I will have to do it sooner or later.

Applicants for Canadian permanent residence who are not protected from exclusion under IRPA’s categories will be penalized in the work practices of state agents because of their eventual use of and dependence on pharmaceuticals. Standpoint informants come to know that the state’s estimates about costs for treating and caring for them set them apart from other applicants for permanent residence. A refugee applicant from North Africa explained,

I attended training on HIV and immigration. We receive a lot of information over two days. I received a certificate for having attended. The table [that the lawyer showed in this presentation] shows which people are good chickens, and which are bad chickens. This chart shows who is admissible and who is not admissible to Canada [because they are too expensive].

_Health as a discursive organizer_

There is ontological dissonance between how standpoint informants understand health and how IRPA defines it. Standpoint informants conceive of health as being the absence of sickness (i.e., asymptomatic HIV infection) and illness (i.e., as a subjective experience) (see Fassin, 2007; Frank, 1995; Herzlich, 1994; Kleinman, 1995; Schepers-Hughes, 1992).
Chantale, a refugee applicant, was adamant that despite her HIV infection, she was not sick.

*L : Est-ce qu’aujourd’hui, tu te dis « malade » ?*

I : Et bien les chiffres disent que je suis malade. Mais moi, dans ma tête, je ne suis pas malade [insistance].

*L : Pourquoi ?*

I : Le diagnostic dit que je suis malade, mais moi, je refuse d’être malade.

*L : Hmmmm . . .*

I : Je ne suis pas malade. Sur le plan de la santé je te dis que je me porte bien. Parce que d’abord je ne savais pas que j’étais malade. Il a fallu que j’arrive ici au Canada pour m’en rendre compte ; pour connaître mon statut. J’ai connu des gens qui sont morts de cette maladie, et moi je vis encore. Je marche, je parle. Bon, je me dis que j’ai de la chance ; et que Dieu est avec moi. Et c’est une grâce.


I : Je refuse. Je n’accepte pas. Je ne veux pas être malade; je ne suis pas malade.

*L : Et tu vas vivre jusqu’à quel âge ?*

I : Moi je peux vivre jusqu’à quatre-vingt dix-ans. Dans ma famille, on est des centenaires. Mon grand-père a vécu jusqu’à cent vingt ans.

While health is not defined in IRPA’s text, the meaning of the term, as the state interprets it, can be inferred from what the text tells us in sections other than definitional ones, and in the texts that derive from it. Health is understood to be the absence of expensive-to-treat diseases or health conditions that the state is able to detect through diagnostic and other examination procedures. Within this understanding, health is not about health at all.\(^57\) Rather, it is about health and social service cost, defined in the Regulations (SOR/2002-227) as follows,

\(^{57}\) A point made by ethicist Margaret Somerville (1999) who notes that health concerns are rarely, if ever, exclusively about health. She wrestles with how to meaningfully define public health, human rights and ethics in the era of HIV/AIDS. Somerville concludes that these are embedded in political, public interest, and economic decision-making.
1(1): ‘Health services’ means any health services for which the majority of the funds are contributed by governments, including the services of family physicians, medical specialists, nurses, chiropractors and physiotherapists, laboratory services and the supply of pharmaceutical or hospital care.

1(1): ‘Social services’ means any social services, such as home care, specialized residence and residential services, special education services, social and vocational rehabilitation services, personal support services and the provisions of devices related to those services, (a) that are intended to assist a person in functioning physically, emotionally, socially, psychologically or vocationally; and, (b) for which the majority of the funding, including funding that provides direct of indirect financial support to an assisted person, is contributed by governments, either directly or through publicly-funded agencies.

In relation to HIV, the idea of ‘health’ enabled under IRPA extends into health behaviour and lifestyle choice of people living with HIV. From a reading of the Handbook for Designated Medical Practitioners (Minister of Public Works and Government Services Canada, 2009), we see that immigrant applicants with HIV are associated with ‘risk’. We also learn that they are in need of being controlled and monitored. The document provides specific guidance to DMPs in their work with people they discover to be living with HIV, which we learn includes HIV test counselling. There are likewise health-condition specific instructions for what the doctor should be on the lookout for when working to write up a medical file on an applicant living with HIV. For example,

HIV infection is not of itself considered a significant public health risk for immigration assessment purposes. However, the behaviour of an HIV-infected individual may present a threat to public health and safety if the applicant does not understand the condition and the steps necessary to prevent its spread. This is why post-test counselling is fundamental to the management of HIV-infected individuals . . . Counselling also provides the opportunity for the physician to identify those rare applicants who may actually indicate that their intention is to infect others with HIV (p. ii-17, Appendix II).58

58 In a June 6, 2011 public presentation to discuss features of the Déclaration québécoise des droits et responsabilités des personnes vivant avec le VIH (http://www.coglsida.com/assets/files/mediatheque/AfficheDeclaration18x24.pdf), Ken Monteith, a former practicing lawyer who is currently the executive director of an AIDS service organization in Québec, said that in his twelve years of involvement in the Canadian AIDS organizational milieu, he has never known any person with HIV expressing the intention to infect another person. This information appearing in the DMP Handbook is dangerous, irresponsible, and serves to propagate myths about people living with HIV.
Safety as a discursive organizer

The concept of safety is also not defined in IRPA’s text but as above, inferences can be made from attention to language and what the documents that come into force under IRPA instruct state agents and others to do in their work practices associated with applicants to the country. In requesting to stay in Canada, standpoints informants expect and experience the state’s collection of documentary information about them. Informants work to gather and submit various documents such as police records that substantiate that they are not risks to the state. A standpoint informant talked about surveillance of her identity in relation to her blood sample, as linked to the mandatory HIV test. She said,

They were very strict. The secretary of the doctor [DMP] gave me forms to fill in prior to the blood tests. She glued a picture of my face to a form. The person who drew my blood had to sign, on diagonal, over my face to be sure that they took my blood and not the blood of another person.

State data collection on applicants extends to particular forms of bodily evidence that is gathered on all immigrant applicants independent of their medical or health condition. Seydou, a family class applicant, said,

Our lawyer told us, ‘It is going to take you half a day [at the DMP office]’. This is what you need to prepare for; this many photos. They need to be this size. This is where you go to get the pictures. Three copies. He told us the painstaking detail of what we were supposed to do. He said, ‘Now you need to request local police records for the last ten years; every city that you have lived in. They need to find out if there is any criminal background. Fingerprints, FBI [United States Federal Bureau of Investigation] check. That check and fingerprints goes directly to CIC [Citizenship and Immigration Canada].’ That is what he told us.

Standpoint informants also suspect, imagine or expect that because of their HIV status, they will be the subjects of unique forms of scrutiny that applicants who are not HIV-positive will not experience.

When you test positive, your health information is shared. The health system knows when you test HIV-positive. I think that labs and results are centralized. When the DMP asked me about who I had been having sex with, and if it was with men, I really knew at that moment that results were shared between offices. I thought that I was in the police records! I felt like that. For immigration medical screening, I had to give the DMP numerous photos, so there was a relationship between my face and the positive HIV results. Once you test positive, they know. These were sent to the nurse, which is why they call you. They always know. Everyone in Ottawa knows I am positive.
Indeed, there is a health condition-specific government work apparatus organized around HIV. There are specific tracking systems that monitor immigrant people living with HIV who are in Canada and prospective immigrant people with HIV who are physically outside of the country. There are also particular rules that apply to these persons. These systems are brought into being and coordinated through the work of provincial and federal government agents who maintain and operate them. A first example is the 2003 immigration policy directed at spouses of Canadian citizens or permanent residents who test HIV-positive through immigration testing overseas, as per Figure 10 (CIC, 2011b, p. 9). This policy triggers situations where a prospective immigrant’s HIV-positive status can be disclosed to the applicant spouse, sponsoring spouse, or an employee of Citizenship and Immigration Canada (Sayani, 2003).

A second example is from September 2004 when Citizenship and Immigration Canada introduced a “process . . . in consultation with provincial and territorial chief medical officers of health” by which it has since produced monthly reports to nine provincial and territorial government public health authorities on the HIV status of immigrants resident in their jurisdiction (CIC, 2011b, p. 9). These reports provide the names of applicants who tested HIV-positive during immigration screening outside of Canada and who later entered the country.59 These are just two examples of the types of state focus on HIV and immigrant applicants with HIV.

I talked to a health director working in the provincial public health department of one of the Canadian jurisdictions where the positive HIV status of new immigrants is communicated via monthly report. She spoke about her work and that of her staff in connection with these reports from Citizenship and Immigration Canada.

L: What is involved in being notified of an HIV-positive report?

I: Whether the person was tested in or outside of Canada, CIC [Citizenship and Immigration Canada] gets in direct touch with [health department name]. We then figure out which health area the refugee is resident in, and CIC sends the file to our department. Then it is up to the public health nurse to find that person. Then the refugee gets a letter stating that you must get in touch with public health in twenty-eight days.

59 For immigrants who take up residence in Québec, Citizenship and Immigration Canada provides non-nominal HIV-positive test reports to provincial health authorities. Citizenship and Immigration Canada does not issue an equivalent report for immigrants who take up residence in Nunavut, Nova Scotia, or Newfoundland and Labrador (CIC, 2011b, p. 9). I understand that the difference in reporting between jurisdictions has to do with different disease notification requirements under provincial legislation.
Figure 5. State's policy on notification of a partner’s HIV status

I: What is the connection between an HIV-positive test and your office?

I: Ours is a direct link to public health and people who test positive. We know about all cases. We know about all tests [i.e., immigrant applicants and other people such as Canadian citizens and permanent residents; informant emphasis]. We may lose them to follow-up, mind you. When there is confirmatory Western Blot test, the lab result comes to us. The lab gives us as much info as possible, like who did the test. We follow-up on all of them. Someone should interview them.

L: What exactly does this work look like?

I: My public health nurse is the one who connects with the clients; to talk about the Public Health Act [provincial legislation] and do partner notification, stuff like that. These are reportable diseases, of course, so they get the list of partners. We do anonymous partner notification. As long as someone has talked to them about the [provincial] Public Health Act, how to practice safe sex, safer injection, disclosure to partners. We note in their file that conversation has taken place in the case that in future the records are subpoenaed by the court in the case of a criminal procedure. We PDF [portable document file] the files; all electronic. The client does not sign this document. We say that we have verbally informed. This is so they cannot be altered at another point. Signed and ‘PDF’ed’.
I: What about inter-provincial migration and movement? How do you track people?

I: A refugee has an obligation to advise CIC [Citizenship and Immigration Canada] of a change of address. For one thing, they are receiving interim health coverage [health insurance for refugee applicants; Federal Interim Health Program], and this is one of the stipulations of the agreement. For an immigrant, this is not the case. We just have to do good detective work. It is not easy.

Organization of the state’s immigration medical work
The minister of Citizenship and Immigration Canada has the authority for administering IPRA (s. 4(1)). The minister in turn delegates people to carry out the day-to-day work of managing and implementing the immigration health program. This work is overseen and coordinated through the Health Management Branch whose headquarters are located in Ottawa. The branch is divided into four sections under the supervision of a director general (see CIC, 2010b, p. 4). There are two branches of greatest import for purposes of this study. First, the Strategy, Policy and Communications Directorate, develops and communicates policy relating to immigrant health. It is under this section that the HIV testing policy was developed in 2002. Medical doctors generally occupy senior positions within the Health Management Branch.

A second Health Management Branch section of note to this analysis is the Operations Directorate, which is in charge of coordinating the organization of the Canadian immigration medical examination program and managing regional medical offices. One of these is in Canada, with additional offices in the following nine countries: Austria, China, France, India, Kenya, the Philippines, Singapore, Trinidad and Tobago, and the United Kingdom. The people employed in this section interact with DMPs in Canada and abroad. For example, medical officers are responsible for supervising and auditing the work and workplace of DMPs. These officers are also charged with preparing training materials, including the Handbook for Designated Medical Practitioners (Minister of Public Works and Government Services Canada, 1992, 2003, 2009), through which immigration physicians are to carry out their work of examining applicants to Canada.61

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60 The two other sections include: the Program Management and Control Directorate whose employees manage the Interim Federal Health Program, Medical Surveillance Program, and other “health outcomes” (p. 4); and, the Centralized Services Directorate whose employees are responsible for the Health Management Branch’s human resources activities.
61 What I do know of DMP auditing procedures comes from an Immigration Medical Examination Program Officer of the Health Management Branch of Citizenship and Immigration Canada. She informed me that medical officers perform checks to see that DMPs have properly completed government forms. It was expected that in mid-October, a “standardized tool” that medical officers would use during their site visits to audit DMPS would be in effect. (M. Brassard, personal communication, October 4, 2011).
Medical officers in Canada and abroad do the work of medically assessing applicants to Canada. This work consists of evaluating an applicant’s medical file, which has been submitted by a DMP. Medical officers are office-based employees who do not personally interact with applicants. They generally only communicate with DMPs to request further details about an applicant’s medical file. Usually this means that the applicant will be sent for additional diagnostic medical tests, results of which will be collated and sent to the medical officer by the DMP. There are two such medical officers who work in the Ottawa regional office of the Health Management Branch, and eleven who are employed in overseas medical offices. Generally, the medical report that DMPs prepare for each applicant is sent to the regional medical office located in the world region corresponding to where the applicant filed her or his immigration application. For example, applications submitted by people located in Canada and the United States are transmitted to and treated by medical officers in Ottawa.

The institutional working relationships and processes described above and in the following section are illustrated in Figure 11. In this diagram, we see the standpoint informant in the bottom centre of the diagram, and the medical officer and DMP located in the centre. The standpoint informant is represented to the state as a medical form that makes its way through the hands of numerous state agents. This schematic illustrates the relationships between people’s work and those who are involved in the processing of an applicant with HIV. All of the day-to-day work activities in which Citizenship and Immigration Canada employees engage, including medical officers and DMPs working in Canada and overseas, come into being as organized and regulated practices under IRPA.

*Doing the work of medical assessment*

The institutional work process involved in assessing the medical file of applicant immigrants involves several steps that occur through time and connect numerous places. This is depicted in Figure 11. On behalf of an immigrant applicant, the DMP sends her or his completed medical report to the regional medical office in her or his region. From there, an employee of the Health Management Branch screens, reports, and divides them into two categories. First, for “normal cases” where there is “no need for additional medical information”, the employee enters the decision into “the computerized system” (CIC, 2010b, p. 8). For “abnormal cases”, these are “reviewed by a medical officer and/or contract physician” (CIC, 2010b, p. 8). These include “problematic cases” such as an application from a person testing positive for HIV (state informant). Detection of an “abnormal” or “problematic” condition prompts the medical officer to write to the applicant or contact the DMP to commission additional medical information.
Figure 6. Processing of an immigrant applicant's medical file

- Medical assessment work documents: HIV policy framework, OP 15, other (?)
- Assessment report of inadmissibility

Medical officer assessment

DMP medical examination

Official medical report

- HIV, TB, syphilis tests

- Canadian Border Services Agency
- Immigration and Refugee Board
- Citizenship and Immigration Canada
- Interim Federal Health Programme

Health Management Branch

DMP Manual Policies Instructions

10 Regional Medical Offices in World
This request is called a furtherance. This describes both a document and an action: a written document and a request prompting additional exploration and bodily analysis. Standpoint informants described receiving such correspondence by mail. They reported fright on receiving a government-issued envelope reading ‘do not open’ beside instructions that they return to the DMP who examined them. Some DMPs I interviewed for this study talked of not waiting for the Citizenship and Immigration Canada medical officer to ask for furtherance. On diagnosis with HIV, for example, doctors talked of ‘saving time’ by sending standpoint informants for additional testing before this was officially requested. An example of a furtherance (and my critique and comments of it), appears in Figure 15 in chapter seven. Here we read details of the counselling (and other) work that a Canadian-based HIV physician did with an immigrant applicant who was instructed by Citizenship and Immigration Canada to bring this form to an HIV specialist. Once complete and returned to the government, this document will be textual proof that HIV test counselling was done (by the HIV specialist). This document is used in analysis appearing in the next chapter.

Buried within the terms ‘medical file’ or ‘official medical report’ (Figure 11) is a set of completed forms that the DMP has filled out during the immigration medical examination. The sum of these documents communicates doctor’s findings based on the apparent health of the person’s body, including results from the mandatory diagnostic testing, which includes the production of texts about the presence or absence of HIV, tuberculosis and syphilis. The DMP might have ordered other diagnostic tests from laboratories associated with her or his office. This happens at the discretion of the DMP. In carrying out this work, there are various forms that DMPs are instructed to complete and submit to Citizenship and Immigration Canada medical officers.

These official forms are organized into two families. The distinction between them is the degree to which the person’s body will be probed, scrutinized and reported on through medical screening. For the applicant who the DMP has discovered is living with HIV, this means whether or not she or he will have to submit blood for the production of CD4 and viral load laboratory reports. The set of forms is stamped ‘excessive demand exempt’ and ‘non-excessive demand exempt’, respectively. The DMP is directed to use the form that matches the applicant person’s immigration category under IRPA. Examination of additional body parts or closer investigation of the blood in the case of the person living with HIV is animated by the spirit of generating information that medical officers will in turn use in their medical in/admissibility work.

The medical officer’s work intends the determination of an applicant person’s inadmissibility as structured and coordinated by IRPA. After the triage work outlined above has accomplished the division between “normal” and “abnormal cases”, the Citizenship and Immigration Canada medical officer reviews the medical file of persons with “abnormal” results (CIC, 2010b, p. 5). Through her or his review, the medical officer produces what is called a medical opinion. This is a rendering on applicant’s
“admissibility/inadmissibility under health grounds to a visa/immigration officer” (CIC, 2010b, p. 5).

The written opinion on medical in/admissibility that the medical officer renders is sent to a visa or immigration officer located somewhere else. This person’s work is to scrutinize the entire immigration application file. It is ostensibly the visa or immigration officer “who has the ability to deem an applicant inadmissible under health grounds” (CIC, 2010b, p. 5). In preparing a letter to the applicant that will communicate the decision about denial or acceptance, this officer asks her or himself: Will this applicant pose a risk to public health in Canada? Will this applicant threaten public safety? What are the hypothetical long-term costs for caring for this applicant, and is it reasonable to expect that these will be ‘excessive’?

At this point in the process, the visa or immigration officer prepares a letter that is sent to the applicant person. The content of this letter is a standardized text that the agent tailors to the applicant person’s particular circumstances. For example, the person’s particular medical condition will be mentioned in relation to possible inadmissibility on medical grounds. The letter will also have a date by which the person can respond to the government’s determination by submitting documents. It was this type of letter Susanne, from the previous chapter, talked about. In this letter she was told that she had the “opportunity to respond to the conclusions of the designated medical officer with additional medical information of your own regarding your health at the present time”. The state frames this occasion to respond within the principles of natural justice, described as people experiencing procedural fairness or due process when a burden is imposed on them, or where a benefit is withheld from them. Changes to this standard form are issued and publicly available in the “OP [Overseas Processing] Medical Procedures” (CIC, 2011c).

While my access to Citizenship and Immigration Canada was challenging to organize and my contact to employees significantly limited, I had the opportunity to conduct one interview inside the Health Management Branch in Ottawa. I took field notes on the events just prior to my interview with a Citizenship and Immigration Canada senior employee. The following excerpt from these notes is long, but it provides useful insights into some features of the organization of the government workplace through which we detect linkages to extra-local practices and institutional arrangements. Entry into this workspace provided me with valuable opportunities for considering the space, conversing with people who work there, and uncovering clues into the organization of people’s daily work life as it is coordinated with the work of people in other places as related to the processing of prospective applicant’s medial files.

I signed in and provided photo identification to gain entry into the securitized office space at Citizenship and Immigration Canada. To my surprise, I was offered the opportunity to be escorted around the Health Management Branch; a sort of a guided tour. During this walkabout I was introduced as ‘the researcher doing

199
her doctorate’, presupposing that some of the people I met knew of my presence that day, or perhaps of my work. My informant was the self-appointed tour guide. Like in most government offices, there were dozens of people to greet.

Some of the most useful ethnographic observations from the ten minute or so tour came from sources other than human interaction. For example, in rounding a corner in the Health Management Branch office, my guide and I came nose-to-nose with stack after stack of immigration application files. In that instant, because the visual impact of the thousands of catalogued files, it occurred to me just what a huge and hugely regulated machine Citizenship and Immigration Canada is. I became aware of just how extensive and complex an institutional world I had entered. Is how things get done in this workplace, in direct association and connection with the many Canadian immigration offices around the world, as mysterious to employees as it is to the standpoint and extra-local informants I interviewed who are baffled by internal working of this department?

Rounding another corner in the office, I saw what I would come to know as a pair of medical officers; at work in their workstations, which were comparatively spacious cubicles. As we approached their desks, I saw that one of the physicians, whose back was facing me, was in the process of reviewing someone’s file. I was intrigued by what I saw: projected on the officer’s computer screen in front of her was the reproduction of a pair of human lungs in black and white x-ray form. (I wondered whose they were. Did I know the person?) From prior interviews with DMPs, I had learned that they send results of tuberculosis tests to Immigration Canada on CD [compact disc], whenever possible. (HIV and syphilis reports are sent as paper texts.)

Perhaps related to their workload or because I was there to conduct an interview with their colleague, interaction with the medical officers was brief. I asked them about what was on the monitor. What was the medical officer doing with the projection of the human lung? We all turned our heads to look at the screen. I was told that it was a ‘problematic’ file. It occurred to me that I was in the company of the very doctors whose work it is to evaluate and assess people with detectable medical and health problems; at least ones that are traceable through diagnostics. Would that person, lungs on monitor, be denied a visa?

The assessment work of the medical officer is most certainly important: through the officer’s reading, thinking and evaluative work, a report will be produced that will “contribute to a decision of considerable significance in the life of the person being evaluated” (D. Smith, 2006, p. 69). With this in mind, there remain some unanswered questions from the examination of the work of Citizenship and Immigration Canada medical officers. What reference materials inform the medical officer? What is this person looking for, exactly? On what criteria are medical opinions being based, as per state agents work practices? What day-to-day activities are involved in carrying out this
work? And, what forms of knowledge inform these practices? I explore these questions below.

**Textual production and projection**

In this last section, I look at the HIV testing policy text as a window into the everyday work of the state, its agents, and medical officers. Doing this offers the opportunity to start from the policy text and move beyond the local work setting where the policy is used. In this way, the policy can be situated within the social and ruling relations that permeate and shape local and extra-local working environments. I draw this text into my ethnographic analysis to investigate the ways in which it operates in the local world of medical officers in coordination with other people’s everyday activities beyond the immediate place where any of these people do their jobs. Appendix D4 shows some of my annotation work on the HIV testing policy document that I used for purposes of this analysis.

My textual analysis works from the understanding that Canada’s HIV testing policy framework is actively integrated into people’s current and future practices. In this analysis there is emphasis on forward motion, fluidity, and concreteness; where the policy document is part of what people bring into being through their labour as opposed to being treated as a static object. The document enters into people’s day-to-day work and coordinates sequences of actions.

I investigate how the policy projects actions that people should undertake, and these can be located and examined because they are discursively present. My use of the term ‘projects’ matches Dorothy Smith’s (2006) deployment of the term. She explains,

> I am not assuming that the text determines what comes next. I’ve rather carefully chosen the term *projects* to preserve the analytic constraint of remaining with and within the text itself. Just how a text is taken up and incorporated into a sequence or sequences of action is always an empirical question (p. 75; italics in original).

Figure 12 illustrates the lens through which I approached the analysis of the HIV testing policy within state medical officer’s work practices, and where, built into the policy, is the “movement from act to text and from text to act” through time (D. Smith, 2006, p. 72).\(^62\)

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\(^62\) I explicate this production and projection from what is found within the policy’s text since I unfortunately did not have the opportunity to speak in any depth with Citizenship and Immigration Canada medical officers whose review and assessment work is of analytic focus and interest here.
The HIV testing policy framework

The “Operational Processing Instruction 2002-004: Medical Assessment of HIV-Positive Applicants” is the state framework that has been used since 2002 as a guiding tool in the medical assessment of immigrant applicants who are detected to be living with HIV through the immigration medical examination (CIC, 2002). The document instructs the medical officer how to categorize, conceptualize, and know the applicant whose medical file she or he works on.

Excerpts from the policy text also appear in the public relations and education work that Citizenship and Immigration Canada employees do about HIV testing and medical in/admissibility decision-making (Appendices B2 & B3). These educational materials produced by Citizenship and Immigration Canada confirm that the HIV testing policy is a guiding text in the work carried out by state employees of the Health Management Branch of Citizenship and Immigration Canada (CIC, 2010b). To clarify how the state uses this document, and to identify what texts comprise the state’s immigration HIV testing program, a Citizenship and Immigration Canada informant wrote the following in an email to me,

La politique de dépistage de CIC concerne tout ce qui a trait au VIH dans le contexte de l’immigration. Le document intitulé ‘Operational Processing Instruction 2002-004’ est une partie des directives opérationnelles supportant la politique de dépistage . . . La politique d’immigration relative au VIH couvre le test de dépistage, le counselling, la détermination de l’admissibilité/interdiction de territoire au Canada, et la collecte et l’analyse de données liées au VIH (personal communication, March 1, 2011).
Public policy is intended to produce effects and structure the work activities of those who work with and maintain policy. From this perspective, the HIV testing policy is at once a working tool for medical officers, and a document that is a ‘how to’ instruction for filtering out applicants living with HIV based on their medical condition or disability.

**Authoring the HIV testing policy**

Three employees, then physicians with the Health Management Branch of Citizenship and Immigration Canada, authored the policy in July 2002. The document’s lead author, Doctor Neil Heywood, was senior Citizenship and Immigration Canada decision maker in his role of Director of Health Policy of the then Medical Services Branch of Citizenship and Immigration Canada. Heywood was also involved in research and invested in public education about Canada’s immigration health program at the time he was developing the HIV test policy (Heywood, 2001). The HIV testing policy text is written succinctly to the point of dryness; it is a document written by doctors, for doctors (Appendices A1 & D4).

The policy text is a conversation between professionals who share a language and common set of discursive reference points. Their distinctive speech genre is hyper rational and firmly within biomedicine, where a genre is a sort of formulae that brings to bear “a horizon of expectations . . . [and it] both unifies and stratifies language” (Bakhtin, 2004, p. 428). Within the construction of the policy text lie exclusions: the lay reader will have difficulty understanding its technical language of AIDS treatment, medical technology, and market-based financial calculations.\(^{63}\)

Established in the policy text are the so-called ‘facts’ about HIV and AIDS. However, these are narrowly interpreted to within medical science and aetiology. This frame prevents the reader from thinking of HIV and AIDS as other than palliative, contagious, and costly conditions. We see that the HIV testing policy document reproduces limited understandings of HIV infection and AIDS that exclude the possibility of social considerations of the conditions. Interpretations that fail to consider the “political sociology of bodies”, that is, the social circumstances and production of illness, reinforce inequities and perpetuate inequalities (Klinenberg, 2001, p. 123; 1999).

The HIV testing policy text is technically dense and emerges from the medical subfield of AIDS medicine. The authority of medicine and the voice of doctors are thus built into the document, and biomedicine is the established lens through which the document’s users read, orient, and prepare to use it. For example, the policy lists two references. These are given as “current Canadian criteria for ARV [antiretroviral] treatment” (p. 1) and “current guidelines for ARV therapy” (p. 6), which were (presumably) used and up-to-

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\(^{63}\) To assist me in my understanding of the language of the policy document, I called on the expertise of several colleagues. I am grateful for their sharing, knowledge and insights about the complex world of medicines and international and domestic treatment options for people living with HIV.
date in 2002. However, the criteria listed in the policy text are out of date and, furthermore, there are actually no Canadian guidelines for antiretroviral therapy per se: physicians in Canada are generally guided by the United States Center for Disease Control guidelines on when an HIV-infected person should begin treatment (United States Department of Health and Human Services, 2011). As such, the references in the HIV testing policy to “current criteria and guidelines” are, at best, ambiguous.

The devices, constructions, and authority of medical science anchor the language, notions, and concepts of the HIV testing policy document. The term “salvage therapy” (CIC, 2002, p. 6) appears in the policy text as part of the considerations about which medical officers must be concerned with regards to the medical files of applicants living with HIV.\(^{64}\) Previously, this referred to medical and treatment interventions given to an HIV-infected person whose body developed resistance to drugs. The term has (thankfully) not been in regular usage in Canada since the late 1990s because there are treatment options for most people who develop resistance to antiretroviral medicines. The dominant position and coordinating effect of medicine within this policy framework is also found within what I am able to comment about its text: my knowledge of these issues is likewise from within the lens offered by medicine. The social organization of the HIV testing policy text shapes what is brought into view for the reader and structures what the person who will use this document can know about HIV, AIDS, and a person living with HIV.

A key point that I am making is that the HIV testing policy and the medical language employed in it are explicitly linked to cost considerations. The policy does not offer a neutral medical overview or opinion. This quality of the testing policy’s organization links the document to the social organization of the immigration medical examination and some of the practices that are supposed to happen there, such as pre- and post- HIV test counselling. The idea of counselling and the official forms that are associated with it, for example those that are provided to the DMP who is to complete them and transmit them to Citizenship and Immigration Canada to attest that the HIV-positive person has received post-test counselling from the DMP, are accountability tools. Interests of cost containment and contagion supersede the medical understandings of a person living with HIV and the treatment options available.

The mandatory HIV testing policy entered into the historical record at a time where there were numerous state reviews of immigration and health law and policy. It was published in July 2002 — a full six months after mandatory HIV screening came into practice. The publication of the policy text coincided with the appearance of Canada’s new immigration legislation; preparation for which had been ongoing since the Legislative Review Advisory Group was appointed to evaluate Canada’s immigration system in 1996. The Romanow and Kirby Reports were published in 2002, which

\(^{64}\) The HIV testing policy is published in French and English. However, no equivalent term is employed in the French-language text.
investigated health care service in Canada. Numbers of health care workers, medical intervention waiting lists, and costs for delivering medical care were the focus and preoccupations of these reports. During this period, Health Canada led up the Health Protection Legislative Renewal that aimed to replace “outdated statutes with a new health protection legislative regime, better adapted to modern technology and society” (Health Canada in Ries, 2005, p. 8). There was thus considerable government attention to health service resources around the time the HIV testing policy was implemented.

Also during this period, highly effective antiretroviral drug therapy that prolonged the lives of people with HIV had recently started to be available in highest income countries such as Canada. In the HIV testing policy text there is evidence of institutional concern for the cost of medication treatment for people living with HIV. In fact, this was, and remains, the state’s central preoccupation, which can be measured in the frequency that the policy text uses the language of IRPA. For example, in the first three pages of the document, there are twenty-eight references to ‘excessive demand’ as defined by IRPA. The document is written with an emphasis on ‘inadmissibility’, a word that is used twice as much as ‘admissibility’ in the first three pages. The policy text frames the subsequent work of the DMPs and medical officers, and within their work are contradictions that echoed the experiences that standpoint informants I interviewed described.

This issue of expense, expressed in terms of the cost of various drug regimes, brings into view the policy’s relationship to the pharmaceutical industry and in turn a relation with government. In Canada, drug costs are regulated by provincial governments that work with pharmaceutical (private sector) bodies to set prices. The mandatory HIV testing policy outlines how “[t]he costs of “antiviral” [sic] therapy are borne entirely by some provinces and territories, and in some provinces and territories, the patient pays a small proportion thereof” (p. 5). The relevance of this statement to the directions being provided to the Citizenship and Immigration Canada medical officers who will use this text is not explicit. The emphasis on costs of treatment embedded in the HIV testing policy is reinforced with the references to expenses for the clinical care and diagnostic testing of people living with HIV. It is notable that no other medical condition with which a prospective applicant to Canada might be diagnosed during the immigration medical examination is subject to the careful directions that the HIV is through the testing policy and the resulting practices of DMPs and other Citizenship and Immigration Canada employees.

**Inscriptions within the HIV testing policy**

As a subordinate text to IRPA, the HIV testing policy provides the authority for what can be done to standpoint informants in the work practices of state agents. It speaks to and directs the work of Health Management Branch medical officers. The policy also lays out for the latter, on its own terms, the basis for knowing and understanding applicants living with HIV. The framework is an instruction for the institutional coordination of applicants with HIV. It begins,
Applicants may be divided into two groups:
[First,] those who are Excessive Demand exempt (EDE), according to section 38(2) of the *Immigration and Refugee Protection Act*; and
[Second,] those who are non-Excessive Demand exempt (non-EDE) (p. 1).

This stratification places refugees, refugee applicants, and family members in one camp (‘EDE applicants’), and economic class applicants in the other (‘non-EDE applicants’). The latter are submitted to more detailed bodily scrutiny than the former. From the policy we learn that,

Non-EDE applicants who are HIV positive:
Should be assessed according to public health, public safety, AND [emphasis in original] excessive demands [on] health grounds for inadmissibility (IRPA s. 38(1)(a)(b) & (c)).

When appropriate, examining physicians or medical officers should request further tests, such as CD4 or pVL [viral load] tests, to help determine whether an applicant represents excessive demands (p. 1).

Medical officers assess economic class applicants for how much cost they anticipate might be involved in treating the person’s HIV infection as a marker of in/admissibility. This assessment work involves probing of the person’s body using available medical testing technology.

The policy instructs the medical officer to,

See Annex A for the paper prepared by the consultant, which includes information on HIV costs [from 2002]. It should be noted that the consultant does not separate HIV positive applicants into EDE and non-EDE cases. Thus, although the paper refers to ALL [emphasis in original] applicants, *the information pertains solely to non-EDE applicants* [my emphasis] (p. 1).

In this way, IRPA’s separation of applicants into two groups at the policy’s outset coordinates, in particular ways, the work practices of Citizenship and Immigration Canada medical officers, DMPs, and HIV physician specialists. The latter will be called on by medical officers to produce blood test results and draw up ‘expert evidence’ about economic class applicants who, the document indicates, are target of this policy; since refugees and family members cannot be excluded from Canada for reasons of anticipated medical expense.

The HIV testing policy reveals how the state organizes its workers to conduct highly specific and prejudicial assessment work of immigrant applicants living with HIV as opposed to other medical conditions for which costs for treatment and care might be
incurred by the Canadian state. Directing attention to features and assumptions inscribed in the text for what these tell about the policy’s social organization also reveals what is projected into the decision-making practices of those for whom it serves as a working tool. There are other assumptions woven into the larger story that this policy tells, I discuss a selection of these.  

In reading the HIV policy, we first learn that applicants living with HIV are conceived of in institutional forms and various categories. ‘People’ rarely appear in HIV testing policy text, and there is only a single reference to “individual” (p. 5). People feature in this document only as juridical-legal, medical or financial bodies, such that their presence is inferred in the following terms, used generously: applicant (which is the policy’s first word); HIV-infected person; patient; mean patient; and, prospective immigrant. People with HIV are conceived as biological agents of concern to Canadian society (population health) and the state (public cost); reproduced as incidental bodies, their presence as people is suppressed. By the time the applicant’s medical file reaches the desk of the medical officer, another Citizenship and Immigration Canada employee has already screened it as “abnormal” (CIC, 2010b, p. 8). Certainly, the applicant whose file is not ‘normal’ is received and responded to differently than the equivalent file of a ‘normal’ person.

Through the construction of such categories transformations of people living with HIV occur. Reducing applicants with HIV into medical files, cases, blood and cellular test results, and cost estimates sees people reborn into standardized laboratory test scores. These results are reviewed by medical officers who are instructed to look for results above and below certain numeric thresholds; despite that there are a great number of other blood tests that could be used as a measure of an applicant’s future health status and hypothetical costs to the public purse.  

It is only HIV that produces the rigorous regulatory framework and ongoing surveillance of applicants for Canadian permanent residence. Medical officers are told that many applicants with HIV will be precluded

65 Examples include the consistent and repetitive use of certain legal terms and institutional categories, and the persistently vague language. These could be objects of study unto themselves. In a May 2011 email, a colleague knowledgeable about HIV medicines wrote, “They are making so many assumptions, they should be assuming positively about applicants, too; that they probably won’t have a long history on antiretroviral medication and will therefore not have developed too many resistances. Reading this [policy text], I felt the language very reminiscent of American HIV and immigration language before last year” [from 1986 to 2010 during which time the United States maintained an immigration, entry, and travel ban on people living with HIV].

66 For example, cholesterol levels as predictors of coronary disease or glycated hemoglobin as predictor for diabetic complications. The broad point I am making is that HIV is treated differently than other ailments as per state texts and practices that are HIV-specific. This is not to suggest that people diagnosed with other conditions are not similarly medically inadmissible to Canada. There is a bulk of current and historic evidence to show that applicants to Canada have been deemed inadmissible to Canada for a range of conditions.
from successful immigration to Canada because of their CD4 count and viral load test results. The HIV testing policy reads,

HIV infection will frequently meet the CIC [Citizenship and Immigration Canada] definition of excess demand due principally to the high cost of drug therapy (CIC, 2002, p. 5).

And while ‘people’ are not conceived as such in the policy, the document relies entirely on the work of applicants as they submit to HIV screening; details of which are explored in the following chapter. The text constructs a subaltern status of the people on whom medical officers and others work. Through this process of mandatory screening, people’s bodies are summoned to produce evidence of the presence or absence of HIV antibodies. Medical officers find within the policy the rationale for commissioning particular types of testing of applicants living with HIV. Even ‘borderline’ bodies infected with HIV are addressed in the HIV testing policy text that states,

[It is suggested that cases in which the applicants have CD4 and pVL [viral load] values very close to these thresholds [they] be referred for an opinion by IMAB [the then Immigration Medical Assessment Branch, precursor to the Health Management Branch of Citizenship and Immigration Canada], or a Canadian HIV treatment expert (p. 7).

The assessment work of medical officers is organized at the interface with the biomedical technology of AIDS medicine. The numerical reading from the CD4 count and viral load reports become two things: the sum of the person’s current well being (and health status) and a barometer for (extrapolated) health, longevity, and medicine needs. This points to an additional interface, this time with the pharmaceutical industry and its embedded position within biomedicine. The policy instructs medical officers on how to think about the applicant’s participation in the pharmaceutical industry.

The natural history of untreated HIV infection is characterized by progressive CD4 cell depletion. The rate of CD4 cell decline is determined principally by the pVL [viral load]. A significant percentage of HIV-infected persons with CD4 counts over 350 cells/mm³ will experience a decline . . .

What does the policy tell us about what actually happens in the assessment of prospective immigrants who test HIV-positive through Canadian immigration screening, and who are physically outside of Canada? The answer to this question points to one of the policy’s two exclusions of and limitations for people living with HIV. Drawing from the text of the HIV testing policy Table 15 shows how medical officers’ work is organized. We learn that a person taking antiretroviral medication is automatically ineligible for immigration because of the projected cost of her or his eventual participation in the pharmaceutical industry. We can imagine that this might incite applicants with HIV who are taking antiretroviral treatment to take leave from
The policy also reveals features about the social organization of the Health Management Branch workplace. The work processes described above (illustrated in Figure 11) show that divisions of labour are based on medical specialization; a parallel to the divvying up of the applicant person’s body for state scrutiny into authorized parts (blood and cells, in this case). Practitioners working within these processes have some notion or knowledge about what sort of work people produce before and after them in a work sequence, but each of these people plays a specialized and limited role in the overall
processing of an applicant’s medical file. Informants are generally not certain about the details of the work of those people with whom their own production is coordinated and tied. This point is illustrated by the substance of a conversation I had with a DMP.

L: *Who is making the decisions about people? Like, about whether they are accepted to Canada?*

I: It is a dollar amount that is the formula for accepting or denying someone. I am not aware how and if it is updated or calculated. It is all balanced out on cost of medical care. There is a book. [The previous director’s of Citizenship and Immigration Canada’s Health Management Branch name] would know. I have not seen the book. I am the front line man. It is not my role to make an opinion. I don’t make those decisions. I give people all the information they need. I would love to know from you in your research; about how decisions on people are made. I have no idea.

Of course, professional specialization and sectioning of workplace labour is not distinct to the treatment of immigrant applicants living with HIV or the institutional organization of the Canadian immigration program. For one thing, what is achieved through these arrangements, alongside those mentioned above about the reduction of people into categories, is a diminishing of workplace complexity and reifying institutional priorities. These features of bureaucracies also elide bodily experience and bring into view only that which is institutionally relevant. For example, Wilson and Pence (2006) report on the social organization of government employee work practices and some of the devices through which this work is coordinated.

The [institutional] system creates a myriad of mechanisms by which institutions elicit conformity from its workforce. These mechanisms include the use of forms, institutional categories, matrices, guidelines, specifically crafted definitions, risk assessments, scoring devices, and so forth (p. 220).

The authors continue,

As practitioners document what they see, hear, and observe in cases through administrative forms, computer screens, narrative reports, and case notes, the reality [of people with certain sets of experiences] has been transformed into an institutional representation [of a case]. All of the texts act as filters; they select what is relevant and make other aspects, determined not to be of institutional relevance, hard to see (p. 213).

These findings reported by Wilson and Pence can be more broadly applied to contemporary bureaucracies, including Citizenship and Immigration Canada.
Finally, the HIV testing policy is presented within the logic of biomedicine. It is this form of knowing that establishes for the reader and state employee what is legitimate and accurate. The procedures to be carried out on applicants and medical officer understandings of people living with HIV are fit within the boundaries offered by medical science.

Looking closely at the HIV testing policy text, we see that it simultaneously reinforces the science of its estimations about cost and disease evolution, and absorbs ideas from the social and cultural world. For example, the authors venture into the field of health economics, a separate field to medicine. To be able to make hypothetical estimates about future cost for treatment and care, it is reasonable to expect that authors would have been experienced and trained in doing this work. The HIV testing policy document states,

Most non-EDE HIV-infected persons with CD4 counts between 350 and 500 cells/mm$^3$ will experience a fall in their CD4 count to below 350 cells/mm$^3$ within the five year or ten year time frames placing an excessive demand on health services (CIC, 2002, p. 2).

In this statement, it is presupposed that state medical officers can determine how HIV infection will develop in an applicant’s body over a decade. It is presented as a given that a person’s medical and health care costs over this period can be mapped out. However, these remain hypothetical estimates (see Coyte & Thavorn, 2010).

In the text, the authors overstep ‘science’ and combine industry (pharmaceutical) and public (government) financial interests and intellectual property considerations. As we see in the excerpts below, the document makes highly problematic assumptions about people living with HIV. It does by explicitly associating people living with HIV with sexual predation; criminality and offense; lifestyle and behaviour; sexuality and risk; and, contagion and safety. Medical officers who use this document and the framework that it provides are to understand that,

HIV infection . . . transmission requires specific voluntary behaviours, principally sexual activity and sharing of injection drug using materials.

HIV infection could only be considered a risk to public safety under the unusual circumstance in which an HIV-infected person were [sic] a sexual offender [my emphasis].

A DMP emphasized the importance of his ‘objective’ administrative thinking and how this plays out in how he positions himself relative to the immigrant people from and on whom he gathers and compiles bodily evidence,
I: Can an applicant come to you to inquire about the evolution of her or his Immigration file?

I: No. I am not their advocate. I am impartial and unbiased. I think that this is very important in this business. Am I supportive in their health? Absolutely. I am just the man who is doing the basic work; CIC [Citizenship and Immigration Canada] interprets it for me. It is their lawyer, family, friends and MP [Member of Parliament] who help people in their efforts to become an immigrant. If they [Citizenship and Immigration Canada medical officers] cannot interpret the file, they ask me for more information in the form of a furtherance.

At the beginning of the previous section I indicated that information in the HIV testing policy is out of date. More broadly, this ushers in the question about the currency of tools that medical officers use to assess applicants living with HIV? This is unclear since none of this information is publicly available. Other than tuberculosis, syphilis, and HIV, it is not publicly known what medical conditions Citizenship and Immigration Canada classifies as ‘abnormal’ for purposes of medical in/admissibility. It is notable that the Canadian government is not alone in not making this information public. As of 2009, the Australian government likewise would not make these details public (Papadopoulos, 2009).

At his address at a symposium of the Australian Federation of AIDS Organisations in September 2009, immigration lawyer Peter Papadopoulos made several points about existing barriers to immigration for, and medical assessment processes relating to, immigrant applicants with HIV (and other disabilities) in Australia. First, Papadopoulos suggests that the Australian government should clarify and make public which “health conditions [are] of interest so that people are clear, and can know up front” what to expect about the treatment and evaluation of their immigration application.

His second point is that the state’s decision-making tools about the health assessment of immigrants with HIV should similarly be made public. Guidelines and policies that medical officers in Australia use in their work, called ‘Notes for Guidance’, were not publicly available in 2009. Papadopoulos argues that publicizing these opens the possibility for debate. In this way, civil society has the opportunity to “delve into the criteria” employed in the review of an applicant’s medical files.

Third, Papadopoulos assets that the Australian government should “rely on current data” that is updated annually by relevantly trained personnel. In Australia like in Canada, persons trained in general medicine are the authors of criteria against which immigrants with HIV are measured for inadmissibility based on projected cost of

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treatment and care. Papadopoulos argues that health economists, not medical doctors, are more qualified to anticipate future pharmaceutical and other costs that people living with HIV might impose to the state coffers or other.68

Until 2008, a framework for the medical treatment and care of people living with HIV dating from 1994 informed the work practices of Australian immigration medical officers in deciding about the medical in/admissibility of a person living with HIV. Of course, considerable medical and social advances relating to HIV were made during this fifteen-year period. Papadopoulos draws attention to inequities embedded within the Australian system of processing immigrant applicants with HIV. From the inequities he highlights, we can discern parallels with the Canadian states’ medical assessment protocols relating to applicants living with HIV and those in operation in Australia. In fact, all of the shortcomings that Papadopoulos raises also apply to the Canadian context. When medical officers work with tools that are out of date, there are serious consequences for applicants for Canadian permanent residence who are living with HIV.

The points discussed in this section draw attention to the fact that while the HIV testing policy is as an active, working document organizing the work of Citizenship and Immigration Canada employees and others, it is also a political document set within frameworks that make it a product of social and historical circumstances. The authors of the HIV testing policy integrated ideas from the broader social and cultural worlds in developing the lens through which Canadian government medical officers could know about applicants living with HIV for nearly a decade. Since 2002, very few applicants for Canadian permanent residence go undetected if they live with HIV. This is an example of how medical testing technology as a practice is used as a ruling relation over people. The HIV screening and medical assessment that follows occupy central places in determining whether a person can and will be considered an acceptable immigrant to Canada. The points raised in this chapter show some of the social and political relations within these professional practices.

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68 Coyte & Thavorn (2010) also made this argument referring to the Canadian context. Peter Coyte is himself trained as a health economist.
Chapter 7. Doctoring work and contradictions experienced by immigrants with HIV

This chapter is the heart of this ethnographic dissertation. It is somewhat unusual to have the ethnographic chapter at the end of a dissertation. I chose this approach because it seemed the best way to position the reader to make sense of the standpoint informants’ experiences that are detailed below. This could only happen with prior preparation, which was the intent of chapters five and six.69

The purpose of this chapter is to provide a detailed and descriptive analysis of how the process of applying to become a Canadian permanent resident is socially organized for people living with HIV. I direct closest and most careful attention to the organization of the immigration medical examination as a key activity and moment in time in the larger immigration application process, with emphasis on the mandatory HIV testing experience and HIV post-test counselling that does (or does not) occur during this examination.

The argument I make in this chapter is that the organization of the ideological work practices of the state and its agents related to mandatory HIV testing and HIV post-test counselling in the immigration application process ushers in a set of institutional practices that give rise to serious problems for standpoint informants. I disrupt taken-for-granted assumptions about how we think about or might expect physician’s to carry out their responsibilities towards patients. For example, we see that DMPs clinical reasoning in the immigration medical examination is displaced by her or his textually organized responsibilities to the state, through which the immigrant is subject to a different set of institutional relations and standard of care than a Canadian citizen or permanent resident would be in a visit to the doctor. There are observable, palpable differences between the DMPs ‘ordinary’ clinical reasoning and practices associated with the medico-administrative work that she or he engages in as a state employee in the immigration process; assembling as she or he does a documentary medical file on each applicant that is sent elsewhere for someone to decide about the applicant’s acceptance or denial for Canadian permanent residence.

Standpoint informants expect that a relation of care will follow the DMPs announcement of their HIV-positive status. Problematically for them, however, the organization of the DMPs work shaped by the state’s interest and its regulation of

69 To my knowledge, Li-Fang Liang’s (2010) dissertation using institutional ethnography is the other project that places standpoint informants’ experiences in the latter part of her dissertation. Her decision to organize her dissertation in this way influenced my decision to do the same. In an email to me, Li-Fang doctoral supervisor wrote, “I was also intrigued with Li-Fang’s decision about positioning the standpoint work . . . But, for her project, I thought it worked well . . . In her case, it was quite important to know the legal framework for migrant carework, in order to make sense of some of the experiences of the workers, so maybe that’s why it worked” (M. DeVault, personal communication, February 10, 2011).
Canada’s immigration program as situated in extra-local social relations of in/admissibility for Canadian permanent residence status means that the immigration medical encounter is actually organized against the possibility of a therapeutic relation in the interests of the applicant. The organization of the activities associated with the immigration medical examination also forecloses the possibility of certain practices, such as pre- and post-HIV test counselling, from occurring. These differences and tensions point to complex interfaces between clinical rationality within state ruling practices that rely on physician expertise and medical evidence. Importantly, they also accentuate the contradictory and paradoxical ways in which doctor’s are employed to work for the state.

The organization of social relations in the immigration medical examination and these examples of inadequacies in the Canadian immigration application process, in particular how HIV test counselling is enacted (or not) in the processing of applications made by people living with HIV, are supported by concerns and critiques articulated by standpoint informants. In this chapter I explicate how these serious shortcomings are socially and institutionally organized to occur as they do. I show how DMP work is coordinated by and through the concepts and priorities projected in IRPA and some of its derivative texts such as the HIV testing policy and the Handbook for Designated Medical Practitioners (Minister of Public Works and Government Services Canada, 1992, 2003, 2009). The analytic device that I use to do this is foregrounding the immigration application work of a single standpoint informant, Anna, in interaction with her DMP interlocutor, Dr. Geta, while gesturing to the actualities experienced by a host of other standpoint informants.

Anna’s story begins at a time when she was a student outside of Canada. For approximately three years, Anna took steps to immigrate to Canada. All of the medical testing and associated work that she was required to do at the request of the Canadian state was done outside of Canada. The chapter winds its way through investigating how features of her immigration application work process — and the particular place occupied by HIV — arose in puzzling, troubling, and contradictory ways for Anna. The chapter ends with her acceptance to Canada.

Dr. John Geta, a Designated Medical Practitioner (DMP) located in Canada, is Anna’s foil. His work with Anna is representative of the state’s experience with carrying out mandatory immigration medical screening work. Dr. Geta’s story is a composite and reconstruction of the interviews I conducted with three DMPs. Through exploration of both Anna and Dr. Geta’s respective activities, a narrative and counter narrative about what happens in relation to immigration HIV screening is built. The social is identified and explored in Anna and Dr. Geta’s stories, descriptions, understandings, talk and language. While Anna is the main character in this chapter, woven into the chapter are the immigration application work practices of other standpoint informants that corroborate what Anna explained happened to her. This is an analytic strategy intended to emphasize that there are common organizing features that make Anna’s experiences,
and this chapter’s explications, generalizable beyond her single account. The analytic story that provides the framework for this chapter is actually a composite based in the activities of numerous standpoint informants as they were recounted to me and that I observed.

An organizing assumption in this chapter, and more broadly in this dissertation, is that within language, text, and textual practices there are clues to social relations. These all contribute to how we can recognize and identify what institutional and organizational fields circulate around and interface with the study’s standpoint and extra-local informants’ experience. I bring into view some of the social and ruling relations that join Anna and Dr. Geta’s “local setting and local experiences to sites outside the experiential setting” (Campbell & Gregor, 2004, p. 90). This is done through an exploration and explication of the ways in which Anna and others take up dominant discourses, narratives, or ideological positions. In many cases, as the events and social processes in this chapter illustrate, people adopt these as their conceptual frame for seeing themselves and understanding the Canadian setting of which standpoint informants are new members. Through the generous use of direct quotations from informants, given in double quotation marks, I show the ways in which such integration, appropriation, and mobilization shapes the ways people come to think of themselves; including how they make plans, what they worry about, and what sort of activities they engage in.

It is not analytically important to provide biographical details on the informants that are introduced (brief details about Anna and Dr. Geta notwithstanding). As previously discussed, this is because informants are not the objects of study, and the point is to transcend a single story to reveal the lineaments of social and ruling relations. Where such details are provided, they have been carefully selected and purposefully maintained with the thinking that they substantiate points and support developing arguments. Likewise, there is sometimes a pause to distinguish between informants, but not always. Finally, direct quotations and references are organized around the ideas that they are intended to illuminate.

* * *

“Taken-for-granted” efforts to immigrate
When Anna emailed me after hearing about this study at a local AIDS service organization, she expressed interest in participating because she told me she thought that she had something to say on the matter of immigration and HIV. Anna had been in Canada for about one year by the time we met. I met her for an interview on a fall evening in her apartment.

During our interview, Anna spoke passionately and articulately. What emerged was the portrait of a woman who had worked very hard for several years in an effort to be admitted to Canada as an economic class immigrant. Her efforts had intensified after she was medically tested for HIV, and, to her surprise, found to be HIV-positive. Anna
meticulously outlined the various processes and steps she took as part of her immigration application work: that of an educated African-born woman in her mid-thirties applying to Canada as a skilled worker. She did not have family in Canada.

In listening to Anna, I gained insight into the considerable amount and vigorous quality of thinking, planning, and physical work that she sustained as a result of the intersection of her HIV-positive diagnosis and Canadian immigration application. A large part of Anna’s work to immigrate to Canada consisted of gathering a working knowledge of Canada’s policy environment for prospective immigrants living with HIV. How she learned to position herself is a function of all that she learned through her careful research and information gathering efforts, and what, exactly, this work consisted of, is explained in her story that is related below.

From my field notes and email communication with Anna after our interview I recorded the following,

Anna did not have documents to bring to the interview to discuss because she shredded all documentary traces linking her HIV diagnosis and immigration to Canada. She wrote, ‘I thought I would find more saved letters, but I must have been so paranoid about someone finding out that I probably deleted most of my correspondence’.

Today Anna wrote expressing appreciation for the opportunity to tell her story from an angle that she had not really considered. Anna told me that she had not thought much about, or at least, she had ‘taken-for-granted’, her efforts and the steps she took to immigrate here.

“You will have to do this and that for work”
Anna was a graduate student in Eastern Europe when she decided to apply to immigrate to Canada. For over three years, she worked to compile a range of certified documents that told of her professional experience and educational background. As well, Anna was asked to provide her birth certificate, passport and legal paperwork, proof of marital status, and certificate of non-conviction for over ten years. All of these documents were required parts of her application, as requested by the Canadian state. Anna said,” I got a lot of papers together. I spent a lot of money; paying the fees and all of that.” All of this occurred in the early stages of her application work process; before Anna knew that she was HIV-positive.

At the beginning, I had to go to the Canadian embassy for an oral interview as part of the selection process to immigrate as a skilled worker. You sit for a long time and they go through all your documents. The priority was that the paperwork was authentic [her emphasis]. He asked, ‘Why do you want to move to Canada? What problems will you face there? Are you optimistic?’ The state agent tried to explain that I may have cultural shock; that I may not have a job in
my field. Though I didn’t know what he meant, he said, ‘You will have to do this and that for work [in Canada].’

Anna’s statement evokes a point about employment opportunities for immigrants to Canada. Troublingly for her, the Canadian government agent introduced her to the idea that once in Canada, she might not find work in her field despite that she held a PhD that she thought had made her an attractive candidate for immigration in the first place. Actually, through her conversation with this federal state official, Anna is introduced to the possibility that she might not find work at all. In light of this eventuality, the agent asks her, how is she preparing, and how will she adapt both culturally and financially?

“I am going to work and be productive for this country. I am not going to use it,” said Anna. This was a sentiment shared by numerous standpoint informants. Shortly after arriving in Canada, Anna, like other standpoint informants, got to work with the task of finding employment.

Standpoint informants report expending a lot of effort trying to secure (decently) paid work. They spoke of being encouraged by employment agencies to look for and accept non-unionized, seasonal, manual and labour-intensive jobs. Bonheur, a refugee applicant from Africa recounted,

L’agent m’a dit que les seuls emplois que je pouvais avoir sans expérience d’ici étaient dans les usines. Les manufactures. Je lui ai dit, ‘avec le VIH, ce n’est pas possible’. Il était au courant [de mon statut] à cause des papiers remplis.

In some cases, informants learn of undeclared work opportunities from people in networks with which they are affiliated. For example, a standpoint informant named Winnie, whom I accompanied to her immigration refugee interview, had talked to me about her experiences working ‘under the table’, or “cash-in-hand” as she called it. From my field notes,

At 8h20, I greeted Winnie in the government building just outside the UNHCR [United Nations High Commissioner for Refugees] office located within a federal office complex. She had already been there for thirty minutes. We greeted each other and began to chat about her nervousness; about how many different sorts of people (country of origin) were also waiting to enter the government office. Winnie offered us strawberries. This led us to discuss her recent work (that I did not know about). Through her network (of immigrant women from Africa),

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70 Roxana Ng’s (1988) research on the social organization of job placement programmes targeting immigrant women in Ontario reports on women’s experiences with overcoming unemployment and underemployment. Ng demonstrates how employment programs did not actually work in the best interests of the women involved in her research.
Winnie had set up work picking strawberries in a rural area (she did not know where, only that it was a forty-five minute bus ride away; all the workers rode the bus together). There was hardly any “White Canadians” strawberry picking, she told me. “Who else but immigrants used to hard work could do this type of back breaking work in fields” where temperatures were hot and conditions tough? I asked her about how the company ran things. Winnie told me that things seemed highly organized; that the employers seemed to “know what they were doing; seemed used to it”. She said, “I get cash-in-hand for this work; no questions asked”.  

Standpoint informants come to understand a ‘good immigrant’ as a person who has declared employment; a person who pays taxes; and, a person who is, because of her or his formal labour force participation, a ‘productive’ contributor to Canadian society and the country’s economy more specifically. “I do not want to go back to Mexico or work illegally in factories, etc., where you are paid cash seven dollars per hour for long work weeks. Like a burro [mule]”, said a standpoint informant (refugee applicant). Alexis, a refugee applicant, talked about his job searching work, and touched on his employment history since arriving in Canada approximately two years prior to our meeting. 

To find my first job, I went to the library that I found by locating it on a map. I identified myself as a new person to the area. How can I improve my English and get a job? They gave me instructions about how to reach the learning centre. I did not start immediately at this centre. I found a job agency and applied for a job through them. It was a temporary agency that acted as a broker. I wrote an application letter and they accepted me. I did not discuss my HIV status with the employment agency. I supplied employment history; I had an interview; I had a safety and health presentation; I did the written exam. And, after two weeks, they called me for a job as receiving and loading in a warehouse.

Alexis continued, 

It is a job. It keeps me busy; to have money and exercise. There is no transport access where I live. I would ride my bike to work. It was difficult in the beginning, but I got used to it. Then I got another job. I left the agency. I was there for one and a half years. It was a full-time job in a factory. I also found another job as a housekeeper, where I worked on the weekends. But, I stopped that because the chemicals were hard on me [he emphasizes that this is particularly harmful for a person with a compromised immune system].

71 Marina Lewycka (2007) offers a dark, satirical glimpse into the social experience of immigrant workers employed in the strawberry picking industry in England. She effectively explicates the institutional interests bound up therein.
However, there are distinct impediments that stretch beyond standpoint informant willingness or intentions to work, to be ‘productive’ participants in the Canadian labour force, and to avoid drawing on social programming. “I need Canadian experience to get a job. That is the only way I can get a job”, said a standpoint informant (echoed in statement made by others). In the material conditions of people’s lives, these impediments give rise to contradictions, and there is a disjuncture for informants in relation to their participation in Canada’s labour market. An example is what Anna, and many other standpoint informants including the young woman quoted above, spoke of as the idea of “Canadian [job] experience”.

People report being asked by prospective employers about their employment history in Canada, which, as recent immigrants, they have yet to acquire. Standpoint informants generally saw this phrase as a euphemism for underemployment and a strategy for not fully including immigrants in the workforce; a rather successful strategy, it can be argued, given that hardly any standpoint informants who took part in this study were working. Of the standpoint informants with advanced education such as Anna, most were either unemployed or underemployed at the time I met with them. They lamented that educational and professional equivalencies took a very long time to be certified by Canadian government bodies. Obtaining equivalencies is a necessary step if one wants to work in Canada in the area for which one is trained, or pursue studies from the level at which there was interruption. Chantale explained,

À l’aide sociale ils m’ont dit qu’il fallait que je cherche les équivalences de diplômes. Sans celles-ci, ils ne pouvaient pas m’aider. Je les attends [diplômes]. L’attente est longue. Ils m’ont référé à une école où j’ai passé un test de développement générale.

“Immigration says that this is a non-adversarial event”

From the Canadian government’s early emphasis on what Anna understood constituted “authentic” paperwork for the purposes of an acceptable immigration application, in addition to the line of questioning that she experienced during the immigration interview with the state official, Anna came to understand that there was careful consideration of the authenticity of her documents, and scrutiny of her person more precisely. She gathered that it was important to offer truthful answers to the agents employed by the Canadian state; a perspective generally shared by standpoint informants, as evidenced in the following statement,

I was told that I was going to have chest x-ray, blood, and urine tests. Then there is an interview with the doctor [DMP]. He has a list of questions. Sample: Do you have VD [venereal disease]? Have you ever had syphilis? (I said yes.) The lawyers had told us, ‘If you know, you need to say it. You need to be honest; you need to tell them’.
A Canadian Border Services Agency of Canada employee I interviewed emphasized that obtaining the ‘truth’ from people as they enter the country as refugee applicants is an important part of her frontline work.

And it even takes time in the beginning to tell them, you know, that they’re a refugee applicant and that, you know, what they need to do is tell me truth so that I have the truth on the form and, like, nothing’s going to happen to them that’s bad, if they’re telling the truth, you know? If they withhold information, then you can’t get your paperwork done.

There are several points within Anna’s emphasis on “authentic” paperwork and the expectation that she forms that she should be truthful at all times in her dealings with state authorities. Throughout the entire course of their immigration application work process, standpoint informants talk of being frequently scrutinized for whether — and to what degree — they are telling the ‘truth’ (or not) in their interactions with officials. In the end, Winnie, whom I explained I accompanied to the Immigration and Refugee Board for her interview, had her refugee application denied. She shared an email exchange she had with her lawyer in which the grounds for her refusal are linked to the ‘truth’ of her claims.

Winnie: Please I would like to know the reasons for denial in writing or at least verbally explain if at all she [hearing officer] didn’t write to you so that I can work on her argument. I’m of the feeling that I would like to come to [name of city] for the hearing and I will try to get a couple of days to meet you. And maybe even get the notes you were taking down as she was interviewing me, to add on to my reading and preparations.

Lawyer: She told me the reason she sent the case to the regular process was that ‘there was a problem with credibility’. Basically, she found it hard to believe that someone who lived a traditional tribal life and was forced into marriage and forced to stay married could still get a university education.

There is also recurrent emphasis of this theme (i.e., truth-telling, full disclosure, absence of lies) in official state documents, state processes to which I was privy, and the talk of lawyers, state officials, and DMPs whom I interviewed. For example, the Handbook for Designated Medical Practitioners (Minister of Public Works and Government Services Canada, 2009) indicates that,

[The] integrity of the entire immigration medical examination process is based on verifying the identity of those presenting for examination . . . Good identity management of the applicant, and proper adherence to specific procedures when filling forms, stamping photos and performing exams are examples of fraud prevention (p. 3-5).
Said a DMP, 

There are people who arrive in Canada with an HIV diagnostic already done in other countries. Some people arrive with treatments already . . . At the end of the medical questionnaire, they have to sign; attesting that what they said is true.

Standpoint informants come to think, with a measure of irony, that Canadians tell the ‘truth’, and to tell the ‘truth’ is to be a ‘good Canadian’. Anna said, “I told them about dental problems. I told them about an appendectomy. I had to tell them about everything [i.e., known health problems]. But, I knew I was not HIV-positive.” Another standpoint informant, a family class applicant named Yves, who knew that he was living with HIV before the immigration medical, talked about how he came to think about what he needed to reveal to the DMP at the time of his examination. In Yves’s story we learn that his lawyer was influential in instructing him in this regard.

The lawyer told me, ‘the DMP will ask you about any transmissible, sexual diseases; and tell the truth to the DMP . . . Follow the rules’. He said, ‘this is what you have to prove: that you will not become a liability to the system. Tell the truth about who you are physically and give picture of where you are at [in your disease progression] . . .’ Maybe [my HIV doctor] went to bat for me because I was honest, disclosing all sorts of medical history and behaviour.

In this way, standpoint informants conclude they must be truthful in the hopes of becoming a ‘good Canadian.’ Illuminating the setting of a refugee hearing, the imperative of ‘truth’ within this, and the tensions within such state proceedings, an immigration lawyer with whom I talked said the following,

Having no errors in the PIF [Personal Information Form] is important because in the beginning of the [Immigration and Refugee Board] hearing . . . the adjudicator asks people if this a true copy of the PIF. ‘Are the contents of this document true?’ The burden of proving that you are a refugee falls on the shoulder of the applicant. At nine o’clock in the morning when the hearing begins, you are not a refugee. You become a refugee as you build your case, point by point, during the course of the hearing.

The lawyer continued,

So, I mean, at least from the legal point of view, . . . their purpose really, Immigration always says that this is a non-adversarial event, but I don’t believe it for a minute. I think it’s extremely adversarial . . . in nature and in character. I think if you look at where people are placed in the room, if you look at how it works out, the way the arguments are made, it is always the agent arguing against acceptance, and it’s always the lawyer arguing for acceptance.
However, while standpoint informants are expected to reproduce themselves (and the events of their lives) in ways that are not fictitious, at the same time they experience tensions and dilemmas since they are not always authors of what is written down and communicated about them. Information about informants is commonly summarized and synthesized into reports authored by their lawyers. In the passage above, for example, there are overt traces of an immigration agent, an adjudicator, and a lawyer handling information that has been collected on behalf of a standpoint informant who applies for refugee status from within Canada. A standpoint informant who applied to Canada as a refugee applicant explained,

The lawyer said it was no problem, that I could be his client. He considered my story. He had to help me, ask me questions; frame my story in a certain way. He edited and shaped it. He corrected both the content and the grammar. Like now [what we are talking about], the narrative is jumbled, so he had to make it flow. So, I came and went twice to his office to work on the PIF [Personal Information Form].

Appraisals of an immigrant applicant, such as the immigration interview that Anna described experiencing, are largely mediated through government-issued documents. They are also influenced by transcribed accounts that the applicant might, or might not, have participated in producing. While standpoint informants talk about institutional actors impressing on them the importance of being truthful, another contradiction presents for them when they are encouraged to stray from honest portrayal of events they have experienced in constructing their Personal Information Form (in the case of refugee applicants) or other narratives that will be included in their immigration application. The suggestion of altering events or straying from what they know they have lived is against the idea that standpoint informants have come to hold of what it means to be a ‘good Canadian’.

About the thinking work involved in formulating his Personal Information Form in ways that conflicted with his bodily experience, Lucas, who made a refugee application from within Canada, discussed details of the work he did with his lawyer.

You and your lawyer work with your PIF [Personal Information Form]. They tell you how to fill it out. You write your story in Spanish and they translate it. You have to write all the details of your ‘famous story.’ My first lawyer told me that I had to invent something else; ‘a stronger thing than being HIV-positive because otherwise you will lose’. We had to come up with something. I had no idea of what to write. We began to work verbally. I asked her what to write. She started asking me questions about my family. She asked me whether I had brother and sisters. She asked whether my sister’s former husband was a police officer. Since he was not, she said I should lie and say that he was, and that he threatened to harm me because I am gay. So, I agreed to say this police story. This is the story
that was written in my PIF. The police story was a total fabrication. It was just to push.

The consequences of such misrepresentation feel heightened for immigrant and refugee persons living with HIV. They are, however, ill positioned to discuss or contest suggestions made by their lawyer that run contrary to their personal experiences. Standpoint informants enter a process that is adversarial, as described above by the lawyer, which has been shown to “lend itself to cover-ups, lies, misrepresentations, obfuscation, and distortion of events” (Wilson & Pence, 2006, p. 216). Herein we see that there are contradictions that place standpoint informants in situations of double jeopardy: even though a refugee applicant with HIV will not be evaluated against ‘excessive demand’ criteria, she or he can be denied Canadian permanent residence if the person’s refugee claim is found, for one reason or another, to lack credibility. Disclosure or withholding of HIV-positive status to one’s lawyer or a state official becomes a question of integrity and a reflection of a refugee applicant’s capacity to be truthful.

“It would be great to have you move to Canada”
At the close of her interview with the Canadian state official, Anna was elated to be told that she was an attractive candidate for immigration to Canada.

Upon completion of my interview, the government official said, ‘it would be great to have you move to Canada’. They said in a couple of weeks I would be invited for a medical.

Anna provided some details about how she had lived as graduate student in Eastern Europe. She had lived alone in a small room on the university campus in a city that was distant from the capital where Canadian immigration services were located. Immigration medical examinations for the United States, Australia, and Canada were done within a same centre, she came to find out. Anna’s HIV-positive diagnosis would mean that she would have to save the money to pay for many over land trips back and forth to the capital city to visit the sanctioned facility where she met with doctors and nurses.

Anna talked about how much financial savings work she had done during the entire period of her immigration application work process. It was not easy for her to set aside the monies required. She earned a modest research stipend from which she saved each month. “Back home,” Anna said, her mother was “educated and salaried”. She had helped Anna financially whenever she could. Despite the challenges, Anna reasoned that all the sacrifices required were worthwhile: all her hopes and plans revolved around starting a new life in Canada. “Everything I had done was geared toward immigration,” said Anna.
What evokes the considerable amount of immigration application work in which standpoint informants such as Anna engage is the firm desire to become Canadian citizens. Standpoint informants reported pursuing citizenship as a central, worthwhile goal of their efforts. There is a sense of a Canadian dream within a concept of privilege; predicated on working, contributing, building a new life, bringing over family. Grafted to all standpoint informants’ stories about acquiring Canadian citizenship is the belief that it will bring safety and enhanced opportunities. Said a refugee applicant named Julio,

I think that every Mexican who is in Canada and not in Mexico has a different reason to be outside his country. So, it is personal or economic. Yes, there is a lot of people who ask for asylum, yet they come to work. I think that this is valid. If Mexicans are coming to Canada, it is to work. They are being productive. They work in factories; it is labour. They have faced so many things, living in a different world; not speaking English or French.

The Canadian state cultivates a global reputation for compassion and kindness through an immigration system that welcomes refugees and persons in need of protection. It does so partly in relation to commitments to various agreements to which it is a signatory. It also does so with the understanding that people face hardship for reasons beyond their control in countries around the world. The Canadian state projects an image of a nation that accepts immigrants into its workforce as a mainstay of its immigration program. These are ideological and rhetorical notions about itself that the people and policies — including practices related to the medical screening of prospective immigrants — of a country such as Canada constructs and circulates (see Wiebe, 2008a, 2008b). An expression of how these ideas function and enter the thinking of standpoint informants is found in their talk about the benevolence of the Canadian state; their expressions of thanks for antiretroviral treatment; their praise for health care and individuals care givers. I asked Julio to offer final thoughts on our interview. Using ample metaphors, he said,

I am very, very, very thankful to Canada. I also understand Canada’s position [in excluding people with HIV and other medical conditions]. It is not my country and they do not have any responsibility toward me, still, they have opened doors to me. It is hard to be part of this country. But there are doors. Maybe it is hard to open them, but there are doors. It is an immigrant country, and that is how the country wants to be: with doors. I am thankful for all the health services that I received and for Canada.

However, while standpoint informants are producing the fractious, tension-filled, and time-consuming work that is necessary to the process of becoming Canadians, there is a disjuncture: experiences of privilege are not part of their everyday lives. In the material conditions of people’s day-to-day lives there are the difficult activities and hurdles related to the work of waiting, wondering, hoping, and coping. Standpoint informants report witnessing fellow immigrants experiencing similar struggles to stabilize, to adjust,
to bring family to Canada, to find work. Applicants for permanent residence who are
diagnosed with HIV experience all of these ‘ordinary’ struggles, but the results of their
blood tests add a layer of complexity to their immigration work process.

There is more waiting for a PHA [person living with HIV]. The problem is that this
wait exposes us. It makes us to be liars. I keep on lying about why I do not have
my work permit. I say that I do not know why the wait is so long. The community
I come from, they know that the longer your work permit takes to come, there is
something wrong. If you come in May and there are months of delays, they can
deduce from there. It [HIV status] reveals itself somehow. I kept telling people
that I am not in a rush and that I have not applied. But deep down, I knew that
this was not the case. The delays make us serious liars.

So it is that standpoint informants acquiesce to all the work that is requested of them in
their plan to successfully immigrate to Canada, including submitting to whatever health
screening is obliged.

“I did not ask him direct questions about immigration”
Anna’s experiences happened outside of Canada. Nevertheless, her descriptions of the
details of her immigration application work were broadly similar to much of the work
that I was told about by the standpoint informants whose application work took place in
Canada. I asked Anna to talk about how she prepared for, and what happened during,
her first medical visit with the DMP in the capital city of the country planned to leave.
The extensive, careful details with which Anna provided me about the circumstances of
her immigration and the handling of HIV within this, I was motivated to know and
experience, firsthand, the locales in which immigration medical examinations take place
in Canada. Below I provide details about some observational work I did before turning
to an exploration of the details of Anna’s first immigration medical examination.

From observational and waiting work I did in a Canadian immigration clinic, I had some
context to imagine how the clinic Anna visited might have been organized. DMPs
generally work from within their private practice or a medical clinic. In both cases, DMPs
usually combine a caseload of immigrant and refugee applicants with people they will
see more regularly. In one clinic that I visited, a centre that promoted itself as an
immigration medical clinic, there was a constellation of one dozen doctors working
under a single roof. Several of these were DMPs. There was a considerable flow of
people presenting for immigration medical examinations. Family members frequently
accompanied applicants, which made for a waiting area filled with the sounds of many
languages. From my seat in the reception area, waiting to be received for an interview
with a DMP, I was well positioned to pay close ethnographic attention to the work
practices of employees and immigration applicants. I did so for the duration of the forty-
five minutes I waited.
Just inside the clinic’s entrance a male clerk was positioned at a desk under a sign that read, ‘Immigration Medical Examination’. His job consisted of greeting applicants in English, French and Spanish, briefly reviewing their application documents to verify that they had the requisite supporting documents, and then sending them, flask in hand, to produce a urine sample. All of this was in preparation for the immigration medical examination with the DMP. During the time I spent in the waiting room, there were dozens of prospective immigrants queuing for processing at the clerk’s desk. The time invested in this preparatory administrative work outside of the doctor’s chambers seemed to shorten the amount of work the doctor was required to do, and time the doctor would spend, with the applicant. People were generally not inside the doctor’s office for a very long time. It was through these systems that the immigrant applicants were ‘processed’.

As I waited and observed, I came to better understand that standpoint informants’ waiting room work as they had described it. Their waiting to see DMPs is organized inside relations of scheduling of appointments and waiting to see the doctor. Like the work of clerks, administrative personnel, and DMPs, standpoint informant work is tightly coordinated by the high turnover and hurried pace that characterizes such environments. A standpoint informant named Tony, a family class applicant, talked to me about attempting to see an HIV physician the day after his diagnosis by a DMP. The DMP had neglected to give him a referral, which caused problems and delays for him. Tony explained,

The next day I went to [name of HIV clinic]. The woman at the desk told me that it was not a drop-in clinic, that I needed a referral from the doctor. I had to leave. I felt really, really bad, and I called my partner. I asked myself, ‘who is going to take care of me now?’ He called the DMP office on my behalf. The referral was arranged, and this was faxed from his office to [name of HIV clinic]. This clinic called me, giving me an appointment for one month after that date. This may appear to be a long wait, but everything here takes a while!

In Tony’s statement we recognize that the scheduling of the immigration medical appointments is clearly beyond people’s control, as it is with medical appointments for most of us more broadly. I learned that standpoint informants practice strategies and employ skills that aim at influencing the immigration examination medical examinations in particular ways. For example, Claudio, a standpoint informant residing in Ontario who applied as a family class applicant, used both deliberative talk and silence in interactions with the DMP moments after the latter told him that he was HIV-positive.

The first question was, ‘do you have sex with men?’ [The DMP] asked me if I was having sex with men in Canada. I said [to myself], ‘Oh my God! He is inquiring to see if I am spreading this in Canada’. When he asked me the question about my behaviour, whether I have sex with men, his indirect manner of coming to the point of me being HIV-positive, I knew, without a doubt, that I was HIV-positive.
After that, I began asking questions of him, and he became friendlier. I began asking him about things in Canada. I said to him, ‘so, what next?’ He did not tell me anything about immigration; whether a denial based on my HIV status. I did not ask him direct questions about immigration.

This interaction between Claudio and the DMP exposes that the DMP is above all working with ‘state’ interest in relation to this HIV diagnosis. Claudio has just learned that he is living with HIV, a moment of huge importance for him, not least of all because he will have to adjust to a life with a serious, chronic illness. There was no post-test counselling. On the contrary, the DMP’s understanding of what his responsibility is regarding Claudio’s diagnosis is to report him to the government. To be able to complete official forms that ask him to report on HIV-positive immigrant applicants, the DMP begins asking Claudio questions about his behaviour and sexual orientation. The DMP has also inquired about the probability of Claudio having engaged in unprotected sex with men; gauging ‘risk factors’ associated with Claudio. In this instance, the DMP is filling out forms that he will submit to both the federal and provincial governments for the state’s surveillance purposes.22 The line of questioning pursued by the DMP shows that an organizer of how he works with Claudio is the DMPs ideological position about contagion.

Claudio’s quote also reveals how he tries to engage with the DMP on his own terms and in his own interests. Other standpoint informants to whom I spoke also talked about directing talk in ways that were strategic and comfortable for them. Such strategic work during the immigration medical examination takes a number of forms. This includes talking only when prompted; asking few questions; volunteering deliberate silence; responding to questions with short answers; and, offering no more information through responses than seemingly necessary to satisfy the doctor’s specific query. What people experience through the immigration medical examination is a lot of emotion, tension and insecurity about both the present and future. In enacting strategic skills during the examination, standpoint informants decide to act as opposed to just being acted on by the DMP. Standpoint informants place considerable importance on immigration medical screening in part because they have learned from their colleagues and friends and their own experiences that the Canadian government likewise places a lot of importance on it. This was evident in a standpoint informant’s comment, “On the CIC [Citizenship and Immigration Canada] website, there is mention of a mandatory medical examination, but the HIV test is not mentioned. You know it is important.”

It is important for standpoint informants to ‘succeed’ through the immigration medical examination. They realize that results of the diagnostic tests and general evaluation will

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22 A DMP informant gave me the provincial form identified here. It is the “HIV Serology Test Requisition” form issued by the Ministry of Health and Long-Term Care Public Health Laboratories (form number 1210-44B (04/07)).
influence how they move forward through the Canadian immigration application process. Bethlehem, a woman refugee applicant to Canada, described how,

At the YMCA [Young Men’s Christian Association; shelter] they gave us an information package that contained the steps we had to go to complete steps to immigrate. For example, go to the medical visit, take the immigration course; go to the refugee-receiving centre; fill out the PIF [Personal Information Form]. With that piece of paper, you check off the list. In that way, you know what you have to do, and you know what you have done. You know how much time you have to do each activity. The addresses are listed; for legal aid, for example.

Designated Medical Practitioners report puzzlement at the silences that standpoint informants offer during the medical examination. They also ask themselves whether people they come to diagnose with HIV knew her or his HIV status, but failed to mention so during the examination. Ultimately, this becomes judged as a question of integrity. One DMP said,

There is a good number [of immigrant and refugee people] who are diagnosed at the moment of immigration. Sometimes I wonder if they knew before and just do not say so at their entrance to Canada. You never know.

Some standpoint informants do know their status, but wait for the doctor to ask a direct question about sexual health. Questions about sexual health, standpoint informants report, do not always get asked. Amir, a refugee applicant, said,

When we were doing the test he [the DMP] did not ask us for what purpose we were doing it. He just took the blood sample. We just knew that we had to do this medical test. Coughing, eye exam, potency, reflexes. A to Z. He did not ask whether we already knew about the HIV status. If he had asked us about our status, we would have told him. We knew this years ago!

However, the directed talk and deliberative silences of standpoint informants are meaningful, less mysterious, and more logically understood if seen as a consequence of the social circumstances of the organization of the immigration medical examination and the stakes of receiving a problematic bill of health.

“You just had to fill in the normal paperwork”

These contradictions were fully apparent in Anna’s work when she described how she produced the ‘truth’ about herself in interactions with Canadian state authorities, and how she prepared to undergo her immigration medical examination. She explained to me that she was asked to answer yes or no to “normal” questions listed on a checklist (Appendix E1). She answered truthfully to these. “You just had to fill in the normal paperwork, answering such questions as, ‘has anyone in your family had HIV or AIDS? Have you ever had HIV?’ At that time, of course, I knew I was clean. Negative.”
I was curious about Anna’s certainty that she had not been living with HIV. *Had she tested before?* “I was very sure of myself because I had had my last HIV test one year prior to that. I knew I wasn’t sick”. When I asked her this question, Anna shifted on the couch where we were seated beside each other. She spoke with tension in her voice. It was here that I learned the details of the population-specific mandatory HIV testing practices in the country where Anna had lived and studied for nearly a decade. These were troublesome practices to her over which she had no control. She had been required to submit to annual HIV screens because she was a foreigner, and, she supposed, because she was an African national.

[As per Canadian government requirements] I did the HIV test and lots of other medical tests including x-rays. Of course they took blood for HIV. Immigration did not tell me they were doing an HIV test. They did not need to tell me because I was used to it: every September in [country name] I would have to do my routine HIV test. If you are African in [country name], you are obliged to test before you start your new school year. It annoyed me a lot to know that we were the only ones who were obliged to go through that. Fellow classmates who were born in that country also had to go through routine medicals, but not necessarily HIV screening. We Africans had to *absolutely* go for HIV [informant emphasis].

Within her story we learn that Anna had not been explicitly told that she was going to be tested for HIV as part of her Canadian immigration medical examination. She was not the only standpoint informant to report not being apprised of this information. I really wondered about how that could happen. In a later conversation with a DMP, I queried the point, to which the physician responded,

You are supposed to advise patients, ‘we are doing these tests, and we are doing an HIV screen.’ You do a bit of a screen to see if that is a concern before hand; so that they are aware why we are testing. If it is positive, we will call them in. There is supposed to be pre- and post-test counselling. I suppose you could call it pre-test ‘notification’ [i.e., the test is obligatory, thus there is no informed consent process].

“*We are the guys in the trenches*”

The DMP with whom I spoke about the procedures related to pre- and post-test counselling was John Geta, a general practitioner in his mid-sixties. One of the first things I learned from him was that he had been practicing medicine for the last forty years. Dr. Geta had also been conducting immigration medical examinations in Canada for about as long. When I asked him what his work consisted of, Dr. Geta said, “my work is with Immigration [Citizenship and Immigration Canada]; with Ottawa; the federal government, principally. I also work for various government agencies and families [in private or family practice].”
I was interested to know how immigrant and refugee persons contacted him for purposes of undergoing an immigration medical examination. Dr. Geta explained that Citizenship and Immigration Canada maintains an official list of DMPs that it posts on its website. “This is a formal, worldwide list. The whole country is represented, as is the United States and the whole world. They are all called DMPs.” This, along with word-of-mouth referral from lawyers and people from the same ethnic or language groups, is how applicants commonly find their way to him. “They pick me from the list. They call and book immigration medicals with me. We tell them what documents to bring when they call for an interview.”

Anna and Dr. Geta had both used the word “normal” to describe the questions she had been asked during her immigration medical examination and the experience of the first visit to the DMP more generally. As I came to find out, DMPs use this adjective (and others similar to it such as “standard” or “limited”) to describe their job function and tasks, and forms and questions associated with the proscribed examination. “We do what is called a functional inquiry of people when they come for immigration medicals,” said Dr. Geta. He explained that he begins by asking health-related questions.

We ask them certain questions about their health listed on a template [Appendix E1]. These were the same sorts of questions as before the HIV testing policy was put into place in 2002. The form from which I ask questions dates to 1998. The government mandates these questions. They are standard.

Dr. Geta explained the constituent parts of the examination he conducts of immigrant applicants.

The physical examination is eyes, height, blood pressure, and lungs. It is a complete and normal examination. The lab tests are urine, done here in the labs beside my office. The nurse will do the blood test for HIV and syphilis. This is it.

Dr. Geta picked up a seven-page patient file from his desk and showed it to me. He referred to this as the “standard medical report form IMM 1017 with its sections A to E”. He pointed to the “Medical Report; Section B” portion of this form where there is a list of nineteen questions. This is the form that Anna had described to me some time before as a “checklist”. Number fourteen on the list is the question that she most vividly recalled, to which she had answered in the negative. It reads,

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73 A functional inquiry is the equivalent of a review of bodily systems. Doctors often run through a list of symptoms that patients might experience in any organ system to screen for potential problems. It is a widely understood clinical term. The symptoms are organized by physiological system. For example, the doctor might start with the head and proceed downward through the body (B. Mukhopadhyay, personal communication, September 26, 2011).
Have you ever had a test indicating the presence of HIV virus or have you ever been told that you were suspected of having AIDS, HIV infection, or any other immune disorder?

I learned that DMPs see themselves as functionaries performing highly “standard” and “normal” fact finding tasks for Citizenship and Immigration Canada. These examination are tightly proscribed by government, and Dr. Geta is instructed what information to gather from the people he examines for the purposes of immigration. DMPs with whom I spoke repeatedly stressed that they are not decision makers. Said Dr. Geta,

My role is limited. I am a contract worker. My job is paper-based, and it should be that way. This is totally different than my family practices. Here I am a fact finder; gathering information; giving it to a higher level that has a protocol to make a decision. In sum, we are the guys in the trenches. We do the examination, and the guy in government decides.

That a doctor practicing medicine in Canada can understand his work responsibilities primarily as “paper-based” is part of the contradictions that bothers me and that I examine in this dissertation. Despite the fact that during his working days this DMP is continually face-to-face with people experiencing all sorts of hardships, and not negating that this DMP is likely compassionate and competent, he finds his work being organized in particular ways that he is able to rationalize and discuss with me. Nonetheless, as routine and ‘usual’ as DMPs appear to find their work practices, there are serious consequences for those people applying as refugees to and seeking opportunity in Canada. Standpoint informants who have tested HIV-positive generally report experiencing confusion, disappointment, and anxiety through the medical examination process that most usually consists of two visits to the same DMP. A woman refugee applicant named Tsehaye said,

The DMP I saw presented this [HIV-positive status] simply. The way they present it, someone could commit suicide if they are not strong. It is just like someone throwing something in your face.

These expressions of surprise and disappointment, and the taken-for-granted (and highly problematic) practices that take place during a routine immigration medical examination, are more clearly understood when we inquire into the features of the social organization of the medical examination and consider the interests that are bound up in the work of the DMP.

The DMP works within a proscribed job description set out by the state. The current *Handbook for Designated Medical Practitioners* clearly states that the immigration medical examination is not for “therapeutic purposes” (Minister of Public Works and Government Services Canada, 2009, p. 3-2). Talking about his professional functions, Dr. Geta had specified that his “work is with Immigration; with Ottawa; the federal
government, principally. I am otherwise retired.” In chapter four I referred to the understandings of another DMP whom I endeavoured to meet for an interview. Recall that he told me that he could not take part in my research because all of his medical work was “property of Citizenship and Immigration Canada”. Thus we understand that DMPs work is tightly organized to serve state rather than immigrant applicant interests. Moreover, within a somewhat perverted construction of good medical practice, the work is also specifically organized against the possibility of being therapeutic.74

Standpoint informants I talked with had much to say about how their HIV status was disclosed to them by DMPs, and what events surrounded this. Some people’s comments were evaluative in nature, including comments about what informants appreciated and disliked in the personality and ‘bedside manner’ of the DMP. However, the biggest discovery for standpoint informants was coming to terms with the fact that the purpose of the encounter is not therapeutic.75

There is no relation of care between them and the DMP. However, standpoint informants do not — and cannot — initially know this on their first visit to the DMP. It is during their second visit to the DMP, when their HIV infection is announced to them, that standpoint informants learn that the interests organizing the immigration medical examination are not their own. Here standpoint informants in Canada are generally (though not always) given a slip of paper with the name of an HIV clinic, after which time they promptly leave the DMPs office. Two standpoint informants, both refugee applicants to Canada, described their knowledge about the events surrounding diagnosis with HIV by a DMP.

Dans son bureau, le médecin ne parlait pas beaucoup. Il était âgé. Il m’a dit, ‘tu étais au courant, hein?’ Je m’y attendais autrement. Il m’a donné l’adresse d’un hôpital et le numéro d’autobus.

People I come across tell me that they are just told, ‘you are HIV-positive’. Full stop. Go and call this number. That is it. You can be hospitalized because of shock.

Standpoint informants’ experiences with the handling of their HIV status during the immigration medical examination reveal to them that the relationship between the DMP and them is outside of (or contrary to) what people anywhere would reasonably expect from a visit to a medical doctor. In fact, all stories related to date expose that medical principles and responsibilities that doctors are expected to carry out their work

74 In her work investigating the tensions, contradictions and ruling relations within the work practices of company doctors in Ontario, Vivienne Walters made this same finding (Walters, 1982, 1984, 1985).
75 For a critical analysis about the organization of doctor-patient relations and obligations and responsibilities in care in contemporary settings, see Sevenhuijsen (2000).
are compromised in encounters with people who are prospective immigrants to Canada.\footnote{The four universal principles for practice under which doctors worldwide are trained include: justice, autonomy, beneficence, and non-malfeasance. All ethical codes derive from these four principles.} For example, responsibilities such as confidentiality, non-malfeasance (do no harm), patient well being, appropriate care, and consent (Canadian Medical Association, 2004).

Part of what shapes DMPs’ understandings of what they are tasked to do in examinations with applicants they discover to be living with HIV relies on the organization of Canadian medical care and service delivery that are structured by a division of labour “based on parts of the body, bodily systems, and types of malady, with the hierarchical distinctions between generalists and specialists” (McCoy, 2006, p. 112; Lock & Nguyen). For complex health matters, the DMPs with whom I talked have developed referral systems to facilities that specialize in care for people living with HIV.

If the test is suspected to be positive, the lab sends the sample to the Laboratoire de santé communautaire du Québec. When I receive the confirmation, [colleague’s name] does the same thing. If it is positive, we send the client to special services. For example, the Chest hospital has a special department for this. Over time, we have established good communication with the Chest. They send me a report later. I send this report to Ottawa to complete the file.

Dr. Geta explained how his work practices, of gathering information about people’s bodies and recording these for the purposes of submitting them to Citizenship and Immigration Canada, fit within and contribute to the state’s work of assessing immigrant applicants. Dr. Geta talked about his understandings of what he “zeroes in on” and why during immigration medical examinations. In his talk, despite that his work with immigrant applicants and Citizenship and Immigration Canada is organized by IRPA, Dr. Geta positions himself at a distance from Canadian immigration health legislation. DMPs work practices and organizational consciousness is framed by this legislation.

The government is concerned with three things: danger to public health, danger to public safety, and excessive demand on health or social services. This is what they want me, as the DMP, to zero in on.

First, in terms of danger to public health, they are concerned with communicable diseases. Second, regarding public safety, there would be concern about a mentally ill patient. If there is a person with schizophrenia, they want to make sure no one is homicidal. Someone who is depressed would be of concern to the government.
The more common concern is excessive demand on health or social services. People are turned away on a medical basis. While I do not use legislation in my work, I do know this language, which is out of the Immigration Act [i.e., *Immigration and Refugee Protection Act*].

“There is a standard approach to working with all categories [immigration classification scheme as per IRPA] of people,” said Dr. Geta. He maintains that he delivers a same standard of care to all people. Dr. Geta understands that this standard is upheld when he fills out government-issued forms according to the applicant’s immigration category, detailing whether the person is exempt from detailed diagnostic attention for purposes of assessing inadmissibility for reasons of cost. Dr. Geta showed me the form, saying,

Refugees, spouses and dependents are exempt from evaluation against excessive demand. This is what the form actually says – ‘EDE’ [excessive demand exempt]. The government is not concerned about their excessive demands in terms of them being inadmissible to Canada.

Dr. Geta turned to telling me how the various IRPA categories affect his work. For him, examining a person who is exempt from ‘excessive demand’ evaluation, such as those three categories of people he had just mentioned to me, means that,

[I do] not have to go fishing for information about health history of refugees, spouses, and dependents because the government is not going to zero in on that. They are going to focus on the public health and public safety pieces; as opposed to a general applicant, where I need the operative report. I need the pathology. I need all of that. I need more information.

I wondered whether DMPs could test for other conditions above and beyond those the three — tuberculosis, syphilis, HIV — that were mandatory. The answer was yes, though they are “not part of the routine tests.” Depending on the answer to question seven on the “IMM 1017 Medical Report; Section B” form, which asks about communicable diseases,

I may be twigged to do further tests. This is all self-reporting. Hepatitis B or C can go right over their heads, and we don’t even see it because we are not testing for it . . . The medical history consists of questions that we just have to answer. I ask all the questions on the list.

However, the issue is not just that DMP work is organized textually. Hepatitis B and C are as equally important health concerns as HIV from a cost perspective, but screens are not mandatorily or necessarily routinely done for these in the immigration medical examination. In Dr. Geta’s statement we see that once again the physician’s work is directed away from an interest in the overall, general health and well being of the prospective immigrant, and even from a comprehensive interest in public health, public
safety, and concerns related to public costs of health care. In practice, forms are the basis of the DMPs work and the root of interactions with applicants. Documents structure what the doctor does with and asks of people. The medical chart that the doctor submits to the state outlining the applicant’s medical health becomes the formal record of the person’s existence within the Canadian immigration system. Through this chart, the person comes to be defined and distinguished through diagnostic categories, pathologies, and the cost of services that government medical officers anticipate the person will impose on the Canadian public purse. Seen in this way, an applicant’s medical chart achieves much more than a reporting of the incidence of disease and presence of HIV antibodies as a product of a clinical encounter: it creates conceptual boundaries that define who is an acceptable immigrant to Canada.

Dr. Geta indicated that for the client who is HIV-positive, the person’s medical file is complete when the HIV specialist report is included. At this point, he sends it to Ottawa.

I am the intermediary between Ottawa, the specialist, and the client. Everything goes through our hands. The report from the specialty hospital could be the last step in the process. Then, I am finished with the client’s file. The process is: they come here, I do a medical, I send them for x-rays and the labs, I get the results, and I send them to Citizenship and Immigration Canada. I never get to follow-up on these people because I just do the original immigration medical examination. Public Health follows up with them and then Public Health contacts me to tell me this is done [in Ontario, not Québec].

The social organization of DMP work is to have the physician act, prejudicially, on people to detect conditions that will make the individual ineligible for immigration to Canada. The analysis that I am building establishes evidence that the immigration medical examination is not only a very important step in the life of the immigrant applicant, but built into the examination are snares that are carried out in the work practices of DMPs. This work is mirrored in over 1,000 DMP medical offices across the world. And while the DMP might understand and frame her or his work practices as “routine” and “standard” — almost innocuous — the details that the DMP inscribes in reports to be submitted to Citizenship and Immigration Canada about applicants with HIV have serious consequences for persons who are diagnosed with HIV through the Canadian government’s testing procedures. The DMPs work practices also carry with them contradictory, serious, and unethical practices that are similarly serious to applicants with HIV (i.e., absence of consent and violation of confidentiality, to name but two practices).

“You must pass the ‘Maple Leaf’ test”
Anna left the DMPs office after her immigration medical examination. The doctor’s nurse told Anna that if everything was satisfactory with the results of her medical tests, she would not hear from the doctor’s office. Anna told me that she fully did not expect to have to return to the capital again for the purposes of her immigration application to
Canada. “I felt healthy,” Anna told me. “I was told that they would just invite me to bring my passport and get my visa [permanent residence] issued.”

Six weeks later, however, Anna received a telephone call. “I got scared, suspecting that I might be HIV-positive. They said, ‘there is something wrong with your medicals. We need to see you again.’” Anna pressed to know more and asked, “What is wrong with my medicals? Can you tell me?” The woman on the telephone said that, no, she could not discuss the matter over the telephone. “When you come here it is quite confidential; we will let you know.”

A number of things raced through Anna’s mind at this precise moment. As she provided me with details of the decisions that she made from this point forward, I began to see how she understood how and why her immigration application work process had taken a complex turn. Anna talked about the planning work the possibility of an HIV-positive diagnosis ignited for her and why.

I felt scared because I immediately thought, if I am HIV-positive, I will never get to Canada, ever, because of my HIV-positive status [informant emphasis throughout]. I had really hoped to immigrate to Canada because I satisfied all the conditions for skilled worker. I knew that I would have to go back home because in [country name], where I was living and studying, they would repatriate me. Foreigners with HIV are expelled. I thought going home just meant that I was going to die. And that’s the end of it. I started really wondering what was going to happen to me.

To get into Canada, said Anna,

You must pass the ‘Maple Leaf’ test. This is your health. It is like any other country, they require an HIV test. I understood that HIV was one of the tests for immigration to Canada. I remember that a doctor told me that if someone tests positive, they could be refused. The physician told me that six months ago someone had tested positive and didn’t get in [to Canada]. So, I was expecting the test by the Canadian government.

In Anna’s talk, there are traces of institutional relations, expressed subtly, that shaped her immigration application work. There is reference to her understanding of global mobility including immigration restrictions for people living with HIV. Approximately half of the two hundred countries in the world for which there is data restrict in some way the mobility of people living with HIV (Wiessner & Lemmen, 2010).77 Anna was acutely aware of these arrangements that prevent people from successfully acquiring visas (travel or other) to certain countries.

77 See data on each of these countries as available in the Global Database on HIV-Specific Travel and Residence Restrictions at http://www.hivtravel.org/Default.aspx?pageld=142
However, Anna’s understanding of which countries actively restrict entry, stay or immigration of people living with HIV was not entirely accurate. Not all countries in the world impose mandatory HIV screening on prospective immigrants. In fact, countries that operate mandatory testing programs throughout the world are increasingly in the minority. No European Union country operates a mandatory testing program of immigrant applicants, however, there are restrictions placed on people living with HIV who want to remain in Cyprus, Germany (Bavaria), Hungary, and Slovakia for more than ninety days.\textsuperscript{78} Among African countries, Egypt, Equatorial Guinea, Namibia, and Sudan maintain some form of mobility restriction for people living with HIV. In 2010, the Namibian state reversed a regulation that prevented people living with HIV from entering, staying or residing in the country. The Egyptian state requires foreign people to undergo an HIV test and reportedly refuses applicants with HIV based on health. It also expels foreign people who are diagnosed HIV-positive while in the country (Wiessner & Lemmen, 2010). In 2010, the United States relaxed its global ban on people living with HIV that had been in place since 1987. Given the global influence of the United States in many realms, it is possible that Anna’s understanding that Canada — “like any other country” — tests prospective immigrants for HIV was mediated by her knowledge of the longstanding practice of the United States towards people living with HIV.

I was intensely interested to know what steps Anna took as a result of the telephone call from the Canadian authorities that signalled that she would have to travel back to the capital to meet a second time with the DMP and, possibly, other allied medical personnel.

Anna informed me that she decided, almost instantly, to take herself to the local health centre in her town for an HIV test. This was to “eliminate the possibility that I might be HIV-positive. Three days after I did the test, my results turned out to be positive,” said Anna. This was an emotional blow, and betrayal, and she was immediately conflicted. Not only did the confirmation of Anna’s HIV-positive status have implications for her desire to settle in Canada, her diagnosis also carried the weight of what would become a fractured intimate relationship. There were also the implications of seroconversion.

Said Anna,

\textsuperscript{78} Nuance to such reporting on country conditions and restrictions for foreigners living with HIV is necessary. Taking a country-by-country look at how laws, policies, and regulations are actually being applied and carried out in people’s work practices is revealing. In Namibia, for example, residence permit visa forms still ask HIV-related questions. “Applicants are . . . required to answer the question whether they are ‘carrying the AIDS virus’. Thus, theoretically, if someone was found to be HIV positive they could be deported, as the ‘AIDS virus’ is a prohibited disease in terms of current law and regulation. However, it seems that this law and regulation are not enforced” (Wiessner & Lemmen, 2010, p. 33).
It is the same old story. You trust the person you are with . . . Everyone would know why I didn’t get to Canada. Basically there is only one reason. Everyone knows or suspects that if you do not get a visa to the US [United States], Canada, or a European country — and everything seems to be okay with you — everybody just kind of suspects that you tested positive.

Within Anna’s statement is the problematic if not specious relationship between HIV diagnosis and confidentiality: the practices and processes associated with the HIV testing procedures seem to consistently ‘out’ or expose prospective immigrants to Canada who are HIV-positive. Anna’s social circles at the time of her application to Canada were like most other standpoint informants I interviewed: populated by people from same native country or language group. People find one another and discuss their application work together. This networking among applicants is indeed one of the unacknowledged work processes that became evident in the standpoint informant data.

The implication that Anna’s application to Canada could be denied when she appeared, outwardly, to be in good health, felt very serious to her. The stakes were high because she faced utter uncertainty about her future in both the country in which she had lived for nearly a decade and her country of birth if the former decided to “repatriate” (deport) her. Within the requirements of the Canadian immigration application process, Anna had become more vulnerable to hardship than had she not embarked on her quest to work and live in Canada. The eastern European country in which she had been living and from which she applied to immigrate to Canada is currently one of thirty-one countries worldwide that are known to deport foreign nationals living with HIV or require that they leave the country (Wiessner & Lemmen, 2010). These sorts of consequences are neither addressed in the HIV testing policy nor are they captured in the official accounts about how and whether the mandatory HIV testing policy is functioning, as per my critique in chapter one of the authoritative accounts of how the HIV testing policy functions in practice as authored by Zencovich et al. (2006) and Gushulak and Williams (2004).

Anna moved beyond her fears and misgivings about the impressions that others would possibly hold of her. She began to harness her energies and attention to the work of information gathering consisting of self-schooling and contacting resource people via the Internet about immigrating to Canada for a person living with HIV. She combed the Internet in an environmental scan of available information about HIV, the law, and immigration in Canada. In particular, Anna was concerned with answering two questions that pressed down on her; outstanding questions that prevented her from sleeping at night. Namely, “does Canada accept immigrants who are HIV-positive? Or, should I just forget about immigrating altogether?” Anna recounts,

Some days later, I looked at CIC [Citizenship and Immigration Canada] and Health Canada sites with certain keyword functions such as ‘immigrating to Canada with HIV’. Searches [in those sites] turned up nothing helpful linked to HIV. On the
other hand, most things I was finding elsewhere on the Internet and in immigration and HIV-positive chat rooms, for example, were killing me because, bottom line: if you are HIV-positive, you won’t get into Canada [as an economic class applicant like me].

Amidst anxious, high-pressure circumstances, Anna sat in her small apartment and persisted with her resourceful knowledge work. Her computer was her ally and an essential work tool.

After Internet searching, I started writing some emails. I needed some information about the laws in Canada. I found the email address of a Canadian-based lawyer. I wrote to him, and he replied to my request about HIV status.

In an email that Anna sent to me shortly after our interview, she forwarded the one-time exchange between herself and the Canadian-based lawyer. She had been surprised to find the letters in the archives of her email since she thought that she had discarded all files relating to her HIV status. Anna created an alternative email account and used an assumed name, an alias, in correspondence with this lawyer. Their messages read,

Anna: ‘I am HIV positive, not on treatment, and filed for immigration to Canada. I was requested to do a test for Viral load and CD4 count. What is the minimum CD4 count that by legislation permits me to gain admittance to Canada?’

Canadian lawyer: ‘I have attached the current guidelines for HIV used by the Immigration Department. This is not legislation but policy. What kind of an application are you considering? It makes a big difference, as some categories are exempt from the provisions for medical inadmissibility due to excessive demand on health or social services.’

Describing that period in her life, Anna said that she had been “living in a state of fear and confusion.” She continued,

[The lawyer] really gave me hope. He replied and directed me to a link that said that you could be admitted if your CD4 count is above 500 and your viral load is undetectable and you have never been on antiretroviral medication. He emailed me Canada’s seven-page HIV testing policy [CIC, 2002]. That is when I started hoping. All the other Canadian immigration criteria excluded me: I have no family in Canada. I have no sponsors. I could only hope on my CD4 count and viral load.

This email exchange is significant for a number of reasons. Anna, like other standpoint informants, only uncovered the HIV testing policy document quite by happenstance, and after considerable combing of available resources posted on the Internet. Most standpoint informants have never read the policy text, which might in part be because
the document is not posted on the Internet. By all accounts (including my own), the policy is a difficult document to locate.

Email communication with this lawyer in Canada introduced Anna to Canada’s HIV testing policy with its regulatory and policy language shaped by terms imported from the world of medical science and ideas adapted from IRPA. Anna did not have prior knowledge of CD4 count and viral load diagnostic measurements. The terms and all of the language in the testing policy were new to her. This is also generally true of other standpoint informants with whom I talked. Many informants immigrated to Canada from countries where the viral load test is not widely used in the treatment and care of people living with HIV. Anna had “never been on antiretroviral medication”, and she was relieved to meet this criterion of the HIV testing policy. Anna understood from the policy that she could “really [have] hope” as long as she was antiretroviral free. Had Anna be advised to start medication after her diagnosis, the knowledge that treatment would make her automatically inadmissible for Canadian permanent residence would have influenced her decisions about how to proceed with medicines and the work to minimize the health effects of HIV infection.

Standpoint informants’ diagnosis with HIV through Canadian immigration screening projects them into a world of concepts and procedures with which most have no prior experience. From the point of her exchange with the lawyer based in Canada, Anna worked and organized herself to acquire basic understanding and gain a level of proficiency in using the technical diction associated with HIV and AIDS. She did this primarily through discussions with people living with HIV in Internet chat rooms, and from selected on-line searches. Anna told me that she read extensively during these months.

L: How did you find information on-line?

Anna: It is not on the government site that the details about eligibility are listed. It is on the [Canadian HIV/AIDS] Legal Network website. There is a position paper on immigration testing as it affects PHA [people living with HIV] applicants. It states that if you live with HIV, you are ineligible for permanent residence. I found that information, specific to HIV, listed on the public site. It states that the average Canadian costs $5K [thousand] annually to the government, whereas the PHA costs $15K. So, expenses over average are not allowed. Also, if you are currently taking drugs, you are not eligible. There is no reference to CD4 and viral load counts.

L: Based on your experience, what does a person need to know to immigrate to Canada when they are HIV-positive?

Anna: You need to know all the laws. That because you are highly expensive to the government; that it [HIV] will close the doors for you. I looked for more
information, like a small window of opportunity where ‘maybe you could enter here’ or loopholes; there are none when you live with HIV and are taking medications. No. It is very clear in this case.

Understanding how to use the terms of this lexicon was essential for the self-advocacy work that Anna would need to do if she hoped to successfully immigrate to Canada. Anna engaged in a phase of significant self-advocacy work as the next step in the chronology of her immigration application work process. Her goal was to have the Canadian government pursue its consideration of her application despite her HIV-positive diagnosis. To effectively self-advocate in written communication with Citizenship and Immigration Canada state agents, Anna made skilful use of the policy language she had learned, carefully appropriating the terms and concepts from IRPA and the HIV testing policy to position and promote herself in particular ways. She found using government language strategic. This is illustrated in her statement below.

I wrote to the Canadian embassy in Europe. I said that ‘yes, I tested HIV-positive, but, I do know that with these laws and rules I could still be admitted. All I want is for you to give me a chance to do this test.’ I was really acting quick, quick, quick. I thought, ‘I have no time to waste. I have nothing to lose [in writing to the Canadian government]’.

Anna pressed forwarded with a carefully worded written email communication to Canadian government officials. She did not hire a lawyer for this purpose since this option was out of her financial reach. More to the point, Anna did not want to discuss her HIV status with anyone in her current country of residence. Rather, under a carefully constructed nom de plume Anna built on her understandings gleaned from the Internet, chat rooms, and correspondence with the Canadian-based lawyer. This work informed how and what she wrote to the Canadian government. Anna talked about what she had written to Canadian authorities.

The crux of Anna’s worry at this time, during the time she waited for the date of her second immigration medical examination, was that the results of her CD4 and viral load tests would be adequate so as not to eliminate her from being considered for immigration as a skilled worker to Canada. Anna saw results from CD4 and viral load tests as crucial biomarkers; touchstones in her immigration application work process.

Within Anna’s email, and how she positioned herself in written communication with Citizenship and Immigration Canada, we see that consistent to other standpoint informants, Anna takes up and works from within a medical framework. In doing this, standpoint informants take a position about themselves that is located within an institutional discourse. “Knowing oneself as a person infected with HIV is . . . to take up a position within institutional discourse” (McCoy, 2006, p. 119).
Six weeks went by between Anna’s official letter addressed to Citizenship and Immigration Canada and the response she received. While waiting, Anna anxiously wondered about what the Canadian government response would be. “I wondered if that was it for me.” Anna explained details of the eventual response she received.

The immigration office wrote back to say, ‘Good, you can go for those blood tests’. So, I went to the capital once again to do further blood work. These tests are very expensive. I had to pay for these. It was about $450 for one set of blood tests. There was only one hospital in the capital that did these tests.

I had to go back to the capital again three weeks after giving my blood. The doctor was surprised, and asked me who had told me I was HIV-positive. ‘The ELISA [enzyme-linked immunosorbent assay] test shows I have the antibodies,’ I said. ‘I must be infected.’ ‘But, your CD4 is like for a normal person,’ said the doctor.

Recalling this exchange with the doctor, Anna laughed. “I didn’t know he meant by a ‘normal’ person. I felt like a normal person! In any case, we could not detect a viral load,” she said.

Anna hand delivered her test results to the Canadian immigration centre in the capital city where she was told that they would be sent via special courier to Canadian immigration authorities in Europe. She was instructed to “sit and wait. If they say you are admitted, you are admitted. They will let the embassy in this country know. You cannot appeal.”

So, said Anna, she travelled back home. She hoped that whomever was going to handle her file would see that she was a good person and a “good immigrant”.

I felt that even though I had made it past the marks of a good CD4 count and viral load, I still didn’t believe that they would admit me into Canada. I still thought that there would be some loophole somewhere; something is going to come up; we can’t accept you.

Every day I was praying, ‘Just one more CD4 today! What do I have to do to get a high CD4 count? I would ask my friends on the on-line HIV-positive forum about this, and they said, ‘Have a positive outlook; do sports; eat healthy; don’t smoke’. I stopped drinking. I began to engage in activities to boost my CD4s.

At this juncture in her immigration application work, Anna began fully engaging in the discursive practices of HIV/AIDS, which are heavily influenced by the biomedical frame of understanding. The intentions embedded in the immigration process and its particular links into the biomedical disease prevention models about healthy living, CD4 and viral load counts were transported into the “personal spaces” of her life (McCoy,
2006, p. 119). Anna realized that because of her HIV status, she had become an object of particular government interest and scrutiny. In response, she began to produce efforts to introduce changes into her everyday routine; practices that more appropriately aligned her with techniques associated with common understandings of healthy lifestyle choices and healthy behaviour.

For example, from colleagues in chat rooms, she learned that a “positive outlook”, “sports” and “activities to boost CD4 counts” were positive lifestyle choices in the work of preserving oneself. With all of this in mind, Anna busily set out on a campaign to improve herself. She made conscious efforts to slow the progression of her disease (measured in low viral load levels), and fortify her immune system (measured in high CD4 count levels). Anna understood that such transformations would make her a more attractive candidate for immigration because she would be robust and fit, despite the presence of HIV in her body. As Anna talked, I was reminded of research findings among people living with HIV from a decade before where such campaigns of “self-work” and “self-scrutiny” were found to be common among those “whose lives are embedded in relationships with experts and health care providers through which they work at coping with everyday life and at transforming the ‘self’” (Mykhalovskiy, 2002, p. 58).

“They were hoping to tell me something I didn’t know!”
Anna turned to talking about the details of her second immigration medical examination appointment with the DMP. Anna reminded me that all of the efforts that she had talked about to this point had occurred before she met the DMP for a second time in the capital city.

Anna spoke about feeling trepidation mixed with determination when she walked into the immigration medical facility for the second time; owing in part to the fact that she had already investigated her health at a domestic clinic that was unaffiliated with Canada’s immigration medical testing. Anna had been acutely aware of what she anticipated the doctor was preparing to reveal to her.

“I sat there with the doctor,’ said Anna. “We were the only ones in the room”. He said, ‘I have some bad news for you.’ I said, ‘yes?’ ‘Did you know that you were HIV-positive?’ I said, ‘No, but when you called, I went and tested at a medical clinic where I live’.”

Here, Anna let out a laugh. “I spoiled their surprise. They were hoping to tell me something I didn’t know!”

To the question as to what sort of interactions then occurred with the DMP, she said, “He had a blank face. He hid his emotions. Maybe there was intended counselling that I quickly aborted, I should put it that way.”

Anna did not trust this doctor because of previous experiences with annual ‘routine’ HIV testing and the medical and national government establishments more generally in her
adopted country of residence. She did not know what the doctor would do with her results. She did not know where he would send them or who would see them. Anna had already and by her own thinking initiated direct communication with agents of Citizenship and Immigration Canada, and because of this, she did not think that there was a need to provide this DMP with any other details about herself apart from what he already knew. In this way, Anna reported subverting any detailed or lengthy discussion about herself.

He gave me a piece of paper that I had to sign that stated that I acknowledged that I was tested HIV-positive; that I am aware that I am HIV-positive; and that I had been educated about the means of transmission. I had not been educated through this doctor. Probably he was going to give me that talk. I read through his paper, and agreed with everything it said. It said, ‘you cannot donate blood; protect yourself when engaging in sex; cannot give organs.’

Anna continued,

That was the attempt at counselling. I eased his job. Or, maybe I made it more difficult. I don’t know! [Informant emphasis] I understood that the form would go into my file and that they would send it to the Canadian embassy in Europe. It was just a form. I did not get a copy.

Critically, though, this form is about much more than her signature. In signing her name to the form that the DMP presented Anna after delivering news of her HIV-positive diagnosis, she attests that this doctor has ‘counselling’ about personal issues and her public responsibilities as a person living with HIV. This form creates an artefact that will enter into the state’s record keeping system and be understood as evidence that Anna received, understood, and agreed to the information contained on the form. Seen in this way, this document becomes a component of the ongoing surveillance and scrutiny that HIV positive applicants endure (that are not replicated in any other incurable health condition).

Within Anna’s statements we are given two important clues about the social organization of the immigration medical examination and the DMPs work. First, that Anna was not given a copy of the form is not surprising given the instructions to this effect given to DMPs by Citizenship and Immigration Canada. Dr. Geta talked to me about the subjects he is permitted by government to discuss with applicants. For example, he is formally instructed not to comment on matters that are not directly related to the questions on the forms used to evaluate the medical health of the applicant. The section ‘Communication Issues Related to Applicants’ in the Handbook for Designated Medical Practitioners reads that the “complexities of immigration processing, including the medical examination, can be frustrating for some individuals” [i.e., applicants to Canada, but not other people, including state employees, for whom my research shows the functioning of the system is both mystifying and problematic]
(Minister of Public Works and Government Services Canada, 2009, p. 6-2). Designated Medical Practitioners are instructed to tell applicants who query processing timelines, policy or “other immigration-related issues” that the DMP is “simply the interface between the department [Citizenship and Immigration Canada] and the applicant . . . DMPs should never provide copies of immigration medical forms to applicants or their representatives” (p. 5-3).

Topics about which immigrant and refugee applicants regularly inquire, such as the evolution of their immigration application or how their health will impact on their chances for successful immigration to Canada, are prohibited. Dr. Geta explained,

I do not ask politics of the applicants who come to my office for an IME [immigration medical examination]. It is not my role to ask the person. I have to be focused on the medical exam and the social part of the medical. Will they be a burden on the system? That is my concern and focus. If I move to a higher level in government to a decision maker, then I need to know more.

Thus under no circumstances is the DMP permitted to provide the applicant with a copy of her or his medical file. This explains how it is that (the small number of) standpoint informants who encountered the post-test counselling form did not receive a copy of it. Dr. Geta said that the government makes the point “quite strongly” that prospective immigrants are not allowed to get copies of the medical report that the DMP files about them.

I have a certain job to do, and Ottawa does, as well. I respect this. I have worked for government on many levels before. My job is not to make decisions or pass on opinions to the client. You must be very careful about that. We all work at a certain level.

“It’s the same language”
A second feature about the organization of the immigration medical examination and the DMPs work is revealed. Anna’s statements about her interactions with the DMP at the time he announced her HIV-positive status points to an interface between her experience and a complex of institutional work processes where “a piece of paper” entered into her experience.

The “Acknowledgement of HIV Post-test Counselling” is the document Anna referred to in her statement above (Figure 13) (Minister of Public Works and Government Services Canada, 2009, vi-1). We see that this form is a standardized, one-page government document bearing a four-line text written in the first-person. In signing, the signatory acknowledges having received counselling “on several topics” related to her “HIV-positive condition”. The person, possibly newly diagnosed with HIV, also acknowledges receiving “risk-reduction strategies such as partner notification”, and a discussion on “follow-up and care” explained by the DMP. The physician is supposed to cover these
Acknowledgment of HIV Post-test Counselling

This is to acknowledge that I received HIV post-test counselling from (name of counsellor) on several topics related to my HIV-positive condition, including an explanation of the test results, risk-reduction strategies such as partner notification, and a discussion on follow-up and care.

________________________________________   ______________________________________
Applicant's Signature                       Counsellor's Signature

________________________________________   ______________________________________
Printed Name of Applicant                   Printed Name

________________________________________
File Number

Signed at ______________________ this ___ day of _________ 200__.

DMP ____________________________________

Affix DMP Stamp
grounds with the applicant and then present the person with the form to sign. Once this happens, the form is date stamped and signed by the DMP who affixes her or his professional stamp. The physician is supposed to include the form in the applicant’s medical file and sends it to Citizenship and Immigration Canada.

When a standpoint informant receives this acknowledgement form, there has just been a diagnosis with HIV. This is a monumental moment. A woman explained,


Whether or not this is a first diagnosis (perhaps the person had already tested HIV-positive in other circumstances, such as the case with Anna), all standpoint informants describe HIV diagnosis as instilling fear, loss, worry, depression, sorrow, and uncertainty; confusion and apprehension about the future; suffering and bodily demise. A positive diagnosis for HIV through Canadian mandatory screening has immigrant and refugee applicants very concerned about their immigration future. Standpoint informants are all aware of the worldwide variation in the availability of medicine to treat HIV infection and AIDS-related illnesses. They also know that in Canada there is a publicly funded health care system.

Despite medicine availability and universal health coverage in Canada, the following two standpoint informants talked of demise and death at the time of diagnosis.

> I kind of expected the results. I think that every gay man expects, or is ready, or assumes you can get it. It was still really, really hard. It is so shocking. The guy [DMP] just told you that and you do not know anything, anything [informant emphasis]. You begin to wonder how much time you have to live, when you will die, etc.

> The big issue for us at the time was that I was positive and he was not. We wondered about our immigration file, and whether we were going to be turned away because of the HIV status. Our main concerns related to how my status would be perceived by government; how our relation [marriage] would be perceived. We went to a lawyer at that point.

Dr. Geta and I spoke about the content of the messaging that he communicates to applicants who test HIV-positive. During our conversation, he shuffled through the considerable amount of papers on his desk in an effort to locate a form that he wanted to show and discuss with me.
In the end, amidst all the paperwork, Dr. Geta did not find what he was looking for. “Well, anyway, everything is on the web,” he said. He continued,

Citizenship and Immigration Canada asks us to fill out a form called “Acknowledgement of HIV Post-Test Counselling” form. This is in the [DMP] Handbook [i.e., Minister of Public Works and Government Services Canada, 2009]. This is to acknowledge that people have been counselled. I sign, and the client also has to sign. It is mandatory for us to do counselling. It is mandatory to submit this signed form to Immigration when we submit the file; the client acknowledges having received counselling. The idea is to stop transmission. It is a relative question as to whether we succeed in this mission. That is another matter. This is more than for documentation purposes, it is for therapeutic reasons [though it is not]; you are supposed to look after people. I could see some [people] as a family physician; this form would not be part of it. This is part of my submission to Citizenship and Immigration Canada.

This study’s findings point to a stark contradiction between standpoint informant accounts with this acknowledgement form and how DMPs use it in their work. In practice, the form does not appear to be routinely integrated into the work that DMPs do with standpoint informants. Hardly any standpoint informants reported knowing about or putting their signature to this government form. Above, when the DMP gave Anna the “piece of paper” to sign, she understood that she had no choice in the matter because it was integrated into the protocol of the immigration medical examination.

Despite the reported infrequent use of the form, the government frames the form as an important administrative and accountability tool. According to a Citizenship and Immigration Canada policy advisor, this form is an obligatory component of a finalized medical file submitted by a DMP. State medical officers are said to ensure that the form is included in all submissions. Thus a completed file is said to include this “Acknowledgement of HIV Post-test Counselling” form.

Standpoint informants generally do not know about the state’s own, recorded emphasis on delivery of HIV test counselling. At the same time, people are surprised at the absence of this form of care because they expect that counselling would be integrated into what happens at the time of diagnosis. Here we see that standpoint informants draw on their working knowledge that HIV testing is often accompanied by counselling, and they express disappointment that they do not receive it. Informants from countries where HIV is endemic, particularly people from Africa, spoke of public health programming around HIV in their home countries through which people are encouraged people to voluntarily test for HIV. In these testing situations, counselling is a part of the service. A woman refugee applicant named Pauline commented,

I have never heard of anyone [in Canada] who had counselling or who were sent to a social worker. In my country, we have to be counselled. You are counselled
before and after, whether you are positive or negative. The government encourages us to get tested. Here it is not the way it functions.

More broadly, standpoint informants are surprised and most often significantly disappointed at the character of the encounters with the immigration physician. Informants draw on their prior knowledge of visits to doctors, and experiences with health personnel in their home countries or other surroundings. As such, they bring certain expectations into the required immigration medical examination. The DMP is an authority figure as well as a representative of the Canadian state. The examination is the first contact of a intimate bodily nature with a person employed, albeit contractually, by the state. Pauline continued,

This testing [by Citizenship and Immigration Canada] is good, at the same time. Let me say so. If you did not know before, then you will know. This will help you to go into therapy on time. The way they present the information, that is the question mark. That is the most important thing. If you are due for medication, you will live knowing your situation. At the same time, the way it is just said into your face, take it or leave it; there is no counselling.

Through these statements we see that whether implicitly or explicitly, standpoint informants draw on their working knowledge of what they understand to be notions of good public health practice and patient care in framing what could, or should, have occurred to them when their blood was drawn and when they received their HIV-positive diagnosis. Standpoint informants offered evaluative statements about DMPs. For example, speaking about the doctor’s communication of her HIV status and what was not said during the visit, a woman refugee applicant commented,

J’étais surprise qu’un médecin blanc me parle et se comporte comme ça. Même en Afrique, chez le médecin des africains, ce n’est pas comme ça. Il ne faut pas transmettre une nouvelle comme ça. Et en plus, devant des gens. Ici je suis faible, je pourrais même tomber et mourir.

Another standpoint informant, a family class applicant named David, reported,

Something that bothered me was that the doctor began talking about my HIV in the hallway, outside his office, in the reception area. I opened the door, there were people in their fifties waiting in the waiting room, and he spoke to the nurse, inquiring where the forms related to HIV were located [AIDS service organization pamphlets]. I felt as though people thought they were looking at a monster! As if they all knew that I was positive. Later, when I met with the public health nurse, I told her about this. She told me that I could report this. I decided not to do this, because I did not want the man to get in trouble. I decided not to
do this, maybe others will. I did not want to have the finger pointed at me; the positive person. Let’s leave it like that.\footnote{As with the writing that I have done analysing the social organization of ‘lawyering work’ that standpoint informant’s do through their immigration application process (see foonotes 41 and 43), I have done tracts of writing explicating the frontline, interactive ‘nursing work’ they engage in. I interviewed four nurses in this study, two of whom live in Ontario and regularly do the work described here (see Table 9). That is, they meet with immigrant applicants who test HIV-positive through mandatory immigration screening. The nurses set out to inform the new arrivals about their rights and responsibilities as people living with HIV. The \textit{Map of the first 30 days in Canada for refugee applicants} situates the public health nurse within the immigration process as lived by immigrant applicants.}

By all standpoint informant accounts, DMPs do not do the work of education and counselling very well. Some informants, such as the two people quoted above, reported being told about their diagnosis with HIV within earshot of other people. Standpoint informants express surprise that the medical visits are short; that in many cases there is limited dialogue with the doctor; that messages they receive focus on the population health of Canadians, with less apparent emphasis on their personal well being; and, that the initial check-up is largely based on what they disclose to the DMP about what they know of their health history and medical conditions. Ashmin, a refugee applicant from Asia, talked with frustration about her and her family’s experiences with Canadian immigration medical examination. She, like other standpoint informants, talks about inequalities in the organization of immigration medical screening. Ashmin says,

My brother-in-law has epilepsy. He applied for Canadian permanent residency. Because the medical examination was self-reported, he did not reveal that he had this condition. He is here now. On the other hand, if you have HIV, it will be known because of the testing. If you are found to be positive and are outside of the country, you will likely not be admitted. This would seem unfair. Why is there a variance between illnesses?

Leila, a refugee applicant, offered her thoughts on what Citizenship and Immigration Canada could do as corrective measure to address the shortcomings she experienced with her diagnosis with HIV during the immigration medical examination.

The problem is the doctors at immigration. Maybe they have been told that this is how you should tell new cases and deal with them. I do not know. They are working on time. Given this time constraint, actually maybe it is the government who should make the effort to put different staff at the front; to inform new people. [DMP name] should have a social worker working with him. If a client comes and is HIV-positive, before telling her the result, she should undergo counselling. The social worker can take care of this. I call myself client and not patient because I am not sick . . . I understand. They are making money. They do not have time to sit with me. They are working on time. My wish is that they
could work with social workers to handle such cases. Some people who are very fragile can do things they are not supposed to be doing.

Some standpoint informants reported having difficulty communicating with the DMP. For example, in the quotation below, we learn that a native Spanish speaker named Juan chose a DMP based on his professed ability to speak Spanish. The DMP had listed himself as fluent in this language on the Citizenship and Immigration Canada site. A DMPs name, contact details, and the languages she or he reports speaking are provided. Standpoint informants reported choosing a DMP who speaks their mother tongue, whose office is close to the place they live at the time, and/or who came recommended through acquaintances or friends. Juan told me,

The immigration office gave me a paper for the medical exam. They gave me a list of the number for the doctors. The list explain about who’s the doctor, what language he speaks. But, everything was in English. One doctor said ‘Spanish and Portuguese’, so I choose this doctor. When I went to the doctor, he didn’t speak Spanish. He spoke Portuguese. I said, ‘what happened’, and he tells me, ‘it’s the same language’. But, it was not the same. I didn’t understand what he was doing. He explained everything, but it was in Portuguese. Maybe I understood forty percent, but it was not enough. So, when he asked me information for example ‘what is your HIV status’, I said, ‘I never make a test, or I suppose I am HIV negative’. But, I can’t explain what happened to me in my country because I didn’t speak English at the time.

For standpoint informants, whether they apply for immigration from within Canada or outside, the DMP is the first face they associate with the Canadian health system. On many levels, what they experience during their immigration medical examination at the time of their diagnosis for HIV sits uncomfortably with ideas they hold about Canada and what they would have expected from a medical doctor employed by the Canadian government.

“You do not know these people as patients”
Dr. Geta told me that when he receives an immigrant or refugee client’s HIV positive laboratory result, he has his assistant telephone the person to tell them to return to see the doctor. “She asks them to come in. It is very important to let the person know how the disease spreads. I tell them they are reactive for HIV antibodies. We go through all the body fluids and such. We also like to know how they may have got it. They have an obligation to get in touch with former partners.” Dr. Geta elaborated,

At the same time, we do some counselling. If the client knows that he has the problem, if he is coming from France, for example, and already has medication and is fully aware of his condition, we still deliver some messages, even if he has received these before. The person with more education and knowledge is easier to explain. The person from the countryside, you have to use a lot of metaphors.
If the person is newly diagnosed, well then the details are more in-depth. These would consist of protecting himself, protecting the community, with the idea of public safety of other people. But, the problem is, people start getting careless; not taking their medication; don’t practice safe sex. It is never an easy scenario.

I was curious for Dr. Geta to tell me how he knows what to say to a person whose blood work has revealed a positive result. He told me that the information he provides is “a routine that has been like that for a long time. We do it in the same way. I slowly break into it. I am eyeball to eyeball with the person. We are alone. I must give them tremendous encouragement, explaining that the face of the disease has changed as of ten years ago.”

My experience has been that these people are in shock. It is a delicate situation. You do not know these people as patients. You have to deal with a lot of emotions. You have to make sure when they leave your office that there is no concern for them doing something silly. It can be a bit challenging in this way, but it can always be worked out. Talk. Reassure these people. Explain different treatments. It takes from twenty to thirty minutes.

I queried Dr. Geta about how he uses the most recent Handbook for Designated Medical Practitioners in his counselling work and his work as DMP more broadly.

If you are starting off, it is likely an important tool. It is well done. It encompasses everything a DMP should know about his job. Because I have been doing this for so long, there is not much that is enlightening. For me, there is nothing really new between the previous edition and the revised [2003 and 2009 editions].

I thought that we could review and discuss the manual together to examine the variety of forms that are provided as appendices. This became somewhat of a problem when Dr. Geta looked high and low for his copy. From his search in the adjacent office, he emerged with a copy. I asked Dr. Geta to tell me about the changes that had been introduced between the previous and most recent editions of the Handbook for Designated Medical Practitioners (i.e., 2003 and 2009 editions). He was aware of the Citizenship and Immigration Canada request of DMPs that they post their fee schedule for consultations with immigrant and refugee applicants in their office, in plain view (which Dr. Geta decided against posting stating that he found this crass).

However, if we compare successive editions of the Handbook for Designated Medical Practitioners (Minister of Public Works and Government Services Canada, 1992, 2003, 2009), we see that there are, in fact, substantial changes. This most recent version provides explicit instructions about public health messages and instructions for pre- and post- HIV test counselling. There is four times the number of appendices directly related to HIV compared to any other health condition. The pre- and post- HIV test counselling
guidelines provided in appendices four and five of the *Handbook* are informed by the Canadian Medical Association guidelines to this effect. When I asked Dr. Geta how the overview of counselling in the *Handbook for Designated Medical Practitioners* coincided with the counselling protocols outlined by the Canadian Medical Association, he told me that he was not familiar with these. “Do you know?” he asked me.\(^8^0\)

When Dr. Geta immigrated to Canada, he reported that any physician could conduct an immigration medical examination. It was during the 1990s that Citizenship and Immigration Canada created the DMP program and began to set out guidelines for doctor roles and responsibilities. Dr. Geta explained that currently, doctors in Canada and those outside the country must make an application to serve as a contract immigration physician.

To become a DMP, I had to apply to the medical centre in Ottawa. You ask to be accepted. You send in your CV [curriculum vitae]. You must have a strong CV that demonstrates your knowledge; that you can handle pathologies, medical problems, and different cultures.

The term of appointment for DMPs is up to five years, and it is a renewable contract. “They issue a certificate such as the one hanging on my wall. This is valid for three years.” Doctors re-apply to be re-appointed by Citizenship and Immigration Canada. Dr. Geta told me that this is a relatively new feature of the DMP program. “Before, you got to be a DMP for life. Now, based on your performance and their needs, they re-assess you. They review what you have been doing in your practice. Though, I think that everyone gets to serve as DMP and have their contract renewed if they behave themselves,” he laughed. In this exchange with Dr. Geta, I detected traces of other features that shape immigration medical examination and interactions between DMPs and standpoint informants. These include physician’s formal education, on-going professional development, training related to HIV, and the doctor’s understandings of the DMP job function.\(^8^1\)

Canadian DMPs are most often general practitioners. This means that they usually have had four years of medical training and three years residency. The general practitioner

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80 My searches to find this document were challenging. They were also circuitous because the text is not in circulation. A contact at the Canadian Medical Association reports that the organization does not have an electronic version of thee guidelines (E. Czanyo, personal communication, May 17, 2011). On the website of the Public Health Agency of Canada, there is a text that is listed as being the guidelines. The document is cumbersome and hard to find. In a policy resolution from 2008, I learned that the Canadian Medical Association endorses the United States Centers for Disease Control position on counselling, which is that a physician deliver “clinically appropriate pre- and post-test counselling” (E. Czanyo, personal communication, May 17, 2011). An accessible summary of the Association’s Guidelines is published by the Canadian HIV/AIDS Legal Network (2007b).

81 About training, education, and auditing of DMP work, see footnote 61 (p. 195).
training might or might not have provided the doctor with the tools to dispense certain types of information and care that people diagnosed with HIV need or might expect. One extra-local informant, an HIV physician, speaking about his DMP colleagues, said that in his (informal) survey, DMPs that he knew through professional association were all around or above retirement age. Results from a national survey of seventy-six DMPs exploring career tenure as state immigration doctor confirm this HIV physician’s observation (Tran et al., 2011). This point directs attention to the timeline of the epidemic, which appeared in the early 1980s in North America (as per Table 13 and the Ancestry of Canada’s HIV testing policy timeline at the start of this dissertation), and the fact that HIV education would not have been part of the formal medical education that DMPs of a certain age would have received. About training through Citizenship and Immigration Canada, a DMP said,

Sometimes CIC [Citizenship and Immigration Canada] organizes forums that we can attend and they present us revised science and administrative procedures. We don’t have to attend. Everyone is treated as an adult. You do get credits. They want DMPs who are focused on immigrant health and immigrant concerns; so you have fewer people who are more aware of and sensitive to issues. They don’t want a DMP doing an immigration [examination] here and there; they want it to be a significant part of your practice.

Under current medical training in Canada, specialization in HIV necessitates two to four years beyond residency. It would be unreasonable to suggest that DMPs should be specialists in care to people living with HIV. However, because Canada obliges applicants to submit to blood testing for HIV, as coordinated in the work practices of DMPs, it is reasonable to suggest that DMPs be inclined and skilled to deliver individualized support and care for people immediately following their positive diagnosis for HIV.

Herein lies a disjuncture in the knowledge practices of DMPs and Citizenship and Immigration Canada. While this federal department has gone about researching, producing, updating, and availing DMPs with successive versions of the Handbook for Designated Medical Practitioners by which they are to carry out their immigration-related medical activities, in the material circumstances of their professional work practices, DMPs report not using this resource. Instead, doctors mobilize their working knowledge and “common sense” when an applicant is found to be living with HIV (DMP informant).

The production of a Handbook for Designated Medical Practitioners provides the basis for which Citizenship and Immigration Canada can reference its “standards” governing

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82 Herein lie other clues about the social organization of DMP work. For one thing, in their interactions with immigrant applicants during the immigration medical examination, DMP work is more about administration and processing than it is about practicing medicine.
the conduct of the immigration medical examination and the work of DMPs (CIC, 2010b, p. 6). The public availability of this document on the department’s website provides the opportunity for Citizenship and Immigration Canada to promote and reproduce the idea that Canadian state agents are carrying out certain work practices and maintaining “standards”; namely, those relating to care and counselling of people who test HIV through the state’s mandatory screening program (http://www.cic.gc.ca/english/pdf/pub/dmp-handbook.pdf). The appendices in the Handbook make explicit the features of counselling and public health education messages that DMPs are to deliver to HIV-positive persons (Minister of Public Works and Government Services Canada, 2009). These, along with the template for the “Acknowledgement of HIV Post-test Counselling” form, serve to reinforce the notion that DMPs are both informed about counselling conventions and that they put these into practice in their interactions with immigrants found to be HIV-positive. However, these claims are inconsistent with the material happenings of the immigration medical examination as reported by standpoint informants.

In a spring 2010 presentation by Citizenship and Immigration Canada to the Association québécoise des avocats et avocates en droit de l’immigration (Québec Immigration Lawyer’s Association), “providing appropriate counselling” appears as one of the five “duties” of DMPs (CIC, 2010b, p. 6). The presentation slides list the state’s specific care and treatment to immigrants who test HIV-positive. Through these texts, the reader (or viewer) is led to understand that the practices listed are achieved in the material work practices of DMPs. Listed as among the DMPs professional “responsibilities related to standards”, from the Handbook for Designated Medical Practitioners (Minister of Public Works and Government Services Canada, 2009) we learn,

The DMP is charged with “providing appropriate counselling to clients who undergo HIV testing” (p. 3-2).

These government textual work tools contribute to the image that the federal state works to cultivate of itself: a protective and “caring country” that receives people with disabilities and refugees, for example, as per the “greatest country in the world[s]” “humanitarian tradition” that rewards “legitimate” refugee people in need of protection. The Minister of Citizenship and Immigration Canada said,

It is important to note that while Canada is maintaining its humanitarian tradition of providing a safe haven for legitimate refugees, we will not stand by while our immigration system is being abused . . . (Jason Kenney, February 13, 2011, press release; CIC, 2011a).

In response to the ruling of medical inadmissibility of an applicant for permanent residency living with Asperger’s Syndrome, a member of the Canadian general public wrote,
Canada is a caring country and can absorb the cost of Chris's needs. If people with Asperger's were heading to Canada in droves that would have to be considered. Canada will get humanitarian requests from time to time because we are the greatest country in the world. Show some class even through these tough economical times and extend a helping hand. That is what Canada does best as a world leader (Clydeascope, June 14, 2011, on-line comment to P. Keung, 2011).

As I explained in chapter five, during the lead up to the policy’s introduction in 2002, the Minister and Citizenship and Immigration Canada stated that a component of the immigrant HIV testing program would be counselling service for people who tested HIV-positive. I interviewed extra-local informants who work closely with immigrants with HIV. They talked at length about this particular point or “service gap”, as one social worker called the absence of post-test care to people diagnosed with HIV at the moment they are apprised of their status. I also interviewed an immigration lawyer with a clientele of immigrant and refugees living with HIV who told me that he was prompted to write to the Health Management Branch of Citizenship and Immigration Canada after clients, over a period of a number of years, talked to him about the (difficult) circumstances of their immigration medical examination. One of his clients, a refugee applicant, said,

My diagnosis by the DMP was very impersonal. You are given only the name of the clinic. They give all the responsibility to the clinic.

In the letter that this lawyer wrote to the Citizenship and Immigration Canada in date of April 2009 he requested information about what sort of care was expectedly delivered to applicants diagnosed with HIV. He queried and sought clarification for who was responsible for providing this care to people. The following is an excerpt from the government response to the lawyer’s inquiry,

Based on these provisions [on post-test counselling, as per the Handbook for Designated Medical Practitioners from 2003], it is clearly the DMPs duty to provide HIV post-test counselling to all HIV positive applicants and to sign the Post-Test Counselling form . . . the form should be signed by the DMP . . . We will also create a reminder to all DMPs on our website on this subject.

The DMPs I talked with understand that the government puts a lot of emphasis on counselling as form of care, as per Figures 14 (CIC, 2011b, p. 8) and Figure 15 (on file with author). Practically speaking, however, we see that the interpersonal dimensions of care, such as individualized counselling — practices that are explicitly written into the instructions for how DMPs are to do their work with immigrants they diagnose as living with HIV — are actually commonly shifted to specialist doctors and perhaps other persons working within the Canadian AIDS organizational milieu confirmed in the government issued form called a ‘furtherance’ that appears as Figure 15. The
significance of this for the person with HIV is considerable. Where the responsibility for
counselling is transferred to the specialist doctor or facility, in real time, this means that
counselling does not happen when there is acute need at diagnosis.

**Figure 14. Post HIV test counselling in state’s educational materials**

As noted in chapter four, DMPs I interviewed most commonly use the fax for document transmission. While a DMP with whom I talked mentioned that the state recently issued email addresses to DMPs, he also emphasized the infrequency with which he uses the Internet. The Internet is not generally among the work tools of the physicians I interviewed. Seen in this way, the practical effectiveness of posting a message as a “reminder to all DMPs on our website on this subject” is highly questionable.

*“I hope that I am not a financial burden to the economy of Canada”*

After seeing the DMP in the capital city, Anna boarded a train and returned home. She knew that she had to be patient and wait for the Canadian government to be in touch by telephone or letter with her about the success, or failure, of her application. Anna explained that she had done everything that was asked of her; everything that was within her control.

During this time of wait, Anna worked to conceal both her health condition and the evolution of her immigration application from friends. Over the years since the beginning of her application, Anna had advised fellow students who were similarly educated to apply to immigrate to Canada. Many had.
The applicant has brought this form to the HIV physician. The applicant would have received this document in the mail with instructions to bring it to the GMP and NOT open it. He would have done so.

The GMP would already have provided the two HIV test results. So, CIC is not looking for test results.

And, since counselling is underlined, emphasized, I take it that this work is the work that CIC wants done and confirmation for. This process reveals, textually, that counselling was likely not given to the applicant. What is certain is that the government does not have in its possession, and wants to get, a signature from the doctor attesting to counselling that he will have given to the applicant.

This I see as “how” the government can say that it has proof of counselling: it sends a furtherance to the HIV physician, he provides a declaration (which is not the same thing as the applicant, himself, giving his signature).

***The policy is that CD4 count must be above 500 and VL below 50,000. It seems to me that asking for both is evidence of the double filter that precision test avant PPHI to. I talk about this point in Ch 2 and in Ch 8.

**This is very key part of the form . . .

Law, risky behaviour, sexual practice, contamination, he is “fully aware” of how to stay out of jail. He “understands” how to avoid “high risk situations”. He is “knowledgeable” about PEP technology now used in prevention of transmission.

Messages all public health rather than individual.

It does not say by whom he was counselled.
Anna had been advisor to numerous people since she was the veteran where this sort of work was concerned.

The difference between them and me is that I know they were not HIV-positive because they did not go through certain stages that I did. I could not tell them why I was really going to the capital city so often; for blood works, and going here and there, for example. It is one of those things I had to hide from them. It was my little dirty secret.

Meanwhile, Anna busily continued her on-line researching. Anna had engaged in much thinking work around the structuring of immigration policy and health care service in Canada. She had questioned and tried to make sense of the organization related to who is accepted and who is denied because of their health. It was during this phase of searching that Anna learned that if she were to be admitted to Canada as person living with HIV, she would cost the Canadian government a lot of money.

I was scared and apprehensive. I knew from reading documents on-line that the government speaks in economic terms. I kept thinking, ‘I hope that I am not a financial burden to the economy of Canada’.

Anna paused before continuing, quite pensively,

When I came here [Canada], I came with the feeling in me that I should not go on disability because I do not want to be a burden to the government. Health care represents huge sums of money. The government wants skilled workers, people who can come in and contribute to the economy. The fear I have is that should I go on [antiretroviral] medication, I want my employer to pay for it, not the government. This is so that I am not considered a burden.

In this statement, Anna reflected on numerous points. Among these was her understanding of the organization of the Canadian economy. She considered her eventual place within the job market and her possible participation in social services. A striking finding in this study is the character and frequency with which standpoint informants come to understand, describe, and judge themselves against economic criteria.

From the early days of their arrival in Canada, and, in Anna’s case, prior to her arrival in the country, standpoint informants begin getting exposure to, learning about, and immersing themselves in assumptions and ideas bound up in Canadian legislation, regulation and policy texts. For example, Anna said she quickly learned, from on-line reading of the state’s HIV testing policy and immigration legislation, that the Canadian “government speaks in economic terms”. As discussed in chapter six, within the language of these documents is a very strong preoccupation for the costs of medical care for prospective immigrants; and pharmaceutical treatment costs for people living
with HIV. This is an example of an interface between Canadian legal environment and the country’s economy, which I am calling a legal cost discourse. This discourse shapes standpoint informants’ immigration application work in discernable ways. Standpoint informants repeatedly use terms such as ‘costly’ and ‘burdensome’ in reference to themselves and what they anticipate they could impose in terms of expense to the Canadian purse. For example, standpoint informants were generally able to quite easily summarize the significance of the sections of IRPA and the Regulations that are of particular salience to immigrants living with HIV. One man said,

My understanding from first meeting [with the lawyer] was that HIV could block immigration. We had to prove that I was not going to be a burden on the system. This was stressed from the very beginning. [Lawyer’s name] was very interested in knowing the details of [husband’s name] HIV infection.

Through their immigration application work, standpoint informants become acquainted with this terminology in one of two ways: either through the AIDS organizational milieu in Canada, including from lawyers working to process their applications, or through key texts that are directed to them or written about them. “I did not know before talking to [lawyer’s name] that we were undesirable because of our costs to the Canadian government. He taught us that,” said Eskinder, a refugee applicant.

I: With HIV you can be medically unfit to be in this country.

L: What does this mean?

I: Well, I could have HIV and be unfit to be in Canada because I will be a burden on the government. Because the government would have to spend a certain amount on me. For example, if I had AIDS, I would be a burden on the treasury because they would have to spend a lot on medications. Maybe this is why they are looking at everyone, doing the screening on everybody to see who is sick and who is not. If they do not do it, they cannot tell who is who. They are trying to keep expenses low by keeping out some people with the mandatory testing. They are trying to save some dollars. That is what I understand and get about what is happening.

L: How do you know this?

I: I have been to workshops. I read about it. I have heard about it. I have been to many forums. I got a certificate for immigration and HIV. I have been with [names two AIDS service organizations]. I have spoken to PHA [people living with HIV] and people who are involved in HIV and AIDS.

Informants appropriate certain sets of words and a vocabulary that are generated by and borrowed from IRPA, the Regulations (SOR/2002-227), and the HIV testing policy.
One way in which standpoint informants do this is to speak about themselves in economic terms as economic objects. Standpoint informants easily spoke of themselves as members of a community of people living with HIV who, collectively, imposes considerable expenses and ‘burdens’ on the Canadian government. From the earliest times prior to or after immigration to Canada, applicants are gearing up and preparing to participate in particular ways in their new society. Through this process, standpoint informants integrate the conceptual frame of a legal cost discourse into their understandings and critiques of themselves. The immigration work engaged in by one standpoint informant illustrates this point.

In a lecture to university students, a standpoint informant and I co-presented on the topic of immigration and HIV. I started by giving students background on the Canadian legal and policy environment for immigrants and refugees living with HIV. Speaking from the front of the auditorium for the second hour of our presentation, Raymond, an American citizen, provided a testimonial of his personal experiences as a gay man living with HIV who immigrated to Canada from the United States in 2004. The features of his story and manner of storytelling captivated the students.

As Raymond talked, familiar features of his experiences emerged (our interview in Raymond’s home some months before had spanned more than two hours). Raymond was married to a Canadian citizen. He explained that their “same-sex family class” application took approximately two years to process. Raymond had worked on the application full-time for months; collecting and collating what would become a more than two hundred-page submission to Citizenship and Immigration Canada. The dossier included written and visual artefacts that documented some of the most personal details of their relationship. “Large portions of our emails were blackened. You know what lovers communicate about,” joked Raymond. The lawyer had encouraged them to include such private details despite the missing tracts.

I listened attentively to how Raymond talked about the immigration application work in which he and his husband had engaged. Raymond’s testimonial was shaped by and told from within a legal cost discourse. He spoke of becoming aware, once in Canada, that because of his HIV, he was understood to place a ‘burden’ on the economy of the country; despite that as a family class applicant, he was exempt from state scrutiny for hypothetical costs related to his treatment and care. Raymond told the students that he learned this language from conversations with their lawyer. His declaration revealed his awareness of cost implications of a chronic condition requiring daily doses of medication. Raymond humorously referred to himself as the “Gay Moses” because he had been living with HIV for more than twenty years. He revealed that his medication costs are approximately $1,200 per month.

Consistent with what many standpoint informants do when talking about their medication expenses, Raymond rapidly outlined how he arranges things so that he is not financially cumbersome to the Canadian state. These costs, he told the auditorium of
students, are covered through the private health insurance of his spouse, both of whom live with HIV. Raymond worked to debunk the mythology of HIV health tourism as motivator for immigrating to Canada.\textsuperscript{83} He told us that the choice of settling in Canada was related to the United States prohibition on immigration by people living with HIV. While he and his spouse would have preferred to settle in the United States, they took steps to initiate a family class immigration application to Canada because they had no other choice.

"These things are a little bit complicated"
When Anna said, “When I came here [Canada], I came with the feeling in me that I should not go on disability”, she called attention to the category of disability in reference to HIV. Another finding from this study is that standpoint informants work to manage contradictory narratives that are in circulation about HIV in Canada. These informants come to learn that in Canada, HIV is associated with words such as manageable, chronic and episodic disability.\textsuperscript{84} They are told by social workers not to worry, that things will be alright; that there are many Canadian and immigrant people living with the same condition; that they should seek social support at AIDS service organizations. A woman refugee applicant said,

Je me suis orientée dans une clinique spécialisée en VIH/sida. Le médecin m’a référé à son collègue, une travailleuse sociale. Elle m’a calmé. Elle m’a dit, ‘tu vas suivre les traitements. Il n’y a rien de grave. Il y a beaucoup de gens qui viennent ici. Vas voir les organismes pour de l’aide. Vas voir tes amies femmes là-bas. Vous allez jaser ensemble.’ À partir de là, j’ai été cherché des services sociaux dans plusieurs organismes communautaires.

It could be that informant’s ideological capture about what it means to live with HIV in Canada is that the condition has evolved into one that is at par with other illnesses. In the material circumstances of their daily lives, however, HIV introduces situations for standpoint informants that underscore, time and again, that the condition is, in fact, not equal to others in social practice or imagination.

In Canada, HIV is classified as an episodic disability. This classification comes as a surprise to standpoint informants. Many dislike it. Still others wrestle with and push back against it. Of her discovery of this labelling of her HIV, a woman refugee applicant said,

\begin{footnotes}
\item[83] For an investigation of the issue of immigration to the United Kingdom by people living with HIV ostensibly motivated by availability of antiretroviral medicines, see National AIDS Trust, 2008.
\item[84] For details about the classification of HIV and AIDS as a disability and related issues, see the Canadian Working Group on HIV and Rehabilitation at http://www.hivandrehab.ca/EN/index.php. Another relevant resource on these subjects is the Australian Federation of AIDS Organisations (2009).
\end{footnotes}
À l’aide sociale tu remplis des papiers. Tu écris si tu as un handicap. J’ai trouvé ça bizarre. Je me suis dit, ‘pourquoi je dois écrire que j’ai un handicap?’ Mais non, le VIH n’est pas un handicap! Je ne suis pas handicapée! J’ai juste le VIH! Je n’ai pas écrit VIH. J’ai posé la question à la dame de l’aide sociale. Elle m’a dit qu’il fallait que je précise mon handicap, et que si non, le formulaire était incomplet. Pourquoi est-ce qu’il a fallu que je mette mon VIH sous la catégorie d’handicap? J’ai posé la question au médecin. Il m’a dit, ‘c’est comme ça avec toutes les maladies. C’est obligatoire d’écrire ses maladies. Toutes les maladies non-guérissables sont groupées ensemble’. Même aujourd’hui, je me pose des questions parce-ce-que je ne suis pas handicapée.

Other standpoint informants struggle to make sense of the categorization of disability. A refugee applicant named André said, “There are government programmes to which I can apply for financial support. I have not decided if I will apply for the disability support program. The advantage is that they will pay the deductible for the antiretroviral medication that I take.” André explained that he is unsure if he will apply for this program because,

Giving your information without getting any support is difficult. You have to explain why you need the government support; putting your disability down on paper. Maybe I will share my information and they will not allow me to get benefits. These things are a little bit complicated. You have to accept you are disabled, then.

A further surprise to standpoint informants residing in Ontario is the financial support for which they are eligible because of the designation disabled. This is through the Ontario Disability Support Program. This program supplements the earnings and provides housing and other subsidies to people with disabilities who work or study. Under this program, and at the time I interviewed standpoint informants, they talked about being eligible to apply to receive a ‘special allowance’ for dietary needs. Standpoint informants understand this allowance to be for the purchase of high quality foods, vitamins or minerals, or other supplements that people living with HIV are advised to consume to fortify their immune system. Generally, these informants learn of the Ontario Disability Support Program through AIDS service organizations. From my field notes and a conversation with Stefanos, a standpoint informant in Ontario, I wrote,

L: He shows me an Ontario Disability Support Program cheque and forms. There are two forms: one income statement, and one special needs. These are sent to him every month along with the cheque. We look at these together.

85 While there may be an equivalent or similar program in Québec, no standpoint informants resident in this province talked of experiences with or benefits resulting from this sort of social programming.
Stefanos explained what he does with these government forms,

I: Firstly, special needs. They give you a form for people with special needs; people who are taking medication, people who have special needs in terms of diet. You can apply for this and it has to be approved for special diet. Some people can get $100.00 for a pet under this program. Canada is very generous. Some parts are filled out by the doctor. They send you a lot of forms. It took me about two months to understand this application form.

In some cases, an Ontario Disability Support Program employee schedules a certain day in the working week where she or he will work from within an AIDS service organization. On appointment, people living with HIV can work with this employee in initiating the processing of their Ontario Disability Support Program file. In the end, most standpoint informants in Ontario resign to accepting the label of ‘disabled’ because it is attached to financial benefit. When asked how it felt to wear a new-found label such as disabled in exchange for state support, standpoint informants from Ontario said that ultimately, while they were puzzled by such labelling, they appreciated the support.

Anyone who has HIV is disabled. We are categorized as disabled. You are on a long-term disability. There is no cure. Who cares about the title? It is just a title. They have to give you that title to give you long-term disability. In what way do you think that I am disabled? Do I look handicapped? You are giving me all the benefits because you want to call me disabled. Under disability they have taken away a lot of things.

Thus in spite of their desire and commitment to work, to be ‘productive’, and to avoid being financially supported by the state, standpoint informants are drawn into a set of institutional relations that are organized to conceive of them as disabled bodies and to subsidize them for this reason.

A disjuncture between the discursive and material conditions of standpoint informants’ lives is the contradiction between understandings that they come to assimilate of the ‘good immigrant’ — a person who is healthy and economically ‘productive’ — and what they know to be their embodied situation: they live with an incurable disease that necessitates their likely eventual participation in the costly pharmaceutical industry. People living with HIV are not, according to discursive medical understandings, healthy, even if their infection has not advanced to AIDS, or their virus is suppressed through medication. This diagnosis rubs up in uncomfortable ways with how standpoint informants see themselves as linked to their emergent understandings of what constitutes a ‘good’ citizen and ‘productive’ Canadian immigrant.

My HIV doctor and lawyer explained to me about filters. The [HIV] testing policy is a filter, because they cannot accept everybody. But if you are a productive person, and you will give a lot to the country, I feel they should accept you.
According to the legal cost discourse, a person who is fit and able to fully participate in the paid labour force in ways that will generate tax revenue for the state is a ‘productive’ and successful immigrant. Standpoint informant’s position in relation to the dominant discourse will in this way always remain tenuous and fraught with tension.

“I hold this paper in high moral value”
The conversation with Anna returned to the topic of the “Acknowledgement of HIV Post-test Counselling” form. She spoke as earnestly about the meaning of putting her signature to this form as she just had in relation to her firm intent to not be a financial onus on the Canadian health care system.

When the immigration doctor made me sign that form, this reinforced that it is not only a moral, but also a legal engagement. I hold this paper in high moral value; that my partner knows my HIV status; that I will not go around not using protection.

Anna added,

As much as there are people with different views on criminalization, I go with that document I signed. I know that I am morally and legally bound by it. If someone in Canada takes me to court, I will have signed a document on which I admitted and acknowledged that I am HIV-positive. This document is somewhere in my file.

There are several institutional relations shaping Anna’s talk and her understandings of the form to which she attributes “high moral value”. Her references to the work of the Canadian government indicate that she linked public health messages appearing on this form to the Canadian legal system, criminal courts, and surveillance work of her that she presumes takes place. Anna understood that if the points on the form were not respected, there could be serious consequences for her. She realizes that her health is not benignly or only about health or her own health. Messages on this form make implicit connections between her, her health condition, public health tracking systems, and the criminalization of people living with HIV in the Canadian legal system.

Information on this “Acknowledgement of HIV Post-test Counselling” form foreshadows for the immigrant and refugee person living with HIV the institutional relations within which she or he will come to engage in Canada. Its targeted messages are shaped by IRPA through the references to government concern about public health and safety. Anna speaks about the document’s moral and legal “value” through which she commits to using “protection” during sex; protecting others from herself. In this way, Anna’s immigration application work becomes caught up with and tied to the work and public health priorities of the state and possibly its enforcement activities. We increasingly witness that failure to notify partners of HIV-positive status leads to criminal convictions for people living with HIV in Canada (Mykhalovskiy, Betteridge & McLay, 2010;
Mykhalovskiy, 2011; Symington, 2010). Standpoint informants were generally aware that persons living with HIV, and first generation heterosexual male immigrants of colour in particular, are disproportionately brought up on charges related to non-disclosure of their HIV status (Mykhalovskiy, Betteridge & McLay, 2010). Anna’s immigration application work, and her developing understandings of her civic duties in a society that is new to her, are thus bound up with the state’s law enforcement work.

“They know I am kind of a health hazard”
It was on an August morning that Anna received a call from the Canadian embassy. She was in her room with friends. A state agent she was not familiar with was calling with some good news: she had been accepted for immigration to Canada as a skilled worker.

That was the best day of my life. They knew before that I was HIV-positive. They accepted that [Informant emphasis].

Some weeks later, Anna later received a letter by mail. This letter made her acceptance official. The letter stated that Canada was happy to welcome her.

I really had to hide it very well because it stated that HIV was detected through my immigration process. It advised that immediately after I arrived in Canada, I must see a doctor. That surprised me.

In the same package Anna told me that there was a page on which there was a list of DMPs. There was also a listing of organizations for people living with HIV in each province. “There is that very, very strong suggestion and they put it there: immediately when you get into Canada, one of your priorities should be to present yourself for medical follow-up.”

That was very helpful. I was happy I got it, and I kept it very well. But, when I moved here, you have to stay within the African community. So, I tore up quickly and threw it away [since this document exposed her HIV status] because I knew that I would go onto the Internet to address HIV issues. That letter made me feel valued. ‘Not only have they have accepted that I immigrate, they were thinking what next; giving me resources.’

Anna remembered thinking that since the government knew that she was HIV-positive, she thought that perhaps it was “keeping an eye on” her.

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86 For topical and recent blog postings on the matter of criminal convictions of people living with HIV in Canada, see Positive Lite (2011a, 2011b). See also http://criminalhivtransmission.blogspot.com/. For a summary of the current state of law in Canada with regards to criminal law and HIV (non)-disclosure see the Canadian HIV/AIDS Legal Network (2011b).
probably they are watching out to see what I am going to do or do not do. They put all the facts in the letter; legal facts; about no blood donor; must use prevention; notify partners, etc. If I make a mistake, they will still send me back. They know I am kind of a health hazard.

Anna went on to say that new friends in Canada tell her that the government cannot send her back because of her HIV status. “You have rights, now, they tell me.” However, she said,

I am new to this society, so I do not know the rules yet. I believe that there are those rights, but I lived in a country for ten years where I knew you get deported if you are HIV-positive. I am happy that I am here. But, I think of all the immigrants who go through the process to the end, just like me — who are intelligent, with good experience, wanting to immigrate — but who would get blocked because of a low CD4 count and a high viral load. This troubles me.

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Chapter 8: Discussion, conclusions and recommendations

In this ethnography I have called attention to and argued that ideological practices associated with Canada’s policy and practice of mandatory HIV screening of immigrant applicants have some negative effects, and lead to tensions and contradictions, for standpoint informants. Although my interest was examining standpoint informants’ experiences, my research also found serious contradictions for DMPs. Mandatory testing gives rise to problems and contradictions for applicants for Canadian permanent residence who are living with HIV. The diagnosis with HIV at immigration organizes standpoint informants to come into the state’s view in particular ways whereby they experience specific forms of social control enacted around HIV. The day-to-day, empirical work practices of state agents enable the ideological work of the Canadian state. I point out how the conduct of the immigration medical examination serves state rather than standpoint informant interests. Moreover, the exam organizes suspect medical practices that are at odds with the stated aims and values of the medical profession.

The full range of experiences that HIV-positive immigrants undergo within the mandatory HIV immigration testing is neither fully nor accurately portrayed in the official reports published several years after the policy was introduced (Zencovich et al., 2006; Gushulak & Williams, 2004). This difference in knowledge claims was the opportunity and catalyst for inquiry into the examination of what was actually happening for standpoint informants through immigration testing. The official published reports elided people’s knowledge with the functioning of the policy and some of its associated practices. The material conditions of standpoint informant’s everyday lives in relation to immigration testing as they endeavour to relocate to Canada on a permanent basis were opened up in this investigation. I analyzed and critiqued what I uncovered to be happening to standpoint informants in ways that were problematic and troubling for them.

This empirically informed inquiry described standpoint informants’ immigration application work process as consisting of a myriad of practices, activities, and events occurring over time and place. Using empirical evidence, I provided an important corrective to the above-noted official accounts of what happens during and as a result of HIV testing in the immigration medical examination. A more complete and just portrait of what happens in the lives of those who test HIV-positive through a state process about which they have no choice and little control is produced. The textual basis of standpoint informant work is an application composed of a number of state documents, and the medical file that is prepared by the DMP is among the most important set of documents prepared about the standpoint informant. It is through these texts that government agents who do the work of processing permanent residence applications come to know the applicant; deciding her or his immigration fate: as disease, infection, transmission and sexuality, and immigration status categories, respectively.
Focusing on the doctoring work that people do everyday provided the empirical basis for opening and examining where people do their work, what sorts of activities they are drawn into, and how they interact within the complexes of Canadian immigration and medical regimes. I inquired into standpoint informants’ experiences within these complexes from their specific social location as immigrant and refugee people living with HIV. Applicant, physician, and federal government employee work practices associated with this HIV testing came into view for critical consideration. I showed that what standpoint informants can do and say is limited by how these interactions are socially organized.

I point out that there are numerous discursively and institutionally organized fields that circulate around standpoint informants. As newcomers to Canadian society, standpoint informants are exposed to, and are quickly initiated into, these fields. Through my research process for this study, I developed the metaphor of a railroad track to think of standpoint informant’s immigration application work process. The rail line, as the immigration work process, is laid out without end in view. Ties intersect the track, which are the various institutional fields with which standpoint informants come into contact: the Canadian AIDS organizational milieu, IRPA, the law, pharmaceutical industry, and medical and legal regimes are some of the strongest organizers of standpoint informants’ experiences. My analytic work (and challenge) in this research was to uncover details and explicate how this railway system is put together to function from the starting point of the discursively organized and material happenings of standpoint informants’ everyday lives.

**Thoughts on study findings**

My critical inquiry in the interests of Canadian permanent residence applicants living with HIV illuminated assumptions that are embedded within the in/admissibility work of the state and its agents, as well as the Canadian AIDS organizational milieu, IRPA, pharmaceutical industry, and medical regimes. I made visible the ways in which these fields organize the experience and activities of standpoint informants. I emphasize that the health conditions in question in this research are HIV and AIDS, and it is *this specific set of illnesses and none other* that is organized in particular ways within the Canadian immigration medical program. Tuberculosis and syphilis are the two other conditions for which applicants to Canada are mandatorily screened. People can ‘pass’ or ‘clear’ these conditions, however, and if they do, neither tuberculosis nor syphilis can preclude a person’s successful immigration to Canada. The historical record in Canada as it relates to the enactment of the mandatory immigration HIV testing policy testifies to the exceptional and uneasy place that HIV and AIDS occupy. While there are incurable and chronic medical conditions that are costly to treat in the long run like HIV and AIDS, the Canadian state does not mandate the testing of prospective immigrants for these conditions (for which, as with diabetes, there is higher global incidence than HIV/AIDS).

There is an extensive state work apparatus organized around HIV and immigrant people the state discovers to be living with HIV. For example, the state has organized health
condition-specific work practices and systems of surveillance, tracking, and recording of immigrants with HIV. Special directives, instructions, review panels, and policies are the basis of the state’s treatment of HIV and immigrants with HIV. There are more of these practices relating to HIV and people living with HIV than there are for any other medical condition that can be diagnosed through screening protocols and technology. These institutional arrangements confirm that HIV infection and AIDS illnesses occupy unique social locations in the state’s ideological work practices; HIV and AIDS present a particular form of contagion, where particular forms of state engagement are mobilized around the conditions. Diagnosis with HIV at immigration adds a layer of complexity to standpoint informants’ immigration application work. Their status brings standpoint informants into contact with forms of scrutiny and institutional complexes that their HIV-negative counterparts who apply for Canadian permanent residence do not experience, and that their Canadian citizen and permanent resident counterparts would not lawfully experience.

Canada’s immigration framework, the Immigration and Refugee Protection Act, is organized around notions of the country’s economy, and the health and safety of its citizens and permanent residents. It is a text that exists because of and in relation to the regulation of the foreign person, where the foreigner is conceived of differently and apart from Canadian citizens and permanent residents. The text instructs government agents to do medical and health work on non-citizens in specific ways and through particular practices. Agents work mindful of the government’s priorities with keeping health care costs to a minimum and protecting the health and safety of Canadians. On the face of things, there is a logic to cost containment that is understandable. However, there are assumptions built into IRPA and its derivative texts on HIV, immigration, and the prospective immigrant that are troubling and contradictory for people.

At once an ideological, political and instructional tool, IRPA positions the state as a humanitarian and benevolent body politic. Since 2001, there are people who cannot be denied Canadian permanent residence because of estimated costs of treating and caring for their medical condition. These exemptions are heralded as examples of Canada’s humanitarian commitment. Included in this group shielded from the possibility of medical inadmissibility because of ‘excessive demand’ are refugee and family class applicants. However, for standpoint informants within these classes, there is a contradiction within this exemption against ‘excessive demand’. The tension is that from the material conditions of their everyday lives, state exemptions do not outweigh that family and refugee class applicants are persistently concerned that their HIV diagnosis can be used against them: fettering, complicating, or altogether preventing their successful permanent settlement in Canada.

Through its ideological work associated with the immigration medical examination, the Canadian state projects the appearance that certain practices are happening, such as care and counselling for prospective immigration diagnosed with HIV. However, empirical evidence confirms the contrary. In producing manuals and standards of
practice for DMPs, such as the *Handbook for Designated Medical Practitioners* (Minister of Public Works and Government Services Canada, 1992, 2003, 2009), the state is able to maintain the position that it comes into line with standards of ethical care and good medical practice for people diagnosed with HIV. Citizenship and Immigration Canada’s educational and promotional work that informs various audiences about the testing policy and medical in/admissibility determination process also project the appearance that certain care, professional and administrative standards are actually being respected in the work practices of DMPs.

Organizing the immigration application work of standpoint informants is the strong desire that people have to successfully, and permanently, settle in Canada. As such, they, too, come under the ideological concepts within IRPA and other discourses that circulate around them and in which they take part. This ideological capture that standpoint informants experience is part of what is accomplished in the state’s ideological work. Standpoint informants are not often directly or obviously critical of the Canadian government or the practice of mandatory HIV screening; despite that they are singled out for a form of medical screening that would be unlawful to impose on Canadians or Canadian permanent residents. In the approximately sixty-five hours of recorded conversations I had with standpoint informants, I remarked that people tended to follow up even the remotest critique of the Canadian government with statements of praise. They spoke of Canada’s clemency and humanitarianism. People talked about their appreciation for access to medicines without which they knew they would die.

Standpoint informants express thanks for special services that exist especially for people living with HIV. In particular, people spoke about health, legal, financial, and social support systems. Informants nevertheless experience tensions and contradictions that are traceable to the HIV testing policy and the specific forms of state treatment of HIV. With their infection forcibly exposed by the Canadian state, what choices do most people face if they are not accepted for Canadian permanent residence? Many standpoint informants who participated in this research were citizens of so-called developing societies. Their experience with HIV is markedly different than the (recent) experiences with HIV and AIDS of many resident Canadians living with HIV. Standpoint informants bring to Canada their understandings and personal experiences with the social and legal responses to people living with HIV, including knowledge of how evenly (and unevenly) the pharmaceutical industry, organized with national and foreign governments, service (or not) their home countries with antiretroviral medication. This form of knowledge is not something that standpoint informants do or can leave at the Canadian border when they enter Canada.

In this research, the HIV test was found to embody ruling relations within the state’s immigration medical framework of things that ‘just must be done’ to immigrant applicants. I demonstrated how, from within standpoint informant experience, and drawing on critical social theory, that the HIV, CD4 count and viral load tests are much
more than simply or benignly medical diagnostic tools. These medical technologies project and achieve a course of action that single out standpoint informants because of their health status. The immigration HIV test opens the way for state actions to be taken on standpoint informants, which in turn enlists various forms of social control over them.

I showed how Canada’s immigration HIV testing functions as a rhetorical device in the ideological work that Canadian government employees carry out. The imposition of HIV screening is a savvy political choice through which government can be seen to be acting on immigrants with concern for cost, health and safety; within the broader interest of the health of Canadians: the HIV testing technology exists, it is easy to administer, and it is acceptable to the public when framed as a necessary strategy to safeguard cost, health and safety. I pointed out that in their work leading up to the introduction of the testing policy in 2002, Canadian policy makers within Citizenship and Immigration Canada and Health Canada did not consider not introducing mandatory HIV testing into future immigration medical examinations.

The ways in which the HIV testing policy organize immigrant applicants living with HIV, state agents employed by Citizenship and Immigration Canada, and a range of other persons with whom standpoint informants interact during their immigration application work have previously gone unexamined. For nearly ten years since the introduction of the HIV testing policy, the knowledge and experiences with the practices organized by the policy were known only in part (Committee for Accessible AIDS Treatment, 2006; Réseau des chercheures africaines, ca. 2005). Since 2002, the Canadian HIV/AIDS Legal Network has examined and challenged the HIV testing policy and associated practices through public commentary. Lawyers have worked to challenge IRPA’s ‘excessive demand’ criterion’s application in various cases (Battista, 2010). Recent health economics research has called into question how the ‘excessive demand’ criterion and supporting algorithms are defined, interpreted, calculated, and applied (Coyte & Thavorn, 2010). Through the state’s current, ongoing review of the HIV testing policy, people’s embodied, working experiences with immigration medical testing are not visible. A policy review that is properly and thoughtfully done should include these and look at the features of the social organization of how things work.

For the permanent residence applicant living with HIV, she or he is conceived as ostensibly threatening to all three of IRPA’s conceptual organizers (cost, health, safety). Expensive ailment. Invisible contagion. Foreign. The applicant who is diagnosed with a communicable disease leads the state to inquire about and report on features of the individual’s social life, including sexual orientation, behaviour, and lifestyle. HIV infection remains incurable, which means that standpoint informants likely will, at some point in their lives, need to take antiretroviral medication. While the state’s official position is that post 1991, people living with HIV are not dangers to public health because of their HIV infection, this position is called into question when the work practices of and tools used by state agents are examined. There is no other medical
condition that commands the state’s attention in the way that HIV does. In this way, the applicant with HIV is not only significantly disadvantaged, she or he will always occupy the social space on the other side of George Smith’s (1990) metaphorical “line of fault” (p. 631).

All of this enters into how ‘HIV/AIDS’ in its ideological form creeps into state thinking and doubles back to infiltrate government decision-making processes about immigrants living with HIV. Numbers and data, medical files, blood and cellular test results, DMP reports, and matrices derived from drug costs inform and organize the work practices of Canadian government employees. I have pointed out that mandatory HIV testing, DMP reporting, medical officer assessment, and immigration or visa officer decisions are ongoing work practices done in Canadian state offices around the world. In following the textual trails that are provided in the wake of these practices, we see how these activities are connected as sequences in a work process intending the detection of diagnosable conditions to render Canadian permanent residence applicants inadmissible. People with certain conditions come under closer bodily inspection, and prospective immigrants living with HIV are among these people. The effects of the state’s work processes are generalizable across many sites, and the ruling relations of these processes have generalizing effects. In this analysis, I explicating how ideological practices are part of the social relations of ruling in the Canadian immigration medical program, and I showed how these organized the work of standpoint informants and state agents.

**And the significance of this for standpoint informants?**

A major difficulty for standpoint informants in their immigration application work process is the absence of HIV counselling at the time their HIV infection is diagnosed by DMPs. The absence of post HIV test care and treatment was generalized in DMP work practices in Canada and outside. This issue propelled me to turn close, critical attention to the immigration medical examination; what happens there; how people experience this; how doctors are organized to work as they do; and, what instructions govern the workday of the latter. This study revealed that there is a convergence of numerous ruling relations that stand above standpoint informants in their work to immigrate to Canada. This subset of applicants to Canada is marched around in ways that set them apart from other prospective immigrants who are not HIV-positive. The obstacles that standpoint informants face through the immigration process would be surprising (if not untenable), for most native-born Canadians.

Findings from this research stretch beyond descriptions of the absence of post-test counselling in the Canadian immigration medical examination. HIV test counselling practices are organized not to happen in the work practices of the DMP. While the state is ideologically committed to HIV counselling, and actively promotes through its education work that this form of care occurs for people who test HIV-positive, counselling generally does not occur. What is more, ethical standards of patient care are not being observed in the work of DMPs. In examining how DMP work is organized, the
ruling relations organizing the immigration medical examination are identified to be in the interest of the state and against the best interest of immigrant applicants.

The results of this study explicate how counselling as a form of care is not organized to occur during the immigration medical examination. Powerfully, understanding the how has us understand what is happening organizationally so that we can focus effective attention to correct the root causes of what is problematic for people. As activists, we would do well to be informed about root causes to achieve maximum benefit for people in whose interests we act. For as laudable as some forms of recent activism on behalf of migrants to Canada with HIV are, this work neglects social organization and ruling arrangements, thus missing what is at root of what goes wrong for people when they are diagnosed with HIV during Canadian immigration procedures (see Tran et al., 2010).

An example of well-intentioned activism that can only ever achieve modest benefit is the organization of accredited (i.e., College of Family Physicians of Canada and the Ontario chapter of the latter) DMP training on HIV and immigration. On May 5, 2010, members of the Committee for Accessible AIDS Treatment with allied health professionals held a session entitled “Canada’s Global HIV Epidemic: HIV Diagnostics, Care and Access Among Newcomers to Canada” for Toronto-based DMPs. The training sought to educate DMPs on how to improve care to immigrants that they diagnose with HIV infection. An extra-local informant who attended the session reported that a key area of focus was HIV test counselling. However, additional education of and information to DMPs about HIV does not respond to the organization of the immigration medical examination, which is found to give rise to problems for standpoint informants and DMPs alike. Study results show that,

- The IME is organized against the possibility of being therapeutic;
- The DMP is organized to carry out her or his work in a grey area;
- The encounter is organized against the best interests of the applicant;
- The possibility of counselling occurring is foreclosed; and,
- Corrective interventions aimed at the level of DMP miss the mark.

Educating people about the social organization and the power relations within the IME – and more broadly the immigration application process – so that they have the opportunity to consider what interests lie behind the clinical encounter is useful. Having people revise their expectations based on better understandings of the implicit politics that are bound up in the IME is most useful. The figure of the DMP is more internally contradictory than one might expect. Exploring tensions, loyalties and contradictions within the DMP role is worth further consideration.

Reporting to extra-local informants, policy makers, and the public
As for the usefulness of these findings for extra-local informants, the social organization of their work relating to the implementation, maintenance, and operation of Canada’s HIV testing policy is found to create tensions for them as well as for standpoint
informants. Detailing results to lawyers, DMPs, state agents, and other health providers from the starting point of the contradictions they experience is a good entry point to informing these extra-local informants about the ruling relations governing their work associated with Canadian immigration medical practices with the immigration application process. My experience with presenting findings from this research suggests that people are interested to think about: how their labour fits into broader organizational processes; how others’ work fits with what they do; how texts and documents coordinate practices and connect different places; and, how people are organized by and participate in discourses.

The intention of producing new knowledge that connects people’s relevancies and experience with the social and historical contexts in which they live is an important orientation of this work. It is also a political stance. I saw this as achievable by using a method whose historical raison d’être was politically engaged and concerned with getting beneath the skin of conventional explanations of social happenings. I saw that employing a method with a critical stance was necessary partly because HIV and immigration are politicized and historically electric issues about which everyone seems to have opinions. Unfortunately, HIV and AIDS are conditions that continue to be connected to understandings of contagion that generate exceptional public interest and practice. This has negative social implications for people living with HIV.

I did fieldwork and I am writing in politically conservative times in Canada. There is a climate of apprehension where domestic health and social policymaking, including immigration policy, are concerned. When I laid out the research plan for this project, it was suggested that my formal access to senior decision makers within Citizenship and Immigration Canada might be limited. As it turns out, I was overly optimistic about my ability to gain entry to these quarters: organizing access was difficult and time-consuming, and results were disappointing because of regrettable barriers.

With the Conservative Party currently forming a majority government, people within the AIDS organizational milieu in Canada are concerned about cuts to public funding for AIDS programming in 2012 and beyond. Workers in this milieu are planning for compressions and possible forced marriages between organizations. The potency of the Ministerial Council on HIV/AIDS, a group that at one time played an advisory role to the federal government related to HIV, has dwindled (or rather, disappeared). Eric Mykhalovskiy, Glenn Betteridge and David Mclay (2010) report that since 2004, “there has been a pronounced intensification of criminal cases of HIV non-

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87 Fifteen years have passed since sociologist Gary Kinsman (1997) wrote about AIDS organizing and relations with government in Nova Scotia. His findings pointed out that the province’s AIDS service organizations were co-opted by government, which meant that they were actually functioning in ways that worked against people living with HIV in Nova Scotia. His explications of how these processes were organized to happen offer useful insights into the current climate of budgetary compression for AIDS service organization work in Canada.
disclosure” (p. 8). This study shows that Black, heterosexual men who are first
generation Canadians living with HIV have been persons most regularly convicted for
non-disclosure of their HIV, regardless of whether their HIV infection was transmitted to
their partner(s) (see also Mykhalovskiy, 2011). The use of criminal law as tool against
people living with HIV is alarming, and standpoint informants are concerned about this
trend.

This project analysis pointed to specific places where forms of social action can be
initiated for effectiveness; informed by the ruling relations governing what does not
work and what is problematic for informants who participated in this study. It is my
sincere wish that results and recommendations be taken up in advocacy efforts and to
promote sound public policy change. To enable this work, I make numerous
recommendations.

**Nine evidence-informed recommendations**

Nine recommendations are explained below. Each of these calls for specific actions, with
the exception of recommendation number four because, for as long as the mandatory
HIV testing policy is in place, there is no possible change that can result from this
recommendation. In light of this, I instead list an important corrective action.

For as long as the Canada’s mandatory HIV testing policy remains in place, I make the
following four recommendations:

1. **Correct the problem that Canada’s HIV testing policy text is now ten years out
of date both medically and socially, recognizing that this has serious
consequences for immigrant applicants living with HIV.** This study has
demonstrated that when Citizenship and Immigration Canada (CIC) medical
officers work with tools that are out of date, this has serious consequences for
people living with HIV who apply for Canadian permanent residence.

2. **Insist that findings and recommendations produced in this research inform the
state’s review of the HIV testing policy within the latter’s review of the
immigration medical program** (details of which “cannot be made public at this
time”; senior medical advisor, CIC, personal communication, September 23,
2011; my translation). The experiences of immigrant applicants with HIV and the
work practices of DMPs provide valuable information and context about the
deficiencies with how the HIV testing policy and practices associated with it are
carried out. These empirical accounts are important counterweights to the
official reports of what is said to happen for immigrants with HIV in their
interaction with the mandatory policy and state authorities, as reported by
Zencovich et al. (2006) and Gushulak and Williams (2004). Immigrant and DMP
experiences with the policy reported herein correct and replace the claims about
consent, counselling, and referral practices contained in these authoritative
reports.
3. **Demand that civil society actors participate alongside CIC agents in the review exercise of the HIV testing policy, opening up details of this review for public scrutiny.** There is currently no public information about this work apart from that it has ostensibly been ongoing since 2006.

4. **Recognize the problem that in servicing immigrant applicants (living with HIV and generally) during the immigration medical examination, acceptable standards of patient care are breached and clinical reasoning is displaced, which has serious implications for immigrant applicants living with HIV.** For as long as the HIV testing policy is in place, there can be no action resulting from this recommendation.

This serious deficiency is irreconcilable because the social organization of the DMPs work and the immigration medical encounter are not for therapeutic ends. Rather, the DMP, as an agent of the state, sets out to detect existing medical conditions that could make the prospective immigrant inadmissible and ineligible for Canadian permanent residence. Standpoint informants were troubled by the absence of pre- and post-test counselling for HIV during the immigration medical examination. However, despite the ideological work practices of CIC (e.g., widespread promotion that counselling, as a form of individual care for a person diagnosed with HIV, is occurring when sometime tests HIV-positive; that the work practices of DMPs in this regard audited in a meaningful way), this research demonstrated that counselling does not occur. Furthermore, textually mediated auditing procedures are unclear. Critically, counselling does not occur because it is organized not to happen. The “Acknowledgement of HIV Post-test Counselling” is a fictitious document framed as a state accountability tool. This form, once signed by the person diagnosed with HIV, could ostensibly be used for other purposes than state accounting purposes. In fact, it is reasonable to imagine that this form, as part of a broader paper trail could, at a future point, be used against the signatory. This is highly alarming given that Canada has one of the highest incidences of using criminal law against people living with HIV in the world.

The only way that standards of patient care will cease to be breached is to remove the imperative of mandatory HIV testing. Abolishing immigration HIV testing will remove the documented problems including absence of counselling, lack of informed consent, and breaches in confidentiality. **Thus, abolishing mandatory HIV screening is the viable, equitable action recommended to correct these problems (and others) that occur in relation to immigration HIV testing.**
I make five additional recommendations, which include:

5. **Let it be known and clarify that in the organization of the Canadian immigration program, HIV is treated differently than any other medical condition, which has effects for immigrant applicants living with HIV.** This is illustrated in the regulatory procedures that are in place for the scrutiny, screening, and surveillance of HIV/AIDS and prospective immigrants living with HIV. *No other* medical condition with which an immigrant to Canada might be diagnosed is subject to the careful directions that the mandatory HIV testing policy produces in the practices of DMPs and CIC medical officers.

6. **Advocate to ensure that non-official publications and information on immigration and HIV is available via easy-to-find links posted on the CIC website.** (e.g., Canadian HIV/AIDS Legal Network, 2007c, 2011a). All standpoint informants in this study used CIC’s site at least once in their immigration application work process. They unanimously report that there is little to no useful information about immigration and HIV on this department’s site. My reviews of exchanges and postings in on-line immigration chatrooms attest to the difficulties that people all over the world experience in locating clear information about a variety of health-related (and other) topics as these apply to the process of immigrating to Canada (e.g., http://www.canadavisa.com/canada-immigration-discussion-board/hiv-positive-can-i-apply-for-permanent-residency-of-canada-t6645.0.html).

7. **Produce research that investigates the costs associated with treating and caring for a person living with HIV in comparison with other chronic and treatable (in Canada) conditions.** The last group of studies that produces estimates of such costs dates from twenty years ago, where researchers evaluated the costs of treating HIV infection with those associated with coronary heart disease (Zowall, 1990, 1992). As part of this, research industry’s mark-up on patented antiretroviral medications. Currently, there is not a good understanding of this because information about these profit margins is “part of confidential agreements” and not made public; making it hard to estimate the extent to which their costs are inflated (R. Rosenes, email communication, April 9, 2010). Most economic class applicants for Canadian permanent residence who live with HIV are denied Canadian permanent residence because the hypothetical costs associated with their antiretroviral treatment meet the IRPA criteria for ‘excessive demand’. Prohibitive cost is the key argument currently used by the state’s adjudicators in denying economic class applicants with HIV, and refusals motivated by prohibitive cost rationale are on the rise according to access to information requests done by lawyers with expertise in immigration law and HIV (extra-local informant, email communication, April 2010).
8. **Demand that CIC clarify and make public through its website:** 1) the list of medical conditions that are of concern that stand to prevent a person’s successful application for Canadian permanent residence because of ‘excessive demand’; and, 2) the criteria on which such determinations are made. Prospective immigrants, will, in this way, have a basis for understanding how their health status, as marked up in the results of their immigration medical examination, will be assessed in the work of CIC medical officers. Immigration to Canada is a costly endeavour, financially, emotionally, and temporally. Providing explicit information of this sort will inform prospective applicants about how to proceed (or not) with their immigration application.

9. **Insist that CIC post on its website all tools, criteria, measures, and algorithms that its employees currently use in their ongoing medical in/admissibility work regarding permanent residence applications made by people living with HIV (and other disabilities).** These include the specific and complete set of auditing tools for monitoring the work of DMPs, and the educational tools designed for and used in the training of DMPs.

**Several possibilities for future research**
This research has brought to light only a snapshot of what standpoint informant immigration application work consists of; much more can (and should) be said about the details and organization of people’s efforts to immigrate whilst managing discovery of HIV infection. Likewise, building on my repository of data, more can be said about extra-local informant participation in these social and ruling arrangements.

There are (at least) two projects to which the results of this study can usefully contribute. First, document the experiences with mandatory HIV testing of immigrant applicants who were not successful in gaining Canadian permanent residence. As I explained in chapter four, despite my efforts to communicate with such people, they were unfortunately not accounted for in this research. Challenging the HIV testing policy is certainly justified on several fronts, and building a knowledge base of the experiences of foreign nationals obliged to submit to an HIV test for immigration to Canada who were then refused a visa will full out understandings of the empirical consequences of the HIV testing policy.

I would additionally seek to understand the knowledge relations organizing people’s immigration work as related to health-based exclusion. To do this, I would review textual artefacts (i.e., peoples’ letters and various communications with the Canadian government, state agents, and other actors) and work practices of a range of people. In the last two years, there have been an increasing number of challenges to the state’s decision to refuse people living with HIV on the grounds of medical inadmissibility. We see evidence of this in a review of the Canadian Legal Information Institute’s public database with a keyword search with the term “HIV” (see http://canlii.ca/en/index.php). More creative and strategic thinking is required of lawyers who invest in social activism.
on behalf of their clients living with HIV who apply to Canada (extra-local informant, personal communication, June 16, 2011). Inquiring into the organization of the circumstances of this jurisprudence — peering into the thinking and planning work that legal teams on behalf of applicants living with HIV do and the work of standpoint informants in collaboration with them — would be useful for advocacy purposes.

Second, research focusing on the exceptional treatment of HIV in state policy and practice would use the Canadian Charter of Rights and Freedoms (s. 15) to challenge Canada’s HIV testing policy. The basis of this challenge, which would fit under the banner of legal reform work in favour of people living with HIV, would be the unconstitutional discrimination on which HIV, understood as a disability, is singled out under the law. Section 15 reads,

15(1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

15(2) Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability. 88

This legal reform work could mobilize data and findings produced in this study to start and remain rooted within the material circumstances of the social worlds inhabited by applicant people who live with HIV; producing a rich and original piece of ethnographically-informed legal research that could contribute both substantively and methodologically.

A caveat must be mentioned in relation to this proposed legal challenge. Section 1 of the Charter provides what is colloquially referred to as a ‘saving’ provision, which allows for limits on Charter rights if these “can be demonstrably justified in a few and democratic society” (http://laws.justice.gc.ca/eng/Charter/page-1.html). There is a jurisprudence developed to flesh out the test for government justifying such limitations to Charter rights (e.g., Supreme Court of Canada judgement, R. v. Oakes, [1986] 1 S.C.R. 013 at http://scc.lexum.org/en/1986/1986scr1-103/1986scr1-103.html).89 A challenge to the treatment of HIV and/or people living with HIV under Canadian immigration law or policy would have to contend with this test. It has been suggested to me that

89 For a summary of the main elements of this text, see pp. 36–38 of the (English-language) Canadian HIV/AIDS Legal Network report on needle exchange and syringe programs in Canadian prisons (http://www.aidslaw.ca/publications/publicationsdocEN.php?ref=948).
succeeding with such a case would be very challenging (extra-local informant, email communication, November 25, 2011).

**Reflections on the method of inquiry**
I am mindful that other approaches and interpretive frames could have been used to conduct this study and analyze its findings. Another set of theoretical and methodological choices would have yielded different results and been a different type of pursuit. Kevin Walby (2007) points out that the ontological frame that a researcher uses orients her or his project in particular ways. These decisions shape the researcher’s thinking about what is ‘real’, and by extension, influences what is sought for and uncovered. He writes,

[Dorothy] Smith’s ontology of the social determines the frame of institutional ethnographic discourse . . . the language that the institutional ethnographer uses in the interview to elicit . . . talk is always governed by the frame of [this] discourse. This line of questioning — listening for and asking about texts — involves [dialogue] that corral[s] what could possibly be said into a form that satisfies the demands of the ontological claims that . . . [guide] institutional ethnography. Observations are likewise fitted to conform to this interpretive frame (p. 1021).

Researchers who use institutional ethnography pursue a certain line of research from an explicit ontological position. This opens up the possibilities for seeing and knowing the social and political worlds in which we live in distinct ways.

While investigations using institutional ethnography are not theory-driven as conventionally understood, they are not ‘atheoretical’. I have pointed out that institutional ethnography offers a highly theorized approach to seeing and understanding the world as it is understood to be put together in people’s textually mediated actions and doings. This is a theoretical position. A particular ontology of the social and the influence of ruling relations frames research drawing from institutional ethnography. The approach “rejects the dominance of theory” because theory is thought of as a conceptual practice that has traditionally been divorced from the actual experiences of people’s lives (D. Smith, 2005, p. 49). I have heard it said of institutional ethnography that it is ‘just’ a method, but I do not agree because methods and choices among methods are always informed by theoretical presuppositions, whether or not these are made explicit.

Analogous to the preceding point is that while many guideposts for conducting institutional ethnography are found in the writings of Dorothy Smith and the those who have used institutional ethnography to frame their social inquiries, it is valuable to look laterally and into the literature of various disciplines and sub-disciplines, including theoretical and methodological sources, to see what is found there to nourish thinking and analysis. From my experiences in academic institutional ethnography milieu, I am
lead to concur with Walby’s (2007) observation that “most institutional ethnographers draw almost exclusively from [Dorothy Smith] for theoretical guidance” (p. 1010). Researchers de Montigny (1995, 2007) and Taber (2010, 2011), who both draw from institutional ethnography, experimented with blending approaches in the spirit of methodological pluralism, which is interesting and valuable for the possibilities these experiments offer. Both researchers employ strategies from autoethnography to analyze the complexities and intersections of their personal and working lives and their participation in ruling relations: de Montigny inquiring into the organization of social work practice, Taber investigating from her standpoint as a woman academic and former Canadian military regular forces helicopter pilot.

Furthermore, it is stimulating to think critically about the research approaches that we adopt, lest we enter into orthodoxy of practice or fetishism. I am intrigued that there are few published critiques of Dorothy Smith’s thought and her theoretical and methodological contributions to sociology. Book reviews of early (Longino, 1993) and later (Krouse, 2000) work by Smith offer some situated, punctual commentary. Most critiques of institutional ethnography are thought to “circulate by word of mouth. People who don’t like it simply ignore it. Since it isn’t a dominant approach, that is easy to do” (L. McCoy, personal communication, September 23, 2010). As part of a critical exchange about institutional ethnography, a fellow researcher wrote, “I think a lot of folks tend to take [institutional ethnography] on its face without raising questions about further enhancing it as a critical research strategy”.

The name of the method bears two words. As such, the conduct of work drawing from the method is (or should be) equal parts about cracking the nut about how institutions function and gathering rich, ethnographic detail about the material happenings in the lives of people; for the latter can tell us much about the former. Being mindful of what people do with their bodies is a strategy for focusing on the material while avoiding having people disappear within the institutions under study. About this issue, I met with a colleague experienced in using institutional ethnography who said (and I paraphrase), ‘this is ethnography. Keep the people in view!’ He talked about a pattern that he had discerned in research using institutional ethnography: where personal accounts of what people do and their experience fall out of prominence in written accounts. Yet, it is the “concrete, sensuous world of people’s actual practices and activities” that provide the

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90 Feminist critiques of Dorothy Smith’s use of theory include five articles appearing in a special issue of *Sociological Theory* in 1992. For a critique of (and response to) Smith’s use of standpoint, see Clough, 1993; Mann & Kelley, 1997; and, D. Smith, 1997. On Smith and feminist standpoint epistemology, see the series of articles published in *Signs* in 1997. The most recent published critique of institutional ethnography is by Kevin Walby (2007). He makes several points about the ontology and research practices associated with institutional ethnography. He challenges two claims that institutional ethnography makes about its uniqueness: the method’s social ontology and focus on connections between the local and extra-local. Walby argues that researchers must critique the social relations embedded in institutional ethnography’s research practices for the method to achieve fullest usefulness as a critical research strategy.
foundation and motivation for research drawing from this mode of inquiry (G. Smith, 1990, p. 633). Similarly, Janet Rankin urged me to return to the ‘nagging hunches’ about people’s experiences with mandatory immigration HIV testing to formulate this study’s research problematic.

Finally, observational work adds much value to projects that use institutional ethnography because the researcher learns about people and their social surroundings in ways that interviews cannot provide. From within his multiple social standpoints as undercover sociologist, nurse assistant in training, and later a certified nursing aide, Timothy Diamond (1992) wrote a very compelling composite ethnography in narrative form that reveals the lineaments of the organization of people’s life and work inside nursing homes in the United States. Making Grey Gold: Narratives of Nursing Home Care intrigued, encouraged, and incited me to find ways to spend time with applicants to Canada living with HIV as they interacted with the state agents and institutions that I set out to know more about: Immigration and Refugee Board, HIV clinics and waiting rooms, lawyers offices, and Citizenship and Immigration Canada offices.

Certainly my limited access to and time spent in these milieus in no way compare to the quality and quantity of Diamond’s immersion in his field surroundings. In the preface to his book, Diamond tells us that his critical report was the product of eight years of labour. From this exemplar, however, I gleaned tips on how to pay careful institutional ethnographic attention when I found myself inside state and clinical offices. I asked people questions about their work and how and why they undertook it. I paid close attention to what people were doing, and heeded Diamond’s counsel not to privilege transcript text over people’s embodied activities and experiences, which I extended to apply to interview settings. Making time and space for observations responds to “immanent critiques” of qualitative research that researchers transcend the “micropolitics” of the interview setting with the purpose of making connections between the personal, cultural, social and political worlds (Mykhalovskiy et al., 2008, p. 195). I am convinced that observational data collection is a key constituent of good institutional ethnographic fieldwork because observation directly contributes to how and what we can know about the institutional contexts we intend to pry open, dissect, understand, critique, and report on.

* * *

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Translations of verbatim statements
PAGE 52
RECAF: Did you have to undergo HIV testing? How many times?
I: I do not remember if I was told at some point in the process that I had to take an HIV test. I went to take the tests at a doctor suggested to me by my lawyer. That is it. He did not tell me that I was going to undergo HIV screening. In my home country, I did not undergo this testing either. My friends and I used to go out from time to time with a diplomat from the Canadian embassy; in my home country. It was he who got a visa to Canada for us; no problem. There you have it.

RECAF: Did you have to undergo HIV testing? How many times?
I: Oh, I see. You want to know how many HIV tests I have taken. Okay . . . when I arrived here, I was again asked to take an HIV test. The first test was inconclusive. The second time, my immigrant agent asked me to return to the same doctor with whom I had done the first HIV test.

RECAF: Did an immigration agent ask you questions about HIV/AIDS?
I: Yes, about questions about my general health; whether I had had risky sexual encounters; how many partners I had had; if I knew my husband’s HIV status, etc. I do not remember other details . . . [laugh] You know, it makes more sense to ask a woman who has escaped from a war-torn country whether she has been subjected to risky sexual encounters . . . this line of inquiry is more fitting.

PAGES 52-53
RECAF: Do you know your HIV status?
I: [Silence and sigh] Yes, I know my status. I tested HIV-positive . . . [tears]. I thought that I had been saved when my first test in the [refugee] camp was negative. Once I arrived here, all of the HIV tests that I have done have been positive . . . [crying intensifies].

PAGE 187
Then I took steps to request permanent residence. I had to pay $550 for myself, and $150 per child. In all, I paid approximately $2,250. My family is still waiting.

PAGE 189
L: These days, would you describe yourself as sick?
I: Well, the numbers indicate that I am sick. But, no, in my head, I am not sick [insistent].

L: Why is that?
I: The HIV test result says that I am sick, but I refuse to be sick.

L: Hhhmmmm . . .
I: I am not sick. In terms of my health, I can tell you that I am doing well. First I did not know that I was sick. I had to come here to Canada to discover that; to learn about my HIV status. I have know people who have died from this disease, and I am still alive. I walk, I talk. So, I tell myself that I am lucky; that God is with me, and this is a blessing.

L: How do you explain that? That the test result says, well, your CD4 count is such, but you do not consider yourself sick.

I: I refuse. I do not accept that. I do not want to be sick. I am not sick.

L: And you imagine that you will live until what age?

I: It is possible that I live ninety years old. In my family, we are long livers. We live beyond one hundred years old. My grandfather lived to be one hundred and twenty years old.

PAGE 218

The government agent told me that the only sort of jobs I could get with no domestic experience would be in factories; in the manufacturing industry. I told him, ‘with HIV, this type of work is not possible’. He was aware of my HIV status because of my completed paperwork.

PAGE 220

At the welfare office they told me that I had to get educational equivalencies for my prior diplomas or degrees. Without these, they could not help me. I am still waiting for them. The waiting is long. They referred me to a school where I took a general development test.

PAGE 233

In his office, the doctor did not talk too much. He was elderly. He told me, ‘you knew, didn’t you?’ I would have expected some other sort of disclosure. The doctor gave me the address of a hospital, along with the number of a bus.

PAGE 247

They told me that I had HIV, and I said, no. It was very difficult. I even experienced breakdowns. I wanted to go back to my country. I accepted to die anywhere, but not of AIDS. It was three months before I decided to take medications.

PAGE 263

I went to a clinic that specialized in HIV/AIDS. The doctor referred me to his colleague, a social worker. She calmed me down. She told me, ‘you are going to take medication. Not to worry. There is a lot of people who come here. Go get some help from AIDS service organizations. Find women living with HIV in those organizations. You will talk together’. From there, I starting accessing social services from several AIDS service organizations.
At the welfare office you fill out a lot of forms. You write that you have a handicap. I found that strange. I said to myself, ‘why do I have to write that I have a handicap?’ No, HIV is not a handicap! I am not handicapped! I just have HIV! I did not write HIV. I asked the woman a question. She told me that I had to specify my handicap, and, if not, the form would be incomplete. Why did I have to indicate my HIV in the handicap category? I asked this question to the doctor. He told me, ‘that is the way it is with all illnesses. It is mandatory to write down one’s illnesses. All incurable conditions are grouped together’. Even today, I ask myself questions because I am not handicapped.
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The Nest by Morgan McConnell, 2011
Appendices
Operational Processing Instruction 2002-004
MEDICAL ASSESSMENT OF HIV POSITIVE APPLICANTS

Background:
Applicants may be divided into two groups:
1. those who are Excessive Demand exempt (EDE), according to section 38(2) of the Immigration and Refugee Protection Act (IRPA); and
2. those who are non-Excessive Demand exempt (non-EDE).

EDE applicants who are HIV positive:
- should only be assessed according to public health and public safety health grounds for inadmissibility (IRPA sections 38(1)(a) & (b)).
- should NOT be assessed for excessive demands. Thus, examining physicians or medical officers should NOT request further tests to determine excessive demands, such as CD4 or pVL tests.
- are medically admissible if they meet health admissibility criteria of public health and public safety.

Non-EDE applicants who are HIV positive:
- should be assessed according to public health, public safety, AND excessive demands health grounds for inadmissibility (IRPA sections 38(1)(a)(b) & (c)).

When appropriate, examining physicians or medical officers should request further tests, such as CD4 or pVL tests, to help determine whether an applicant represents excessive demands.

HIV Positive Non-EDE Applicants - Information Relating to Excessive Demands:
Non-EDE applicants identified as being HIV positive should be asked to undergo CD4 testing by the examining physician. If an applicant’s CD4 count is less than 350 cells/mm³, antiretroviral therapy (ARV) is required in a Canadian setting and applicant will represent excessive demands. - see Annex A which includes the consultant report “HIV Infection in Applicants for Immigration to Canada”. If an applicant has a CD4 count above 500 cells/mm³, he/she should then be asked to undergo pVL testing. [Note: the consultant report refers to pVL testing for applicants with 500 cells/mm³, but this does not take into account what to do for CD4 counts 350-500.] Those applicants with pVL results over 55,000 copies/mL are not medically admissible, because they meet the current Canadian criteria for ARV treatment. If pVL testing is not available, then a second CD4 test should be obtained approximately two (2) months after the first CD4 test was taken – see #6 below.

Non-EDE applicants who are HIV positive are assessed on an individual basis in order to determine their demand on health and social services if granted entry to Canada. These services are assessed over a five year period unless significant costs are anticipated in the five to ten year period following the immigration medical examination.

Antiretroviral therapy (ARV) costs average $1000 per month. CD4 counts and viral loads cost $150 each and are routinely done every three months. Assuming a conservative estimate of four (4) visits annually to a physician, the cost per quarterly visit plus blood work in stable patients is approximately $360 (assuming $30 MD fee and $30 lab fee for other tests). The annual cost for ARV treated patients is thus approximately $13,440
($1,120 per month of treatment). This figure does not include any hospitalizations which may occur. See Annex A for the paper prepared by the consultant, which includes information on HIV costs. It should be noted that the consultant does not separate HIV positive applicants into EDE and non-EDE cases. Thus, although the paper refers to ALL applicants, the information pertains solely to non-EDE applicants.

1. All non-EDE applicants should be requested to provide a current (and any previously available) CD4 lymphocyte count. Failure to provide this information is sufficient grounds to assess the applicant as medically inadmissible since the vast majority of newly diagnosed HIV individuals will require ARVs within the ten year assessment period.

2. The natural history of untreated HIV infection is characterized by progressive CD4 cell depletion. The rate of CD4 cell decline is determined principally by the pVL.

3. ARVs are initiated in Canada if the CD4 lymphocyte count is below 350 cells/mm$^3$ or if plasma HIV-RNA concentration, commonly known as the plasma viral load or pVL, exceeds 55,000 copies/mL.

4. Any non-EDE applicant currently receiving ARV is inadmissible based on excessive demand on health care services.

5. Most HIV positive non-EDE applicants who have CD4 counts between 350 and 500 cells/mm$^3$ will experience a fall in their CD4 count to below 350 cells/mm$^3$ within the five year or ten year time frames placing an excessive demand on health services.

6. Non-EDE applicants identified as being HIV positive should be asked to undergo CD4 testing by the examining physician. If an applicant’s CD4 count is less than 350 cells/mm$^3$, antiretroviral therapy (ARV) is required in a Canadian setting and applicant will represent excessive demands - see Annex A which includes the consultant report “HIV Infection in Applicants for Immigration to Canada”. If an applicant has a CD4 count above 500 cells/mm$^3$, he/she should then be asked to undergo pVL testing. [Note: the consultant report refers to pVL testing for applicants with 500 cells/mm$^3$, but this does not take into account what to do for CD4 counts 350-500.] Those applicants with pVL results over 55,000 copies/mL are not medically admissible, because they meet the current Canadian criteria for ARV treatment. If pVL testing is not available, then a second CD4 test should be obtained approximately two (2) months after the first CD4 test was taken.

7. Non-EDE applicants with CD4 counts above 500 cells/mm$^3$ and pVLs below 55,000 copies/mL will be few in number, and will generally be admissible if all other health factors are unremarkable.

Summary:
EDE applicants who are HIV positive:
• should be assessed only for public health and public safety, NOT excessive demands.
are medically admissible if they meet admissibility criteria for public health and public safety.

Non-EDE applicants who are HIV positive:
• should be assessed according to public health, public safety, AND excessive demands health grounds for inadmissibility (IRPA sections 38(1)(a)(b) & (c)).

Table 1 below includes information useful in determining whether a non-EDE applicant who is HIV positive is likely to represent an excessive demand on health or social services.
### Table 1: HIV Positive Non-EDE Applicants

<table>
<thead>
<tr>
<th>Medically Admissible (assuming public health and public safety criteria are met)</th>
<th>Medically Inadmissible (based on Excessive Demand for health and/or social services)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Non-EDE applicants with CD4 counts above 500 cells/mm(^3) and pVLs below 55,000 copies/mL will generally be medically admissible if all other health factors are unremarkable.</td>
<td>• A non-EDE applicant who does not provide CD4 lymphocyte count information. Failure to provide this information is sufficient grounds to assess a non-EDE applicant as medically inadmissible since the vast majority of newly diagnosed HIV individuals will require antiretroviral therapy (ARV) within the ten year assessment period.</td>
</tr>
<tr>
<td>• Any non-EDE applicant currently receiving ARV.</td>
<td>• Any non-EDE applicant with a CD4 lymphocyte count below 350 cells/mm(^3), as meets in Canada standard for receiving ARV.</td>
</tr>
<tr>
<td>• Any non-EDE applicant with pVL exceeding 55,000 copies/mL, as meets in Canada standard for receiving ARV.</td>
<td>• Any non-EDE applicant with CD4 counts between 350 and 500 cells/mm(^3) will experience a fall in their CD4 count to below 350 cells/mm(^3) within the five year or ten year time frames placing an excessive demand on health services.</td>
</tr>
</tbody>
</table>
Annex A:

Note: The consultant in the report below does not separate HIV positive applicants into EDE and non-EDE cases. Thus, although the paper refers to ALL applicants, the information pertains solely to non-EDE applicants.

HIV Infection in Applicants for Immigration to Canada

Background:

1. CIC has implemented mandatory HIV serologic testing effective January 15, 2002 for all individuals aged 15 years and older applying to immigrate to Canada.

2. Prospective immigrants to Canada can be excluded on medical grounds for 3 reasons: risk to public health, risk to public safety, or excess demand on Canadian healthcare services. Presently, “excess demand” is usually defined as exceeding $15,000 of publicly funded health care costs over the next 5 years, but the assessment time can be extended to 10 years (and costs to $30,000), if relevant to the medical condition.

3. HIV infection is not considered a reason for non-admittance on grounds of risk to public health, because its transmission requires specific voluntary behaviours, principally sexual activity and sharing of injection drug using materials.

4. HIV infection could only be considered a risk to public safety under the unusual circumstance in which an HIV-infected person were a sexual offender.

5. HIV infection will frequently meet the CIC definition of excess demand, due principally to the high cost of drug therapy (see below). The costs of antiviral therapy are borne entirely by some provinces and territories, and in some provinces and territories, the patient pays a small proportion thereof.

Management and Costs of HIV Infection in Canada:

HIV-infected persons typically require quarterly medical appointments when they are doing well medically, with more frequent visits (and occasional hospitalizations) when they are experiencing problems.

At these quarterly visits, bloodwork is required, including both CD4 lymphocyte and plasma HIV-RNA (viral load) quantifications, usually with additional blood biochemistry. The CD4 and plasma HIV-RNA quantifications each cost about $150. Hence, the cost per quarterly visit plus blood work in stable patients is approximately $360 (assuming $30 MD fee and $30 lab fee for other tests). These costs are all borne by the provinces/territories. This does NOT include x-rays and serologic tests for potential co-infections, such as hepatitis B and C, which are routinely done, or the additional medical costs borne by those co-infected with either of those hepatitis viruses.
If the HIV-infected person requires antiretroviral (ARV) therapy, the costs of care increase markedly. Modern ARV therapy requires 3 drugs in most patients, and more than 3 in certain patients, particularly those who have failed to respond to prior ARV therapy. The cost for 3 drug containing ARV regimens ranges from a low of $698.40 per month for the combination of stavudine 40 mg BID plus (non-enteric coated) didanosine 400 mg QD plus delavirdine 400 mg TID to a high of $1560.60 per month for abacavir 300 mg BID plus lamivudine 150 mg BID plus amprenavir 1200 mg BID. Neither of those regimens are prescribed frequently. The most commonly prescribed 3 drug ARV regimens range from $849 to $1116 per month. The costs for ARV regimens used in “salvage therapy” for those who have failed other therapies is even higher. Thus, assuming a cost of $1000 per month per ARV-treated patient is likely an underestimate of the mean cost per treated patient. When added to the lab and MD visit costs noted above for stable patients (again an underestimate for the “mean” patient), the annual cost for ARV treated patients is $13,340 or $1112 per month. An additional plasma viral load test is required about one month after starting a new ARV regimen, but these costs have not been included.

Using the above costs and the usual 5 year window, an HIV-infected person requiring ARV for 8 months will incur $8896 (8 x $1112) costs while on ARV and $6120 while off ARV (17 quarterly visits over 4yr 4mo at $360 per visit) for a total of $15,016 Consequently, any HIV-infected adult expected to require a minimum of 8 months of ARV therapy over the ensuing 5 years is ineligible for admission due to the criterion of excess demand.

Using a 10 year time window, an HIV-infected person who is followed off ARV for 8.5 years and treated with ARV therapy for 1.5 years will incur costs of $12,240 ($360 x 34 assessments) while off ARV therapy plus $18,000 ($1000 x 18) while on ARV therapy for a total cost of $30,240. Consequently, any HIV-infected adult expected to require a minimum of 18 months of ARV therapy over the ensuing 10 years is ineligible for admission due to the criterion of excess demand.

**Recommendations for CIC Medical Officers:**

It should be noted that a large majority of HIV-infected applicants will meet the criteria of excess demand, but there will be a small proportion which will qualify for admittance. Any applicant currently receiving ARV is inadmissible based on excess demand.

All other HIV-infected applicants should be requested to provide a current (and any previously available) CD4 lymphocyte count. Failure to provide this information should be sufficient grounds for non-admittance.

The current guidelines for ARV therapy (MMWR May 17,2002; Vol. 51; No.RR-7; www.cdc.gov/mmwr/PDF/rr5107.pdf) indicate that ARVs should be initiated if the CD4 lymphocyte count is below 350 cells/mm$^3$ or if plasma HIV-RNA concentration, commonly known as the viral load or pVL exceeds 55,000 copies/mL. Hence, persons with a CD4 count below 350 cells/mm$^3$ are clearly excluded, as they qualify for immediate ARV therapy. (In the Northern Alberta HIV Program, the median CD4 count of newly recognized HIV-infected patients runs between 300 and 400 cells/mm$^3$).
The natural history of untreated HIV infection is characterized by progressive CD4 cell depletion. The rate of CD4 cell decline is determined principally by the pVL. A significant percentage of HIV-infected persons with CD4 counts over 350 cells/mm$^3$ will experience a decline in CD4 cells to below 350 cells/mm$^3$ within 4 years plus 4 months, meeting the 5 year criterion for excess demand, and more still will develop a CD4 count below 350 cells/mm$^3$ after 8.5 years, meeting the 10 year criterion for excess demand.

It is reasonable to assume that most HIV-infected persons with CD4 counts between 350 and 500 cells/mm$^3$ will experience a fall in their CD4 count to below 350 cells/mm$^3$ within the 4.33 year or 8.5 year time frames noted above, meeting the criterion of excess demand. Therefore, HIV-infected persons with CD4 lymphocyte counts below 500 cells/mm$^3$ are considered inadmissible due to excess demand.

Applicants with CD4 counts above 500 cells/mm$^3$ should be requested to provide a current (and any previous) pVL result. Those with pVL results over 55,000 copies/mL are not admissible, because they meet the current criteria for ARV treatment.

Applicants with CD4 counts above 500 cells/mm$^3$ and pVLs below 55,000 copies/mL will be few in number, and will generally be admissible, although it is suggested that cases in which the applicants have CD4 and pVL values very close to these thresholds be referred for an opinion by IMAB, or a Canadian HIV treatment expert.

July 2002

Neil Heywood, Kerry Kennedy, Michel Lapointe
Immigration medical screening and HIV infection in Canada

M Zencovich BSc MSc MD, K Kennedy MD, D W MacPherson MD FRCP, and B D Gushulak MD

Medical Services Branch, Citizenship and Immigration Canada, Ottawa; Department of Pathology and Molecular Medicine, Faculty of Health Sciences, McMaster University, Hamilton, Ontario, Canada

Summary: HIV infection, particularly associated with AIDS, is often used by migrant screening nations to exclude entry into the country. The unique feature of the Canadian immigration HIV screening programme is that it was not primarily for determining inadmissibility of HIV-positive applicants, but for health, public health, and disease prevention purposes. All applicants over 15 years of age for permanent residency or temporary residency from designated countries are HIV antibody tested. This includes persons seeking asylum from within Canada. The highest rates of HIV infection were found in migrant applicants from high prevalence areas of the world and reflected the demographic profile of the source region (predominantly women). The majority of HIV-positive persons are exempt from exclusion from Canada due to class of application (refugee, family) or are already in Canada (refugee claimant). Significant issues in notification, reporting and programme management have been identified as a consequence of this programme.

Keywords: medical screening, HIV/AIDS, immigrant, refugee, refugee claimant

Introduction

In 2004 UNAIDS reported the number of people living with HIV/AIDS in the world was 39.4 million. 4.9 million people were newly infected with HIV, and that 3.1 million people had died related to HIV/AIDS. The greatest burden of HIV/AIDS infection and disease occurs in the developing world in Asia and the Pacific region, Eastern Europe and Central Asia, Latin America and the Caribbean, the Middle East and North Africa and Sub-Saharan Africa. These regions represent the source countries for regular and irregular immigration to the western nations. They are also higher prevalence countries for HIV infection.

HIV/AIDS is of concern in high-income countries due to infection and disease burdens, ongoing transmission, shifting at-risk population demographics, health services utilization cost, and the impact of HIV-associated conditions on society.

In 2002, UNAIDS estimated that 80,000 people became infected with HIV, 1.6 million people were living with the virus, and an estimated 18,000 people died of AIDS.

The Public Health Agency of Canada received reports of 56,523 positive HIV test results between November 1985 and June 2004. Positive test reports attributed to heterosexual persons from HIV-endemic countries rose from 2% in 1998 to 8.6% in the first six months of 2004. HIV infection demographic data were not reported by region of birth. It remains unclear how the foreign-born individual who is in Canada through the process of immigration contributes to the national HIV/AIDS epidemiology. Clarity on this issue is essential for understanding the increasing direct link between the epidemics in developing world, national health interests in western countries and the relationship to population migration.

Under Canadian immigration legislation, all immigration applicants must comply with medical screening requirements. The medical screening requirements are applied to all applicants for permanent settlement (immigrants and refugees), or temporary residence from designated countries (some migrant workers, students, and long-term visitors), and irregular applicants (refugee claimants). In 2007, Health Canada recommended the introduction of mandatory, routine immigration-related HIV antibody testing for...
National Immigration Health Policy
Existing Policy, Changing Needs, and Future Directions

Brian D. Gushulak, MD
Linda S. Williams, PhD

ABSTRACT

Canada has a long history of welcoming immigrants and a longstanding immigration policy framework. The historic principles that govern immigration selection and processing also include regulatory policies in the area of health.

Based on historical principles that pre-date Confederation, Canadian immigration health policy has remained relatively constant. Policies are based on the identification of specific individuals and the exclusion, if appropriate, of the affected individuals—an approach that continues today. During the past three decades, however, evolutionary changes in the patterns, volume, and demography of immigration have created situations that may necessitate changes to existing policy frameworks. This paper reviews current immigration health policies and practices in Canada, describes the nature and impact of existing challenges, and proposes some alternatives for future consideration.

Immigration is a fundamental pillar on which Canada has been built. Beginning with European colonization, the medical assessment of immigrants is one of the nation's oldest migration-related activities. Despite this long history, Canada's immigration health activities continue to reflect traditional approaches initially designed for an era when most immigrants and a small number of refugees came from Europe. Later, they were revised to prevent the arrival of migrants with chronic, costly health conditions. In recent decades, however, most immigrants and refugees have come from Asia, Africa, the Middle East, the Caribbean, and South America, and have different health backgrounds and diseases. There is also a growing recognition that migration and population mobility are major factors underlying the processes of globalization. Changes in immigration health policy are needed to reflect these new realities.

Countries have long recognized that travellers can import disease and have taken steps to protect their own populations. In Biblical times, lepers were isolated and their movements controlled to limit their contact with others. By the 18th century, the spread of plague in Europe due to mercantile expansion triggered the development of quarantine. Inspecting arrivals, denying admission, and either holding or treating them due to the real or suspected presence of disease became standard maritime practices. Quarantine practices came to the Americas in the 1700s, as European exploration and settlement brought cholera, plague, and "ship fever" (typhus) to the colonies.

Focus later shifted to other transmissible diseases, such as tuberculosis and syphilis. In the 19th century, concerns grew to include chronic and non-infectious diseases that were likely to make new arrivals dependent on publicly funded social and health services, such as chronic psychiatric disorders, developmental impairment, alcoholism, seizure disorders, and chronic tuberculosis. The masters of vessels bringing passengers to Canada were subject to a fine or bond for landing individuals who later became "public charges" because of disease or infirmity.

Assessing new arrivals for the presence of serious infectious diseases or the presence of illnesses that would impose a drain on public services has remained the funda-
Appendix B: Data collection
B1. Organizations encountered during exploratory phase

Exploratory groundwork

Constituency consultations – January to March 2009; Ontario and Québec

- Ontario AIDS Network – provincial umbrella group
- Alliance for South Asian AIDS Prevention
- Asian Community AIDS Services
- Centre for Spanish Speaking Peoples
- HIV/AIDS Legal Clinic of (Ontario)
- Regent Park Health Centre/Community for Accessible AIDS Treatment
- Voices of Positive Women
- Women’s Health in Women’s Hands/African and Caribbean Council on HIV/AIDS in Ontario
- La coalition des organismes communautaires québécois de lutte contre le sida – provincial umbrella group
- Action Séro-Zéro
- Le Bureau régional d’action sida (BRAS)
- La Coalition Multi Mundo
- Ethnoculture
- Intervention régionale et information sur le sida (IRIS) Estrie
- Le mouvement d’information et d’entraide dans la lutte contre le sida à Québec (MIELS)
- Sida-vie Laval
B2. Immigration medical assessment and inadmissibility under health grounds

Overview

- Legislation

- Organization and immigration medical processes
  - Health Management Branch Organization
  - Roles and duties of CIC Medical Officers and Designated Medical Practitioners (DMPs)
  - Immigration medical examination (IME) and assessment processes (IMA)

- Inadmissibility on health grounds
  - Danger to public health
  - Danger to public safety
  - Excessive demand on health and social services
Overview

- Legislation

- CIC HIV policy and procedures
Invitation à faire partie d’une étude doctorale :

« Cordon sanitaire ou politique saine? »

Une étude doctorale qui fait l’analyse de la politique canadienne de dépistage obligatoire au VIH/sida de toute personne qui demande le statut de résident permanent au Canada débute à l’automne 2009. La politique est en vigueur depuis 2002. Des personnes vivant avec le VIH/sida (PVVIH) ainsi que des avocats, du personnel dans le domaine de la santé, et des fonctionnaires de la fonction publique seront interviewés dans le cadre de ce projet. Les interviews seront d’une durée d’environ 60 minutes.

Ce projet a comme but la réalisation de données pratiques pour les PVVIH, organismes communautaires et politiques publiques.

Si vous êtes intéressé et pensez vouloir participer à l’étude, vous êtes éligible à la condition de remplir les critères suivants :

• Vous avez été dépisté pour le VIH/sida lors de votre demande d’immigration/de réfugié au Canada depuis 2002;
• Vous vivez avec le VIH/sida;
• Vous avez plus de 18 ans; et
• Vous vous débrouillez bien en français, en anglais et, le cas échéant, vous avez la volonté de communiquer par intermédiaire d’un interprète.

Votre anonymat sera assuré. Vous serez rémunéré pour votre participation et vos frais de transport en commun pour vous rendre à l’interview seront remboursés.

S.V.P. contacter Laura Bisaillon pour toute information
Invitation to participate in a doctoral study:

“Cordon sanitaire or healthy policy?”

A doctoral study is underway that will produce an analysis of the mandatory HIV testing policy for immigrant and refugee applicants for permanent residency to Canada. The policy has been in place since 2002. Persons living with HIV, lawyers, medical personnel, and government bureaucrats will be interviewed for approximately 60 minutes for this study.

This study aims to produce results useful for persons living with HIV, AIDS service and advocacy organizations and public policy.

If you are interested in this study and would consider being involved as an interview participant, you are eligible if you are:

- A person who was tested for HIV during medical screening for immigration/refugee application to Canada since 2002;
- A person living with HIV;
- Over 18 years old; and
- Able to speak in English, French or are in agreement to working through an interpreter.

Your identity will remain anonymous. You will be paid for your participation and for costs related to public transportation to participate in study.

Please contact Laura Bisaillon for details.
Cordon sanitaire o la planificación de la salud?

Un estudio doctorado hará un análisis entre la estructura de las relaciones entre la política de solicitar examen obligatorio para el VIH a los recién llegados al Canadá desde el 2002. Las entrevistas, de aproximadamente 60 minutos, serán con gente viviendo con el VIH, abogados, gente que trabaja en el departamento de Sanidad, y los burócratas del gobierno para está investigación.

Los resultados de la investigación serán útiles para la gente viviendo con el VIH, servicios de la SIDA y los grupos de la políticas publicas y para la planificación del público.

Si usted está interesado en la investigación y quisera ser entrevistado, será eligible si usted es:
- Una persona quien fue examinado para el VIH durante un examen médico para inmigrar a Canadá;
- Una persona con VIH
- Mayor de 18 años de edad; y
- Podrá hablar inglés o francés o estará de acuerdo con comunicarse usando un traductor (en Español).

Su identidad será ánonimo. Usted será recompensado por su participación y para el transporte publico si lo usa para participar en está investigación.

Usted puede contactarme para más información y detalles con Laura Bisaillon
Le 18 mai 2010

Docteur ____________________ ,

À titre de médecin désigné par Citoyenneté et Immigration Canada, je vous invite à participer à un entretien. Je suis chercheure au doctorat et ma thèse porte sur les politiques publiques en matière de santé et immigration. Ce travail est financé par les Instituts de recherche en santé du Canada (IRSC) et les Fonds de la recherche en santé du Québec (FRSQ).

L’autorisation du bureau de déontologie m’a été accordé en août 2009. Depuis, le travail de terrain est en cours à Montréal et à Toronto. Plusieurs médecins désignés ont déjà accepté ma demande d’entretien. J’ai aussi eu des entretiens avec immigrants, professionnels de la santé, juristes et fonctionnaires. C’est le docteur Cajal qui m’a référé à vous.

Votre participation consisterait à participer à un entretien d’une heure. Celui-ci pourrait se dérouler à vos bureaux. Les questions porteront sur votre travail auprès des nouveaux arrivants et plus particulièrement sur votre travail d’examen médical et la découverte d’un diagnostic de séropositivité.

Toutes les informations demeureront strictement confidentielles. Il n’y aura aucune utilisation de données nominatives dans les publications qui découleront de cette étude (ex.: noms, lieu de travail). Votre participation serait une très grande valeur ajoutée à ma compréhension.

Je vous remercie de bien vouloir considérer ma demande. Vous pouvez me transmettre votre réponse par téléphone au . . .

Veuillez agréer, docteur _____________, mes salutations distinguées.

Laura M. Bisaillon
Doctorante, Santé des populations
Université d’Ottawa
September 29, 2009

Dear Ms. ________________,

Thank you for expressing interest in my Ph.D. study called “Cordon sanitaire or healthy policy? Mandatory screening for HIV of immigrants and refugees to Canada since 2002.” This letter outlines the project’s aim and your role in the project.

The purpose of the study is to analyze the mandatory HIV screening policy of applicants for permanent residency in Canada since 2002. The aim is to understand how health and immigration systems influence people’s activities, including those who are tested and those who work with the policy. I intend the study to be useful for policy advocacy.

Your participation will consist of one interview of about 60 minutes conducted by me. There may be need for follow-up in person or by telephone. If you are more comfortable speaking in a language other than English or French, an interpreter will accompany me during the interview. We will arrange a convenient place and time for the interview. Questions will be about your knowledge of the testing policy. I will ask your written permission to tape record the interview.

You will receive $25.00 for your participation. I will cover public transportation costs (token or ticket) for travel to and from the interview site.

All information shared is confidential. I will remove your personal information in written materials (e.g., name, place of birth, etc.) I will prepare a written summary of results and send these to you.

Your participation will make a valuable contribution to understanding the testing policy. The results will be shared with persons living with HIV, community organizations and government.

If you have questions and/or would like to participate in this study, please contact me at . . .

Sincerely,

Laura M. Bisaillon
Ph.D. Candidate in Population Health
Institute of Population Health,
University of Ottawa
Invitation à faire partie d’une étude doctorale :
(english below)

« Cordon sanitaire ou politique saine ? »

Une étude doctorale qui fait l’analyse de la politique canadienne de dépistage obligatoire au VIH/sida de toute personne qui demande le statut de résident permanent au Canada débute à l’automne 2009. La politique est en vigueur depuis 2002. Des personnes vivant avec le VIH/sida (PVVIH) ainsi que des avocats, du personnel dans le domaine de la santé, et des fonctionnaires de la fonction publique seront interviewés dans le cadre de ce projet. Les interviews seront d’une durée d’environ 60 minutes.

Ce projet a comme but la réalisation de données pratiques pour les PVVIH, organismes communautaires et politiques publiques.

Si vous êtes intéressé et pensez vouloir participer à l’étude, vous êtes éligible à la condition de remplir les critères suivants :

» Vous avez été dépisté pour le VIH/sida lors de votre demande d’immigration au Canada ;
» Vous vivez avec le VIH/sida ;
» Vous avez plus de 18 ans ; et
» Vous vous débrouillez bien en français, en anglais et, le cas échéant, vous avez la volonté de communiquer par intermédiaire d’un interprète.

Votre anonymat sera assuré. Vous serez...
Ressources et défense des droits

UN PROGRAMME UNIQUE EN COLOMBIE-BRITANNIQUE
cherchera les personnes atteintes par le VIH/sida, qui n’ont pas été diagnostiquées et qui ne suivent pas de traitement
http://www.cfemt.ubc.ca/
http://www.metronews.ca/toronto/live/article/44292/

SASKSTREETSIGNS.CA
est un nouveau site Web dont l’objectif est d’aider à l’enrichissement d’un répertoire de ressources humaines de Saskatoon offert à un endroit unique et accessible. http://www.saskstreetsigns.ca/

Recherche – les politiques d’immigration et de santé au Canada

Je cherche à m’entretenir avec des infirmiers qui œuvrent auprès des nouveaux arrivants au Canada qui vivent avec le VIH. Je m’intéresse à savoir en quoi s’agit votre travail dans le soutien quotidien de cette population. Pour des fins d’interview, je viendrai à votre rencontre dans votre lieu de travail.

L’étude est la première évaluation de la politique canadienne de dépistage obligatoire du VIH/sida de personnes immigrantes. La politique est en vigueur depuis début 2002. Le projet est financé par les IRSC et FRSQ, ainsi que le Centre Métropolis de l’Ontario. Les directeurs de recherche sont Monsieurs Ronald Labonte (Monétalisation contemporaine et l’égalité en matière de santé) et Dave Holmes (Soins infirmiers médico-légales) de l’Université d’Ottawa.


L’autorisation du bureau de déontologie de l’Université d’Ottawa a été accordée en août 2009. Le travail de terrain est en cours à Montréal et Toronto depuis lors. Des personnes vivant avec le VIH, des professionnels de la santé, des juristes, et des fonctionnaires publiques sont interviewés dans le contexte de ce projet.

Merci de me contacter pour de plus amples informations et pour des fins de discussion. SVP faire parvenir cette notice à travers vos réseaux.

********

I am currently seeking to interview nurses working with newcomers to Canada who are living with HIV in a 60-minute session where I will visit your workplace. Questions focus on your work practices involved in supporting and caring for this population.

The study is a policy evaluation of Canada’s mandatory HIV testing policy in place since 2002. It is funded by CIHR, FRSQ and CERIS (Ontario Metropolis Centre). I am supervised by University of Ottawa Professors Ronald Labonte (Globalization and Health Equity) and Dave Holmes (Forensic Nursing).

Health practitioners have been impacted by the policy, but how it has influenced work practices has yet to be systematically documented. Nurse perspectives are crucial pieces in this policy analysis work. I am interested to know what is involved in your daily work with persons living with HIV who are new to Canada. I will present preliminary findings at the Canadian HIV/AIDS Legal Network’s 2nd Annual Symposium on HIV, Law and Human Rights in Toronto in June 2010.

University of Ottawa ethics approval was granted in August 2009. Fieldwork in Montreal and Toronto has been on-going since then. Persons living with HIV, health practitioners, lawyers and government personnel are interviewed for this research.

Please contact me for information and to discuss. Please broadcast this notice through your networks to persons who may be interested in taking part.

Laura Bisillon
Doctorante, Santé des populations
Université d’Ottawa
B7. Sample questions explored with standpoint and extra-local informants

Standpoint informants

Introduction: What troubles me is the difference between people’s experiences with immigration HIV testing and what the government reports happening with testing. I wonder what questions, issues, surprises and/or problems you have stemming from immigration testing. I would like to hear about your lived/actual experiences with immigration HIV testing.

Point of departure: I am interested in exploring your personal story of your immigration process. I am especially interested in what you can tell me about how your HIV status was handled. I am interested in hearing as many details as you can relate about your experience and knowledge of what happened. How does your story begin? How does it unfold?

General cues

• What happened next (clarify)?
• What made this happen as it did?
• How do you know that?
• Does it always happen like that to people you know?
• Where and from whom can I get more information (on that point)?
• What did you really mean by that?

Informant understandings

Statement: I am interested in hearing you tell me what you understood about the role that HIV plays in immigration to Canada

• What did you know about immigration HIV testing before coming to Canada? How did you know this?
• What were you told about how things happened? By whom?
• What was your understanding of how that happened?
• How do you know that happened? Who told you and how?

Contradictions, puzzles, surprises

Statement: I am interested in having you tell me what surprises/puzzles bothers/preoccupies you experienced and continue to experience in relation to HIV testing at immigration

• What is your understanding of why the Canadian government tests for HIV? Has this changed now that you are in Canada?
• What is the understanding of the testing policy by other people you know?
• What do you need to know to immigrate when you are HIV+? (What preparation)
• How do you collaborate with others in preparing to immigrate? With whom do you work?
Questions through immigration with HIV

Statement: I am interested in knowing who you discussed your HIV status with in relation to immigration and what type of discussions you had (content and nature of talk)

- What steps did you take with Canadian immigration after finding out about your HIV+ status?
- What discussions did you have about HIV within your immigration process? With whom did you discuss these?
- What did they tell you about HIV and immigration to Canada?
- What questions did you ask about HIV in your immigration process (or other)?
- What were responses to the questions you asked?

Medical screening

- What were you told about the HIV test at the time of immigration? At medical exam?
- What happened at the time of immigration testing?
- Explain how you prepared for the medical examination. What you did.
- Explain how the medical examination took place.
- Explain what happened after the medical examination.

Documents and texts

Share this to illicit talk and similar experience. This is an example of a surprise with a government document: EM reported having been encouraged by a government agent to indicate that she was disabled on Emploi Québec forms. This revolted her! What are people’s experiences with government forms?

- What documents (i.e., reports, forms, emails, photographs, other) do you use for your immigration? Can you name them? Can you explain them to me?
- How did you come to know these documents?
- How did you work with these documents?
- What documents did you sign through the process? (i.e., consent form)
- What do you understand from them? What do you not understand?
- Where do they go after you are finished with them?
- With whom is the information shared?

Extra-local informants

Citizenship and Immigration Canada informant

Introduction: This is ethnographic work that is focused on what people actually do in their working day as opposed to what people think or feel, in this case, linked to the procedure of routinely testing applicants to Canada for HIV. This means that some aspects of the interview can only come into sharp focus during the interview, through discussions, depending on what I learn from the person to whom I am speaking.
Below are general, thematic areas for exploration, but exchanges are not limited to or bound by these themes. The goal of the interview is to understand you and your team’s work practices associated with files for Canadian permanent residence made by persons living with HIV.

1. **Work activities**
   Can you tell me about yourself professionally, including what you currently do in your daily work as related to HIV screening policy.

   Can you talk to me more broadly about the organization of the Health Management Branch. For example, we could walk through the Branch’s organigram.

2. **Policy-making process**
   Can you tell me about the policy making process involving the HIV policy: how it came to be, who was involved

   Can you explain the steps involved in the crafting of this policy?

   Can you explain and discuss the specific rationale that animates the mandatory HIV screening policy

3. **Decision-making process**
   I understand that assessments of applications for permanent resident status made from within Canada are made in Ottawa. I would like to know some concrete details about this process. For example, what are the steps as a file makes its way through the assessment process?

   How are documents such as the Immigration and Refugee Protection Act and its’ regulations used in your work and the work of your Branch?

   There may be other documents that enter in your individual and/or collective work practices that we could discuss.

4. **Operations**
   Can you tell me about how domestic and international IME contexts operate? About how they are monitored. About how they are evaluated?

   I understand the document guiding the work of the DMP is the DMP Handbook. Can you tell me about this document, including its history, contents, differences in editions, and how the DMP uses it?

   Can you tell me about how the DMP works with CIC? What are the routine steps in communications related to an application for permanent residence status? What extraordinary event would change this routine?
5. Current data
I am interested in reviewing up-to-date data for applications made by people living with HIV as per the Database on HIV in the Health Management Branch of CIC. For example, I am aware that you keep data according to applicant categories (i.e., spousal, refugee, etc.), number of applications per immigration category (i.e., skilled, work permit, etc.), other.

I will send additional, specifically formulated questions for this request if helpful.

6. Policy review
Can you tell me about the current review coordinated by CIC?

-What is the goal of this review? What are the anticipated or hoped-for outcomes?

-Is only the screening policy with respect to HIV under review, or does the review extend to screening for other health conditions? (i.e., query as to scope of the exercise)

-Who are participants in this review? Governments, organizations, institutions, others? What is the time frame for its completion?
Je vous invite à faire partie d’une étude doctorale intitulée « Cordon sanitaire ou politique saine? Dépistage obligatoire au VIH/sida des immigrants et réfugiés au Canada depuis 2002 ». Le projet remplit les critères de mon programme de doctorat en santé des populations. L’étude est financée par une bourse des Instituts de recherche en santé du Canada (IRSC), les Fonds de la recherche en santé du Québec (FRSQ) et CERIS (le Centre Métropolis de l’Ontario).

**Chercheure**
Laura Bisaillon, doctorante, Institut de recherche en santé des populations (IRSP), Université d’Ottawa

**Directeurs de thèse**
Monsieur Ronald Labonte, directeur; Chaire de recherche du Canada en mondialisation et équité en matière de santé, IRSP, Faculté de médecine, Université d’Ottawa; et,

Monsieur Dave Holmes, co-directeur; Chaire universitaire en soins infirmiers médico-légaux, Faculté de la santé, École des sciences infirmières, Université d’Ottawa.

**But de l’étude**
L’étude a comme but de produire une analyse détaillée de la politique de dépistage au VIH/sida aux personnes qui font une demande de résidence permanente au Canada. Elle vise à comprendre comment les systèmes de santé et d’immigration influencent les activités des personnes qui sont dépistées et qui travaillent avec la politique. Elle vise également à informer les politiques publiques et le travail de plaidoyer.

**Implication volontaire**
Votre participation consistera à une interview d’environ 90 minutes et sera animée par moi. Un suivi en personne ou par téléphone pourrait s’avérer nécessaire pour éclaircir certains points. Les personnes vivant avec le VIH et qui ont subit le dépistage durant l’examen médical d’immigration depuis 2002, qui ont plus de 18 ans et parlent couramment français ou anglais ou encore acceptent de participer par l’intermédiaire d’un interprète sont éligibles à participer à l’étude. L’interview se fera pendant les heures de travail et nous nous entendrons sur un endroit convenable. Je vous poserai des questions sur vos connaissances de la politique de dépistage du VIH/sida. Il est à noter que toutes les réponses sont bonnes.

**Participation volontaire**
Après avoir consenti à l’étude, s’il vous arrive de ne plus vouloir y faire partie, je supprimerai les informations transmises jusqu’alors. Ne craignez aucun effet indésirable quant à votre décision. N’hésitez pas de me contacter durant l’étude.
Anonymat et confidentialité
Les informations que vous fournirez seront confidentielles. Toute information personnelle, tels noms, lieu d’origine, autres, ne figurera pas dans les publications qui découleront du travail. Un nom différent du vôtre ou numéro vous sera accordé afin que votre identité demeure confidentielle. Au cas où nous communiquerons par interprète, cet individu atteste à la confidentialité.

Entreposage et utilisation des données
Les enregistrements, transcriptions, et notes qui proviennent de l’interview seront conservés de manière sécuritaire pendant sept ans dans mon bureau à domicile ainsi que dans les bureaux des professeurs Labonte et Holmes. Après quoi, les données seront détruites. À part moi, seuls les professeurs Labonte et Holmes auront accès aux données.

Effets bénéfiques
Votre participation à l’étude représentera une contribution importante dans la compréhension et l’analyse de la politique de dépistage. Les résultats de ce projet seront partagés avec des personnes vivant avec le VIH/sida, organismes communautaires et gouvernements. Je vous ferai parvenir un résumé des résultats.

Rémunération
Comme remerciement pour votre temps et le partage de vos connaissances, je vous donnerai la somme de 25$. 

Risques
Divulguer des informations personnelles peut être gênant ou dérangeant. S’il vous arrive d’être mal à l’aise avec un sujet quelconque abordé durant l’interview, nous changerons de sujet ou nous prendrons une pause. Vous avez le droit de m’arrêter ou de ne pas répondre aux questions. Le choix vous appartient.

Enregistrement audio
Je donne mon accord afin que l’interview soit enregistrée. Oui ____________ Non ____________

Suivi
Vous pouvez contacter Laura ou les professeurs Labonte ou Holmes pour des questions relatives au contenu de l’étude. Pour des interrogations quant à l’éthique du présent travail, contacter le bureau de Déontologie à l’Université d’Ottawa.

Consentement
Je ( _____________________________ ) suis d’accord de faire partie de l’étude menée par Laura Bisaillon de l’Université d’Ottawa qui est sous la direction des professeurs Labonte et Holmes.

Signatures
-Signature du participant/de la participante et date: _____________________________
(*Conserver une copie de ce formulaire pour vos dossiers)

-Chercheure signature et date: _____________________________
Consent form (Extra-local informant)

You are invited to participate in the doctoral study entitled “Cordon sanitaire or healthy policy? Mandatory screening for HIV of immigrants and refugees to Canada since 2002.” I designed the study for my PhD in Population Health. Research funding is provided by the Canadian Institutes for Health Research (CIHR), les Fonds de la recherche en santé du Québec (FRSQ), and CERIS (Ontario Metropolis Centre).

Student researcher
Laura Bisaillon, PhD candidate, Institute of Population Health (IPH), University of Ottawa.

Under the supervision of
Professor Ronald Labonte, Supervisor; Canada Research Chair, Globalization and Health Equity, IPH, Faculty of Medicine, University of Ottawa; and,
Professor Dave Holmes, Co-Supervisor; University Research Chair in Forensic Nursing, Faculty of Health Sciences, School of Nursing, University of Ottawa.

Study purpose
The goal of the study is to analyze the mandatory HIV screening policy of applicants for permanent residency in Canada. The aim is to understand how health and immigration systems influence people’s activities, including those who are tested and those who work with the policy.

Your voluntary participation
Your participation will consist of one interview of approximately 60 minutes conducted by me. There may be need for follow-up in person or by telephone to clarify certain points. Persons who have working knowledge with the testing policy are invited to take part in the second phase of this study. Interview questions will be about your knowledge of and practical working experience with the HIV testing policy. There are no right or wrong answers.

Your voluntary involvement
If you decide to withdraw from the study, I will destroy the information already collected from you. There will be no negative consequences of your withdrawal. Please feel free to contact me at the number and email listed above during the study.

Anonymity
The information you will share with me is confidential. The data collected will be used for the purpose listed above. I will remove all of your personal information in all written materials that result from this study. You will be given another name or a number so that there is no link between you and statements that you have shared with me.
Data use and storage
Voice recordings, interview transcripts, and my notes from the study will be securely kept at my home office and at the offices of Professors Labonte and Holmes. I will keep data for seven years after the study is finished after which time they will be destroyed. The only other persons who could access the data are Professors Labonte and Holmes.

Benefits of study
Your participation will make a valuable contribution to understanding the testing policy. The results of this project will be shared with persons living with HIV/AIDS, community organizations and government. I will send to you a written summary of the findings.

Compensation
Please note that I am not in a position to financially compensate you for your participation.

Potential risks
Should you be uncomfortable with our exchange for any reason, we can change topics or take a break. You have the right to ask or refuse to answer any question. The choice is yours.

Audio recording
I agree to allow for the interview to be voice recorded Yes ______ No ________

Follow-up
Contact Laura or Professors Labonte or Holmes with general questions about the study. For questions about the ethical conduct of the project, contact the Ethics Office at the University of Ottawa.

Acceptance
I, ( ___________________________ ), agree to participate in this study conducted by Laura Bisaillon as supervised by Professors Labonte and Holmes.

Signatures
- Participant signature and date: ____________________________
  (*Keep a copy of this form for your files)
- Student researcher signature and date: ____________________________
You are invited to participate in the doctoral study entitled “Cordon sanitaire or healthy policy? Mandatory screening for HIV of immigrants and refugees to Canada since 2002.” I designed the study for my PhD in Population Health. Research funding is provided by the Canadian Institutes for Health Research (CIHR), les Fonds de la recherche en santé du Québec (FRSQ), and CERIS (Ontario Metropolis Centre).

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Laura Bisaillon, PhD candidate, Institute of Population Health (IPH), University of Ottawa.

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Professor Dave Holmes, Co-Supervisor; University Research Chair in Forensic Nursing, Faculty of Health Sciences, School of Nursing, University of Ottawa.

Study purpose
The goal of the study is to analyze the mandatory HIV screening policy of applicants for permanent residency and refugee status in Canada. The aim is to understand how health and immigration systems influence people’s activities, including those who are tested and those who work with the policy. I intend the study to be useful for policy advocacy.

Voluntary participation
Your participation will consist of your previously scheduled professional interaction with legal and/or federal government personnel. It is understood that you have invited me as participant observer to this session that is expected to take approximately 90 minutes. The session will take place during regular business hours in a public workplace. I will have no role other than a silent observer. It is further understood that the language of communication will be English.

Voluntary involvement
If you decide to withdraw from the study, I will destroy the information already collected. There will be no negative consequences of your withdrawal. Please feel free to contact me at the number and email listed above during the study.

Anonymity and confidentiality
I will hold all information communicated during the session strictly confidential. I will remove personal information such as your name, place of birth, other, in all written materials that result from this study. You will be given another name or a number. There will be no link between you and statements that you or other persons present have made during the session.
Data use and storage
Notes that I take while observing the session will be securely kept at my home office and at the offices of Professors Labonte and Holmes. I will keep data for seven years after the study is finished. After this time, data will be destroyed. The only other persons who could access the data are Professors Labonte and Holmes.

Benefits of study
Your participation will make a valuable contribution to understanding the HIV testing policy. The results of this project will be shared with persons living with HIV/AIDS, community organizations and government. If you request, I will send to you a written summary of the findings.

Compensation
There will be no financial compensation for this session.

Potential risks
After the participant observation session is over, I may request to speak to you. Sometimes talking about personal issues can be distressing. Should you feel uncomfortable for any reason with our discussion, we can change topics or stop the conversation. You have the right to ask or refuse to answer any question. The choice is yours.

Audio recording
There will be no audio recording of this session.

Follow-up
Contact Laura or Professors Labonte or Holmes with general questions about the study. For questions about the ethical conduct of the project, contact the Ethics Office at the University of Ottawa.

Acceptance
I, _____________________________, agree to allow Laura Bisaillon be present as participant observer during the session to which she is invited to attend. She will have no speaking role during the session. I also understand that it is Laura Bisaillon who is conducting the study under the supervision of Professors Labonte and Holmes.

Signatures
- Informant signature and date: _____________________________
  (*Keep a copy of this form for your files)

- Student researcher signature and date: _____________________________
Appendix C: Ethics approvals

C1. Certificate from August 27, 2009

File Number: H06-09-02

Date (mm/dd/yyyy): 08/27/2009

Ethics Approval Notice
Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<table>
<thead>
<tr>
<th>First Name</th>
<th>Last Name</th>
<th>Affiliation</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ronald</td>
<td>Labonté</td>
<td>Medicine / Population Health</td>
<td>Supervisor</td>
</tr>
<tr>
<td>Dave</td>
<td>Holmes</td>
<td>Health Sciences / Nursing</td>
<td>Co-Supervisor</td>
</tr>
<tr>
<td>Laura</td>
<td>Bisaillon</td>
<td>Health Sciences / Others</td>
<td>Student Researcher</td>
</tr>
</tbody>
</table>

File Number: H06-09-02

Type of Project: PhD Thesis

Title: Cordon Sanitaire or Healthy Policy? Mandatory Screening for HIV of Immigrant and Refugee Applicants to Canada since 2002

Approval Date (mm/dd/yyyy) | Expiry Date (mm/dd/yyyy) | Approval Type
08/27/2009                  | 08/26/2010                | Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:
N/A
C2. Certificate from October 28, 2009

October 28, 2009

Ronald Labonté  Dave Holmes

Laura Bisaillon

Re: Cordon sanitaire or Health Policy? Mandatory Screening for HIV of Immigrant and Refugee Applicants to Canada since 2002 (H 06-09-02)

Dear Researchers,

The Health Sciences and Science Research Ethics Board has examined your request for ethics approval of the following modifications to your research project:

☐ The Researchers will also conduct focus groups among the same primary participant subject population. The researchers are convinced that focus groups will enhance understandings, complements data collected during personal interviews, and promote the ability to fully respond to the project’s research questions. The Researchers have been approached by a group of eligible persons from the primary participant subject population who are interested in taking part in a focus group.

Your request has been accepted. The certification of ethical approval granted on August 27, 2009 and valid until August 26, 2010 covers these modifications.

During the course of the study, any further modifications to the protocol or forms may not be initiated without prior written approval from the REB. You must also promptly notify the REB of any adverse events that may occur.

If you have any questions, please do not hesitate to contact me at extension

Sincerely yours,

Germain Zongo
Protocol Officer for Research Ethics
For Daniel Lagarec, Chair of the Health Sciences and Sciences REB
May 27, 2010

Ronald Labonté

RE: Cordon sanitaire or Health Policy? Mandatory Screening for HIV of Immigrant and Refugee Applicants to Canada since 2002 (H 06-09-02)

Dear Researchers,

The Health Sciences and Science Research Ethics Board has examined your request for ethics approval of the following modifications to your research project:

- Laura Bisailon will accompany one of her research participants to her Immigration and Refugee Board hearing in Montreal at her invitation. She will observe the hearing and may use in her study some observations made.
- She will also sit in with a lawyer and a client as they work to prepare the client for her hearing at the Immigration and Refugee Board in Montreal. Both are her research participants and invited her to attend. She will observe the meeting and may use in her study some observations made.

The two observations will help the researcher enhance her understandings of issues and build upon understandings gleaned from data collected to date; will enable her to more fully answer the project’s research questions; will contribute to a better quality and character of analysis and assessment; and will result in a better quality doctoral dissertation.

Your request has been accepted. The certification of ethical approval granted on August 27, 2009 and valid until August 26, 2010 covers these modifications.

During the course of the study, any further modifications to the protocol or forms may not be initiated without prior written approval from the REB. You must also promptly notify the REB of any adverse events that may occur.

If you have any questions, please do not hesitate to contact me at extension

Sincerely yours,

Germain Zongo
Protocol Officer for Research Ethics
For Daniel Lagarec, Chair of the Health Sciences and Sciences REB

C3. Certificate from May 27, 2010
Appendix D: Data analysis

D1. Text and document worksheet

I find it helpful to ask some explicit questions of texts, such as:

In what social circumstances and historical time did the text emerge?

What human experiences (if any) are included, and how are these shaped and discussed?

What is the intended audience (readership)?

Who is the author?

What words (categories, labels) are recurrent?

How is the text constructed (shape of narrative style)?

What does the text intend to accomplish (overtly, covertly)? Is this the same as the text’s purpose?

What social order or institutional organization is presupposed (assumed) in text?

What work is referred to or implied, and who is doing this work?

What sequences of action (work practices) are present in the text? What bigger work processes does this localized work lead to?

What is brought into being (coordinated) through these activities and practices?

What textual records are produced through documentary and other work forms?

What and whose interests (relevancies) are served? Subsumed (disappear)?

What can be said about the dominant ruling relations as written into the text?

What is left unexplained, and where are there question marks?

Keeping in mind how these are referenced or implicitly appear in the texts: state, authority, violence, regulation, policing, surveillance, norms, standards, autonomy, sex, power, people, class, asymmetry, interests being served, and work of society’s institutions . . .
D2. Analytic mapping (1)

Standpoint informant moving from Canadian border into institutions (p. 1) and Discursive references in informant talk about mandatory HIV testing (p. 2)
D3. Analytic mapping (2)

Understanding sequences of action in the processing of standpoint informant’s medical file (pp. 1-5) and Ideological practice work (p. 6)
A. Applicant
- DMP
- Nurse
- Receptionist

B. Ibid.

C. C1 - DC Medical Officer
   - Medical Assessment Officer
   : TBA

C2 - Public Health Nurse (RN)

C3 - Work permit...
   Unknown

D. Ibid
   TBA

C2 RN
   Applicant
   TBA
Physical/Down (Q: What are people doing with their bodies?)

Talk, Work, Texts, People, in A-D.

A.
- Blood Sample, Mtn. X-ray
- Anx/adv ance test
- Limited/brief time
- Go to checklist, self-report (standard form)

B.
- Speculative accounts
  - Homophobia
  - Sero phobia
  - Busy
  - Time
  - Money
  - Disinterest
  - Anti-immigrant
  - Truth telling

C.
- Present for results
  - Follow-up call from DMP
    - Informed of results
      - Questioned
      - Note-taking, DMP
      - Info: rec public health
      - Blood donation
      - Referral, HIV clinic

D.
- "Medical tests reveal..."

C1. TBA, Martin, CIC
- Public Health Info
  - Law in Canada
  - Condom booklets
  - Blood pamphlets
  - Referrals
  - ASO

C3. TBA (Sylvie or someone else by phone)

- One-time encounter, in person or on telephone.

Research

Q: This is problematic. As found in data, as troubling/disturbing in peoples' lives.

Challenge: Unravel how this is organized, how does this happen?
Talk | Work | Texts | People in A-D

A. 
- IRPA gives authority for HIV test
- Policy 2002 Regulations
- Guidelines to BNP are 
  ostensibly in manual (2003, 2009)
- Privacy Act
- Freedom of Info Act
- Government forms
  - Applicant brings these
  - BNP receives applications;
    stores, sends these.
  - Applicant does not receive
    copies (prohibited)
  - Becomes medical file

B. 
- IRPA
  - Guidelines as to 
    conduct & actions
  - "Operational Procedures" (Op)
  - sent by fax/post to
    inform work
  - addendums to 
    practice, reporting
  - periodic updates as
    "things change"

C. 
- IRPA
  - Medical file
  - HIV policy
  - Op
- Public Health Act
  - (PHA)

D1. 
- IRPA
  - Medical file

D2. 
- PHA

C3. 
- TBA
PEOPLE & THEIR THINKING WORK IN A-ID

A. What narrative is presented in "medical file" (by DRP)?
B. How does he know what parts/topics to record?
C. What words/language appear in these narratives?
(Did he just tick boxes [1] = categories?)
D. What else does DRP want to know?
   - Not want to know?
   Analytical
MY WORK HERE AT THIS SITE
- What IRPA concepts/words/language organize conduct of this work and what he reports?
- What is authoritative IRPA for what is recorded: COST, SAFETY, DANGERS TO PUBLIC HEALTH?

Text: what does IRPA aim to achieve? Preserve? How is this related to what DRP reports?

---

How does language reflexively coordinate the work of the CDN state? (Examined them in ideological practice). This conceptually organizes creation of accounts that instead impede "people" (Doctors DRP, CIC assessors, RN...) work/iteration of a course of action coordinated in language of IRPA. Social org. of activities in places sites etc.

IDENTICAL CIRCLE WORK:
  - CDN STATE
  - RE-PROCESSING
  - HIV APPLICANT?
EXAMPLE: GEORGE W. SMITH

I. Ideological circle applied to covert police raids on gay men's bathhouses in To 
  examining ideological practice work of a regime.

BATH HOUSE ACTIVITIES ➔ POLICE NOTES IN NOTEBOOKS ➔ RAIDS BY POLICE ACCOUNTS ➔ CRIMINAL CODE OF CANADA

Intent: Police inscriptions designed to know what was happening inside bath houses to regulate operation (not to have sex)

Q: How did they know how to inscribe these notes? What organized these accounts? ... "Indecent act" of Criminal Code.

"Indecent act" language/Concept in code

... intended/enabled raids on or in bath houses where activities violated forms of social organization in the Criminal Code = Heterosexuality
D4. Canada’s HIV Testing Policy (With my annotations)

Canada’s HIV testing policy

Operational Processing Instruction 2002-004
MEDICAL ASSESSMENT OF HIV POSITIVE APPLICANTS

Background:

Applicants may be divided into two groups:

1. those who are Excessive Demand exempt (EDE), according to section 38(2) of the Immigration and Refugee Protection Act (IRPA); and
2. those who are non-Excessive Demand exempt (non-EDE).

EDE applicants who are HIV positive:

- should only be assessed according to public health and public safety health grounds for inadmissibility (IRPA sections 38(1)(a) & (b)).
- should NOT be assessed for excessive demands. Thus, examining physicians or medical officers should NOT request further tests to determine excessive demands, such as CD4 or pVL tests.
- are medically admissible if they meet health admissibility criteria of public health and public safety.

Non-EDE applicants who are HIV positive:

- should be assessed according to public health, public safety, AND excessive demands health grounds for inadmissibility (IRPA sections 38(1)(a)(b) & (c)).

When appropriate, examining physicians or medical officers should request further tests, such as CD4 or pVL tests, to determine whether an applicant represents excessive demands.

HIV Positive Non-EDE Applicants: Information Relating to Excessive Demands: Non-EDE applicants identified as being HIV positive should be asked to undergo CD4 testing by the examining physician. If an applicant’s CD4 count is less than 350 cells/mm³, antiretroviral therapy (ART) is required in a Canadian setting and applicant will represent excessive demands. - see Annex A which includes the consultant report “HIV Infection in Applicants for Immigration to Canada”. If an applicant has a CD4 count above 500 cells/mm³, he/she should then be asked to undergo pVL testing. [Note: the consultant report refers to pVL testing for applicants with 500 cells/mm³, but this does not take into account what to do for CD4 counts 350-500.] Those applicants with pVL results over 55,000 copies/mL are not medically admissible, because they meet the current Canadian criteria for ART treatment. If pVL testing is not available, then a second CD4 test should be obtained approximately two (2) months after the first CD4 test was taken – see #6 below.

Non-EDE applicants who are HIV positive are assessed on an individual basis in order to determine their demand for health and social services. These
services are assessed over a five year period unless significant costs are anticipated in the five to ten year period following the immigration medical examination.

Antiretroviral therapy (ARV) costs average $1000 per month. CD4 counts and viral loads cost $150 each and are routinely done every three months. Assuming a conservative estimate of four (4) visits annually to a physician, the cost per quarterly visit plus blood work in stable patients is approximately $360 (assuming $30 MD fee and $30 lab fee for other tests). The annual cost for ARV treated patients is thus approximately $13,440 ($1,120 per month of treatment). This figure does not include any hospitalizations which may occur. See Annex A for the paper prepared by the consultant, which includes information on HIV costs. It should be noted that the consultant does not separate HIV positive applicants into EDE and non-EDE cases. Thus, although the paper refers to ALL applicants, the information pertains solely to non-EDE applicants.

1. All non-EDE applicants should be requested to provide a current (and any previously available) CD4 lymphocyte count. Failure to provide this information is sufficient grounds to assess the applicant as medically inadmissible since the vast majority of newly diagnosed HIV individuals will require ARVs within the ten year assessment period.

2. The natural history of untreated HIV infection is characterized by progressive CD4 cell depletion. The rate of CD4 cell decline is determined principally by the pVL.

3. ARVs are initiated in Canada if the CD4 lymphocyte count is below 350 cells/mm³ or if plasma HIV-RNA concentration, commonly known as the plasma viral load or pVL, exceeds 55,000 copies/mL.

4. Any non-EDE applicant currently receiving ARV is inadmissible based on excessive demand on health care services.

5. Most HIV positive non-EDE applicants who have CD4 counts between 350 and 500 cells/mm³ will experience a fall in their CD4 count to below 350 cells/mm³ within the five year or ten year time frames placing an excessive demand on health services.

6. Non-EDE applicants identified as being HIV positive should be asked to undergo CD4 testing by the examining physician. If an applicant’s CD4 count is less than 350 cells/mm³, antiretroviral therapy (ARV) is required in a Canadian setting and applicant will represent excessive demands - see Annex A which includes the consultant report “HIV Infection in Applicants for Immigration to Canada”. If an applicant has a CD4 count above 500 cells/mm³, he/she should then be asked to undergo pVL testing. [Note: the consultant report refers to pVL testing for applicants with 500 cells/mm³, but this does not take into account what to do for CD4 counts 350-500] Those applicants with pVL results over 55,000 copies/mL are not medically admissible, because they meet the current Canadian criteria for...
ARV treatment. If pVL testing is not available, then a second CD4 test should be obtained approximately two (2) months after the first CD4 test was taken.

7. Non-EDE applicants with CD4 counts above 500 cells/mm³ and pVLs below 55,000 copies/mL will be few in number, and will generally be admissible if all other health factors are unremarkable.

Summary:
EDE applicants who are HIV positive:
• should be assessed only for public health and public safety, NOT excessive demands.
• are medically admissible if they meet admissibility criteria for public health and public safety.

Non-EDE applicants who are HIV positive:
• should be assessed according to public health, public safety, AND excessive demands health grounds for inadmissibility (IRPA sections 38(1)(a)(b) & (c)).

Table 1 below includes information useful in determining whether a non-EDE applicant who is HIV positive is likely to represent an excessive demand on health or social services.
Table 1:

**HIV Positive Non-EDE Applicants**

<table>
<thead>
<tr>
<th>Medically Admissible</th>
<th>Medically Inadmissible</th>
</tr>
</thead>
<tbody>
<tr>
<td>(assuming public health and public safety criteria are met)</td>
<td>(based on Excessive Demand for health and/or social services)</td>
</tr>
<tr>
<td>• Non-EDE applicants with CD4 counts above 500 cells/mm$^3$ and pVLs below 55,000 copies/mL will generally be medically admissible if all other health factors are unremarkable.</td>
<td>• A non-EDE applicant who does not provide CD4 lymphocyte count information. Failure to provide this information is sufficient grounds to assess a non-EDE applicant as medically inadmissible since the vast majority of newly diagnosed HIV individuals will require antiretroviral therapy (ARV) within the ten year assessment period.</td>
</tr>
<tr>
<td>• Any non-EDE applicant currently receiving ARV.</td>
<td>• Any non-EDE applicant with a CD4 lymphocyte count below 350 cells/mm$^3$, as meets in Canada standard for receiving ARV.</td>
</tr>
<tr>
<td>• Any non-EDE applicant with pVL exceeding 55,000 copies/mL, as meets in Canada standard for receiving ARV.</td>
<td>• Any non-EDE applicant with CD4 counts between 350 and 500 cells/mm$^3$ will experience a fall in their CD4 count to below 350 cells/mm$^3$ within the five year or ten year time frames placing an excessive demand on health services.</td>
</tr>
</tbody>
</table>
HIV Infection in Applicants for Immigration to Canada

Background:
1. CIC has implemented mandatory HIV serologic testing effective January 15, 2002 for all individuals aged 15 years and older applying to immigrate to Canada.

2. Prospective immigrants to Canada can be excluded on medical grounds for 3 reasons: risk to public health, risk to public safety, or excess demand on Canadian healthcare services. Presently, “excess demand” is usually defined as exceeding $15,000 of publicly funded health care costs over the next 5 years, but the assessment time can be extended to 10 years (and costs to $30,000), if relevant to the medical condition.

3. HIV infection is not considered a reason for non-admittance on grounds of risk to public health, because its transmission requires specific voluntary behaviours, principally sexual activity and sharing of injection drug using materials.

4. HIV infection could only be considered a risk to public safety under the unusual circumstance in which an HIV-infected person were a sexual offender.

5. HIV infection will frequently meet the CIC definition of excess demand, due principally to the high cost of drug therapy (see below). The costs of antiviral therapy are borne entirely by some provinces and territories, and in some provinces and territories, the patient pays a small proportion thereof.

Management and Costs of HIV Infection in Canada:
HIV-infected persons typically require quarterly medical appointments when they are doing well medically, with more frequent visits (and occasional hospitalizations) when they are experiencing problems.

At these quarterly visits, bloodwork is required, including both CD4 lymphocyte and plasma HIV-RNA (viral load) quantifications, usually with additional blood biochemistry. The CD4 and plasma HIV-RNA quantifications each cost about $150. Hence, the cost per quarterly visit plus blood work in stable patients is approximately $360 (assuming $30 MD fee and $30 lab fee for other tests). These costs are all borne by the provinces/territories. This does NOT include x-rays and serologic tests for potential co-infections, such as hepatitis B and C, which are routinely done, or the additional medical costs borne by those co-infected with either of those hepatitis viruses.
If the HIV-infected person requires antiretroviral (ARV) therapy, the costs of care increase markedly. Modern ARV therapy requires 3 drugs in most patients, and more than 3 in certain patients, particularly those who have failed to respond to prior ARV therapy. The cost for 3 drug containing ARV regimens ranges from a low of $698.40 per month for the combination of stavudine 40 mg BID plus (non-enteric coated) didanosine 400 mg QD plus delavirdine 400 mg TID to a high of $1560.60 per month for abacavir 300 mg BID plus lamivudine 150 mg BID plus amprenavir 1200 mg BID. Neither of those regimens are prescribed frequently.

The most commonly prescribed 3 drug ARV regimens range from $849 to $1116 per month. The costs for ARV regimens used in “salvage therapy” for those who have failed other therapies is even higher. Thus, assuming a cost of $1000 per month per ARV-treated patient is likely an underestimate of the mean cost per treated patient. When added to the lab and MD visit costs noted above for stable patients (again an underestimate for the “mean” patient), the annual cost for ARV treated patients is $13,340 or $1112 per month. An additional plasma viral load test is required about one month after starting a new ARV regimen, but these costs have not been included.

Using the above costs and the usual 5 year window, an HIV-infected person requiring ARV for 8 months will incur $8896 (8 x $1112) costs while on ARV and $6120 while off ARV (17 quarterly visits over 4yr 4mo at $360 per visit) for a total of $15,016. Consequently, any HIV-infected adult expected to require a minimum of 8 months of ARV therapy over the ensuing 5 years is ineligible for admission due to the criterion of excess demand.

Using a 10 year time window, an HIV-infected person who is followed off ARV for 8.5 years and treated with ARV therapy for 1.5 years will incur costs of $12,240 ($360 x 34 assessments) while off ARV therapy plus $18,000 ($1000 x 18) while on ARV therapy for a total cost of $30,240. Consequently, any HIV-infected adult expected to require a minimum of 18 months of ARV therapy over the ensuing 10 years is ineligible for admission due to the criterion of excess demand.

**Recommendations for CIC Medical Officers:**

It should be noted that a large majority of HIV-infected applicants will meet the criteria of excess demand, but there will be a small proportion which will qualify for admittance. Any applicant currently receiving ARV is inadmissible based on excess demand.

All other HIV-infected applicants should be requested to provide a current (and any previously available) CD4 lymphocyte count. Failure to provide this information should be sufficient grounds for non-admittance.

The current guidelines for ARV therapy (MMWR May 17,2002; Vol. 51; No.RR-7; [www.cdc.gov/mmwr/PDF/rr/rr5107.pdf](http://www.cdc.gov/mmwr/PDF/rr/rr5107.pdf)) indicate that ARVs should be initiated if the CD4 lymphocyte count is below 350 cells/mm³ or if plasma HIV-RNA concentration, commonly known as the viral load or pVL exceeds 55,000 copies/mL. Hence, persons with a CD4 count below 350 cells/mm³ are clearly excluded, as they qualify for...
immediate ARV therapy. (In the Northern Alberta HIV Program, the median CD4 count of newly recognized HIV-infected patients runs between 300 and 400 cells/mm$^3$).

The natural history of untreated HIV infection is characterized by progressive CD4 cell depletion. The rate of CD4 cell decline is determined principally by the pVL. A significant percentage of HIV-infected persons with CD4 counts over 350 cells/mm$^3$ will experience a decline in CD4 cells to below 350 cells/mm$^3$ within 4 years plus 4 months, meeting the 5 year criterion for excess demand, and more still will develop a CD4 count below 350 cells/mm$^3$ after 8.5 years, meeting the 10 year criterion for excess demand.

It is reasonable to assume that most HIV-infected persons with CD4 counts between 350 and 500 cells/mm$^3$ will experience a fall in their CD4 count to below 350 cells/mm$^3$ within the 4.33 year or 8.5 year time frames noted above, meeting the criterion of excess demand. Therefore, HIV-infected persons with CD4 lymphocyte counts below 500 cells/mm$^3$ are considered inadmissible due to excess demand.

Applicants with CD4 counts above 500 cells/mm$^3$ should be requested to provide a current (and any previous) pVL result. Those with pVL results over 55,000 copies/mL are not admissible, because they meet the current criteria for ARV treatment.

Applicants with CD4 counts above 500 cells/mm$^3$ and pVLs below 55,000 copies/mL will be few in number, and will generally be admissible, although it is suggested that cases in which the applicants have CD4 and pVL values very close to these thresholds be referred for an opinion by IMAB, or a Canadian HIV treatment expert.

July 2002

Neil Heywood, Kerry Kennedy, Michel Lapointe
## E1. IMM 5419 Medical Report: Section B

### Application (or guardian) to answer in the presence of the examining physician. IF YOUR ANSWER IS YES TO ANY OF THE FOLLOWING QUESTIONS, PROVIDE DETAILS INCLUDING DATES.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. An operation/HOSPITAL treatment for any reason</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Convulsions, blackouts, loss of consciousness, &quot;fits&quot; or EPILEPSY?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Anxiety, depression or NERVOUS PROBLEMS requiring treatment?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. High blood pressure, any HEART trouble, CHRONIC COUGH, breathlessness or chest pain?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Recurrent or CHRONIC PAIN in the neck, back, or any joint sufficient to interfere with work or normal day-to-day activity?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Problems with DIGESTION, stomach pain, heartburn, blood in stool, chronic diarrhea?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. TUBERCULOSIS, a SEXUALLY TRANSMITTED DISEASE, or any other COMMUNICABLE DISEASE lasting more than 3 weeks?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. A history of jaundice or HEPATITIS involving you or anyone in your immediate family?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. A history of KIDNEY or bladder disease or complaint?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. DIABETES or history of sugar in the urine?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Any OTHER ILLNESS, injury or medical condition lasting more than 3 weeks or a recurring condition not previously mentioned? Any recent UNINTENTIONAL WEIGHT LOSS?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Are you taking any pills, MEDICATION or receiving any medical treatment?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Have you ever been ADDICTED to alcohol or a drug, or taken drugs illegally?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Have you ever had a test indicating the presence of the HIV virus or have you ever been told that you were suspected of having AIDS, HIV INFECTION, or any other immune disorder?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Are you eligible for or do you receive a PENSION for MEDICAL/PSYCHOLOGICAL reasons?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. AUTISM, MENTAL RETARDATION, DEVELOPMENTAL DELAY or other physical or mental DISABILITIES/IMPAIRMENTS affecting your current or future ability to function independently?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Any medical, psychological, alcohol related, or other TREATMENT in the past 5 years?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Are you PREGNANT? If so, what is the expected date of delivery:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Previously, have you undergone a Canadian Immigration medical examination for any reason (whether completed or not)? If so, when and under what name?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

List all countries (with duration of stay) where you have lived during the last five years:

### List of countries

- [ ] Permanent/long term presence or staying in Canada: ____________
- [ ] Temporary for: ____________

### Declaration and Authorization of Applicant (or Guardian)

I hereby declare that the information I have provided is true and complete. I authorize any physician, laboratory, clinic or hospital to release to the Department of Citizenship and Immigration any information concerning my health or medical history. I also authorize the Department to release information obtained for the purpose of this immigration medical examination to a public health agency or a physician in Canada, if indicated. I certify that the information I have provided on this form is correct.

<table>
<thead>
<tr>
<th>Signature</th>
<th>Date (Day Month Year)</th>
</tr>
</thead>
</table>
E2. Emphasis on post-test counselling for HIV

## IFH Program Rates for Immigration Medical Exams

**Interim Federal Health (IFH) Program Reimbursement Rates**

**Effective September 1, 2008**

<table>
<thead>
<tr>
<th>Immigration Medical Exam Services</th>
<th>Code</th>
<th>Fee</th>
</tr>
</thead>
<tbody>
<tr>
<td>(for Designated Medical Practitioners only)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Immigration Medical Exam</td>
<td>70</td>
<td>$115.00</td>
</tr>
<tr>
<td>“OPM” Immigration Medical Exam</td>
<td>84</td>
<td>$115.00</td>
</tr>
<tr>
<td>2nd Immigration Medical Exam for Convention Refugees</td>
<td>101</td>
<td>$115.00</td>
</tr>
<tr>
<td>Venipuncture - Immigration Medical Exam</td>
<td>67</td>
<td>$9.60</td>
</tr>
<tr>
<td>VDRL - Immigration Medical Exam</td>
<td>69</td>
<td>$15.75</td>
</tr>
<tr>
<td>Chest x-ray - Immigration Medical Exam</td>
<td>71</td>
<td>$42.10</td>
</tr>
<tr>
<td>Urinalysis - Immigration Medical Exam</td>
<td>72</td>
<td>$2.90</td>
</tr>
<tr>
<td>HIV Laboratory Testing</td>
<td>63</td>
<td>$21.00</td>
</tr>
<tr>
<td>Post-Test Counselling for HIV</td>
<td>65</td>
<td>$119.95</td>
</tr>
</tbody>
</table>

---

5 The IFH Program reimburses health-care providers according to rates set by the province or territory for medical treatment, diagnostic services, pharmaceuticals and other health-care services for which the applicable province has published rates for its residents. In the absence of provincial or territorial rates, Citizenship and Immigration Canada has established the rates contained in this schedule. These rates are to be used for IFH purposes only.
Appendix F: Permissions to use
F1. Huan Tran, September 29, 2011

Hi Laura,

thanks for asking for permission. You're welcome to use the image for your paper, cheers.

--huan

--- On Thu, 9/29/11, Laura Bisailon <...> wrote:

From: Laura Bisailon <...> >
Subject: Attachment: Permission to use
To: "" <...> >
Date: Thursday, September 29, 2011, 10:55 AM

Here is the attachment.

----- Courriel transféré -----
De : Laura Bisailon <...> >
A : "" <...> >
Envoyé le : Jeudi 29 Septembre 2011 13h53
Objet : Permission to use

Hello Huan,

I read the article "Uprooted Lives" in CATIE's Positive Side from 2006 where I discovered your very nice illustration.

I write to ask your permission to use in as a cover image on my PhD dissertation on immigration and HIV, the subject of the article, as you know. (I actually interviewed one
Hi Laura

Yes, indeed.

Richard

From: Laura Hisaillon [mailto: ]
Sent: September 24, 2011 11:42 AM
To: Richard Elliott
Subject: Permission to use

Hi Richard,

I need written permission to use visuals appearing in my thesis that are not my own.

I would like LN permission to use cover shots of Klein (2001) and Hoffmaster and Schrecker (2000) that were published by the LN. See attached (from my working draft). I think that LN rather than author permission is appropriate here. Yes?

Replying 'yes' in an email will do the trick.

Thanks.
hi laura,

wow, thanks so much for your words and for the work that you are doing. i will definitely give you permission to use both the nest and dark angel in your thesis, please let me know what dimensions you would like dark angel as i need to prepare it for print use. i’ll give you the relevant credit information for the pieces when i send them off to you.

congratulations of finishing your thesis, and i look forward to hearing back from you.
morgan

On 2011-07-06, at 3:17 PM, Laura Bisailon wrote:

Dear Morgan,

i just came across your etching on page 31 of the unaids outlook 2011 publication. going onto your website, i then remembered that i had seen your work through cas and vodka ice. (i am a friend of shaoy and was on the catie board with don short, who were also artists whose work was chosen for the vodka bottles, as you know).

anyway, i write to ask, would it be possible that i use the nest as a visual in my phd thesis? i am a critical health researcher based in montreal. i am wrapping up my thesis that was a critical investigation of canada’s mandatory hiv testing policy of immigrants to this country. i worked with several asos in to and mfl for this, as well as the legal network. my academic website address is below, in case you want to look.

looking into your website, and to the downloadable prints, this piece of yours also really appeals. http://www.dangerboydesign.com/downloads/dark-angel600x600.jpg. it would seem a really good, visual fit with my study’s findings: that the policy works well in screening out people with hiv who it can lawfully exclude. i looked at the work involved for pha applicants who were resident in canada. your painting/etchings/screen really speaks, visually, to migration flight, contagion, moral positions of the state regarding hiv, architecture of a policy apparent behind the words vs those that are on the page (as per the michelangelo-esque renderings on the man and up the side of the work,

http://cf.mcc1126.mail.yahoo.com/mcm/showMessage?mid=0&filterbyw= &prand=477988&accumb=8&kmw2044dp&view=1&view=print&enc=auto
Hi Laura, you can contact us via email at [email protected]. Not sure where you emailed, but our email address is checked daily, we don't have a direct phone number unfortunately. Not sure which resource you are referring to, but our website is public and all are resources are definitely open for people to distribute/quote from etc. Thanks for being in touch, Harsha.

> Could someone please help me get in telephone contact with the Vancouver office of No One is Illegal. There is no phone information provided on the org's homepage. I have emailed and follow-up by email, and not heard from the office. I seek information on and permission to use a resource posted on their website.
> Thanks,
> Laura
> Laura M. Bisaiion, University of Ottawa
Appendix G: Publications I have produced in connection with this study

G1. Mandatory HIV testing policy and everyday life: A look inside the Canadian immigration medical examination, 2011

Abstract

Findings that detail the social organization of day-to-day practices associated with the Canadian government policy of mandatory HIV testing of permanent residence applicants to Canada are reported. Institutional ethnography was used to investigate interactions between HIV-positive applicants and immigration physicians during the immigration medical examination. A composite narrative recounts details of a woman applicant’s discovery through immigration testing that she was living with HIV. Mandatory HIV testing gives rise to serious difficulties for applicants to Canada living with HIV. Applicant, physician and federal state employee work practices associated with mandatory HIV testing are analysed. These practices contribute to the ideological work of the Canadian state, where interests bound up in the examination serve the state and not the applicant. Findings should be useful for Canadian immigration policy makers whose work it is to develop constructive and functional strategies to address issues that matter in people’s lives.

Key Words: empirical research, health policy, HIV/AIDS, immigration, ethnography, HIV testing

Mandatory HIV Screening Policy & Everyday Life:
A Look Inside the Canadian Immigration Medical Examination

LAURA BISAILLON

Introduction

Story and science are interrelated, interactive, and ultimately constitute each other ... The natural world and the cultural worlds share the burden of creating disease realities.[1]

... I had grasped well that there are situations in life where our body is our entire self and our fate. I was in my body and nothing else ... My body and nothing else ... My body ... was my calamity. My body ... was my physical and metaphysical dignity.[2]

In this article, I report findings from research using institutional ethnography that detail the practices associated with mandatory HIV (human immunodeficiency virus) screening of refugee and immigrant applicants to Canada. Specifically, I interrogate the interactions between HIV-positive immigrant and refugee applicants and federal government appointed immigration physicians, called Designated Medical Practitioners (DMP), during the official immigration medical examination (IME). What are some features of the everyday activities of applicants living with HIV in relation to this examination? What happens during the IME? What are some of the social organizers of the official medical visit and what happens there? These are the underlying questions of this inquiry.

I make two arguments. First, there is relevance and practical value in investigating public policy from within people’s concerns and the material circumstances of their everyday activities. Empirical accounts circumvent speculative, abstract and ideological knowledge and understandings about the side effects of policy. Second, the mandatory HIV

91 For this article, I won the 2011 George W. Smith Outstanding Student Paper Award. This distinction was awarded by members of the Institutional Ethnography Division of the Society for the Study of Social Problems in Las Vegas, Nevada, in August 2011. See http://www.sssp1.org/file/Newsletters/IE/IE%20Newsletter%20(Fall,%202011).pdf
G2. Le dépistage obligatoire ceinture nos frontières, 2012

Éditorial pour Remaides

Le Canada maintient un programme de dépistage obligatoire au VIH dans sa plate-forme d’immigration. Il s’adresse aux personnes de quinze ans et plus qui font demande de résidence permanente ainsi qu’à certains groupes de personnes qui demandent la résidence temporaire de pays désignés. Ce programme, géré par Citoyenneté et Immigration Canada, est en vigueur depuis 2002, et il fut contesté par la société civile depuis ses débuts.

Que le Canada opère un tel programme suscite la surprise de la part de beaucoup de Canadiens à qui j’expose les résultats de mon étude qualitative qui porte un regard critique sur le programme de dépistage et les pratiques associées. Des pays de l’OCDE, seuls les ressortissants de la Lettonie, de la Corée et du Portugal qui demandent de séjourner au Canada pour plus de six mois seront dépistés.


Le Canadien, né au pays, n’est souvent pas informé des étapes pour immigrer au Canada ou l’existence d’une politique de dépistage obligatoire de certaines maladies, dont le VIH. Le dépistage du VIH entraîne complexité et contradictions dans le processus de demande d’immigration. Par exemple, vingt-huit immigrants séropositifs participants à mon étude ont remarqué l’absence de counselling avant et après le diagnostic. Cette lacune est aussi valable au Canada qu’à l’étranger où des informations sur le fonctionnement du dépistage dans les contextes du Brésil, du Kenya, du Soudan et de la Russie ont été recueillies alors que dans ses documents officiels, le gouvernement canadien insiste sur le counselling et octroi une rémunération aux médecins pour faire ce travail.

Cela fait plus de neuf ans que le programme de dépistage obligatoire existe, et il est temps de miser sur son sens ainsi que son fonctionnement. J’ai appris qu’une évaluation du programme coordonnée par Citoyenneté et Immigration Canada est en cours. Peu de

92 Accepted as editorial to Remaides for publication in 2012. See http://www.cocqsida.com/ressources/remaides.html
détails ont été rendus publics, mais les immigrants séropositifs n’y prennent pas part. Comment évaluer un programme de grande importance alors qu’on néglige l’expertise et les connaissances de la population ciblée ?

Il est aussi temps de remettre en question les concepts sur lesquels le programme repose. Par exemple, son statut obligatoire. Le Canada impose aux citoyens étrangers une pratique qui serait inadmissible sur ses propres citoyens et résidents permanents. Est-ce justifiable de dépister pour une maladie encore non guérissable uniquement pour des fins d’une immigration possible ? En réalité, très peu de pays dotés d’un système de santé universel dépiste obligatoirement les personnes qui font demande d’immigration: l’Australie et la Nouvelle-Zélande en font exception. L’Angleterre a rejeté l’imposition d’un dépistage obligatoire, et aucun pays d’Europe ne dépiste sa population immigrante. Il existe un décalage entre l’image idéologique que le Canada cultive de lui-même comme pays humanitaire exemplaire et l’existence d’un programme et des pratiques associées qui trie et exclu selon certaines maladies.
G3. Human rights consequences of mandatory HIV screening policy of newcomers to Canada, 2010

Laura M. Bisaillon

We were uncomfortable with the fact that the Canadian HIV policy did not apply for work visa applications for nationals of all countries. We started to say jokes like, “HIV from Germany is very welcome in Canada. HIV from UK, well, very nice! But, HIV from Brazil? No, we don’t want Brazilian HIV.” It is meaningful! (Informant)

Ethics always has trouble competing with economics.

The promise and implications of a policy are not transparent and easily evident in its text . . . the “architecture of meaning” of a policy is revealed by the systematic investigation of policy categories and labels, metaphors and narratives, programs and institutional places.

ABSTRACT

This paper focuses on the key human rights consequences of the HIV screening policy that applies to all permanent and some temporary resident applicants to Canada. This mandatory policy was introduced in early 2002 by Citizenship and Immigration Canada after consultation with Health Canada. The policy has yet to be evaluated and, until recently, the actualities of the medical encounters where testing occurs in domestic and international settings have not been researched. There is no systematic documentation of the policy’s implications on either the lives of persons who submit to mandatory testing or on health systems. This article argues that there are sound options for responding to the human rights challenges posed by the screening policy.

Data were obtained from secondary literature and findings from empirical fieldwork and research among immigrants living with HIV/AIDS in Canada. This paper adds to theoretical and applied health services and interventions work by focusing attention on avenues for addressing key human rights concerns posed by the policy.

These are identified and critically explored through the framework that Lawrence Coastin and the late Jonathan Mann developed in 1999, which was later extended by Barry Hoffnauer and Ted Schrecker in 2000. The article concludes with four recommendations for addressing the central human rights consequences of the policy.

INTRODUCTION

Since 2002, Canada has required HIV testing of all persons aged 15 years and above who request Canadian permanent residency (such as immigrant and refugee persons) and temporary residence (such as migrant workers, students, and long-term visitors from designated countries). HIV screening, which takes place during the immigration medical examination carried out in sanctioned Canadian and foreign medical offices, is a mandatory component of Canada’s immigration process. Until recently, little has been documented about the empirical functioning and consequences of the mandatory policy on persons tested and on health systems because the policy has not been systematically followed or reviewed since its introduction more than eight years ago.

This serologic screening program is said to be “unique” because its public health goals are said to include health promotion rather than exclusion.

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See Bisaillon (2010c).
Panel — Overcoming exclusion: current research and legal issues in Canadian immigration policy for people living with HIV

This article provides summaries of presentations made during the panel. Laura Bisaillon presents findings on the activities, actions and practices newcomers undertake as a result of being tested positive for HIV during Canadian immigration medical screening. Michael Battista discusses how to challenge the “excessive demand” barrier for HIV-positive newcomers through case law and advocacy.

Examining bodies: putting the HIV testing policy to the test

Laura M. Bisaillon, Ph.D. candidate, Institute for Population Health, University of Ottawa

The purpose of this study — for which field work commenced in Fall 2009 — is to explain how Canada’s mandatory HIV testing policy of immigrants organizes how things happen to newcomers who are managing HIV: that is to say, what activities, actions and practices they undertake as a result of being tested positive for HIV during Canadian immigration medical screening. This is the first work of its kind because the mandatory policy has not been reviewed since its introduction in January 2002.

The motivation for this sociological investigation stemmed from gaps between official reports on the functioning and purpose of the policy, 7 and anecdotal experiences with immigration HIV screening as recounted to the author in her work with persons living with HIV/AIDS (PHAs). Immigrant persons reported certain tensions and contradictions that were not reflected in official reports. Preliminary findings presented here are from the standpoint of persons tested for HIV during immigration medical testing. 8

At the start of 2002, blanket serological screening was introduced as one of the three conditions (along with tuberculosis and syphilis) for which all applicants to Canada are mandatorily tested. According to official reports, immigrants consent to the testing, receive pre- and post-test counselling, and are linked with services following an HIV-positive diagnosis. Canadian testing policy is “unique” because its purpose is health promotion and prevention, and not exclusion of HIV-positive applicants. 9 However, these latter points remain unconfirmed in the regulating texts governing the testing policy. 10

Citizen and Immigration Canada (CIC) contracts physicians called designated medical practitioners (DMPs) to carry out HIV testing on the federal government’s behalf. This procedure is done in medical offices in both in Canada and abroad. 11

Enigma of admissibility determination
To date, four findings have emerged from the study. The first is that the process of determining admissibility into Canada is an enigma to all informants. This is true regardless of how the person entered Canada, what motivated his or her application to remain in Canada and other factors such as level of education, gender or country of citizenship.

Shortly after their arrival, PHA newcomers are exposed to the socio-legal environment in Canada and the jurisdiction in which they settle. Persons quickly become familiar with terms such as “excessive demand” and “medical inadmissibility,” legal terminology found in the Immigration and Refugee Protection Act (IRPA) and its regulations. Although they gain awareness through numerous means of the theoretical background and context of the laws and policies that affect them, immigrant PHAs are ill-positioned to know how their application is making its way through government channels during the years it may take to acquire permanent residency.

Indeed, the application process is structured such that the actual knowing is unknowable. A cast of many intermediaries collects information, speaks, sets dates and represents them on their behalf. Contact with

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94 Summary of my presentation (Bisaillon, 2010b).
Working from Within Endemic HIV Stigma

Developing Canadian Social Workers’ Understanding of the Challenges Faced by Newcomers Managing HIV

Laura M. Bisaillon

Abstract

HIV stigma is central to this article’s discussion and analysis because of the widely documented negative social and health impacts of stigma on Canadians living with HIV in general and ethnocultural communities in particular. The goal of this theoretically and empirically informed article is to provide insight for Canadian social workers on the challenges faced by newcomers infected with or affected by HIV. This is achieved by problematizing sociocultural contexts that sustain stigmatization and exploring how these interact with people living with HIV and AIDS (PHAs). Increased caseloads of migrant PHAs in Canada since early 2002 means that social workers throughout Canada have had to adjust and acquire new competencies. This article is informed by field research and social work practice with newcomers in three Canadian cities. HIV stigma is endemic in Canada, and this article posits that social workers with an increased critical awareness about stigma on individual, social and translocal levels can best support migrant PHAs. This article concludes with two key messages for social workers.

Keywords: HIV • stigma • Canada • immigration • people living with HIV and AIDS (PHA) • social work • newcomers • social interaction • critical theory • determinants of health • ethnocultural

Story and science are interrelated, interactive and ultimately constitute each other….The natural world and the cultural worlds share the burden of creating disease realities. (Goldstein, 2004, p. XIII)

One continually learns and relearns to live with as much as through one’s body, in its various states of health and illness, youth and old age, boredom and trauma, routine and instability. (Biehl, Good, Kleinman, 2007, p. 9-10)

There is a significant body of literature discussing the existence of HIV-related stigma in general (Canadian HIV/AIDS Legal Network [CHLN], 2004; Crawford, 1996; Derlega & Barbee, 1998; Roth & Hogan, 1998) and the persistence and implications of HIV-related stigma among newcomers and long-standing ethnocultural communities in Canada in particular (African Caribbean Council on HIV/AIDS in Ontario [ACCHO], 2006; Committee for Accessible AIDS Treatment, 2008; Lawson et al., 2006). Stigma is “an attribute that is deeply discrediting,” one that negatively impinges upon a person’s identity and self-worth (Goffman, 1963, p. 1). More recent discussions of HIV stigma (Elliott et al., 1986; Herek & Glunt, 1988; Madru, 2003), including feminist perspectives (Fortin, 2005; Goupil, 2002), have informed this article. Social exclusion, denial of HIV status, personal suffering and

95 See Bisaillon (2010d).
Abstract

The characteristics and tensions arising during fieldwork in the two authors’ respective projects using institutional ethnography (IE) as a method of inquiry are examined in this article. The first project focused on mandatory screening for human immunodeficiency virus (HIV), a blood test occurring during the Canadian immigration medical examination. The second project was a nursing study that explored nurses’ work in Canadian hospitals. We argue that the politics of a standpoint position, which commit the researcher to taking up the standpoint of persons whose knowledge and experiential expertise is often at odds with authorized ways of knowing, gives rise to these challenges. How we understood and dealt with the challenges stemming from these politics, and the explicit and implicit politics of our projects, are examined. The location of the research standpoint influences how study informants understand and orient to the project of research when the approach to the social offered by IE is adopted. We explore these orientations through the formulation of numerous insights from our interview research in two separate programs of health research. In doing this, we mention issues related to ethical review arising from our observations and interviews, and offer specific strategies to assist health researchers in taking up IE in their critical health research.

Keywords
Critical methods, data collection; HIV/AIDS; institutional ethnography; interviews research; nursing; politics; sociology

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96 Bisaillon, L., & Rankin, J. Currently in preparation for peer-review submission.