

**The Experiences of People Who Use Injection Drugs with Accessing Hepatitis C Testing
and Diagnosis in Western Countries: A Scoping Review**

Nikki Ho

A thesis submitted in partial fulfillment of the requirements for the
Master's degree in the Science of Nursing

School of Nursing
Faculty of Health Sciences
University of Ottawa

© Nikki Ho, Ottawa, Canada, 2022

Preface

1. Patrick O’Byrne RN-EC, PhD

Full Professor, School of Nursing, Faculty of Health Sciences, University of Ottawa

2. Amanda Vandyk RN, PhD

Associate Professor, School of Nursing, Faculty of Health Sciences, University of Ottawa

3. Cynthia Horvath RN, MScN

Nursing Project Officer, Harm Reduction, Health Protection Service, Ottawa Public Health

4. Taliesin Magboo Cahill RN

MScN student, School of Nursing, Faculty of Health Sciences, University of Ottawa

5. Marie-Cécile Domecq

Health Sciences Reference Librarian, Faculty of Health Sciences, University of Ottawa

Dr. Patrick O’Byrne (PO), the thesis supervisor, was engaged throughout the entire review. PO guided the development of the research topic and the direction of the thesis. PO provided feedback throughout the review. PO also reviewed, edited, and approved every chapter of the review.

Dr. Amanda Vandyk (AV), a committee member, offered guidance on the methodology and results of the thesis. AV assisted in the conception of the thesis questions. AV critiqued and guided the methods (Chapter Four) and discussion (Chapter Six) of this review. AV also reviewed the thesis in full and offered feedback.

Cynthia Horvath (CH), a committee member, reviewed the thesis in full and offered feedback based on her research and clinical experience working with the population.

Taliesin Magboo Cahill (TMC), a secondary reviewer, was trained to screen the citations using Covidence. TMC also assisted in data extraction for the findings and participated in reviewing the data. TMC conducted critical appraisals on all the included studies and engaged in the disputes of the final critical appraisal results.

Marie-Cécile Domecq (MCD), a librarian, critiqued the search strategies for the literature review and the scoping review. MCD also conducted a Peer Review of Electronic Search Strategy on the search for the scoping review.

Abstract

The purpose of this thesis is to scope the literature to understand how people who use injection drug (PWIDs) experience access to hepatitis C (HCV) testing and diagnosis. The design was a scoping review methodology, guided by Arksey and O'Malley, JBI, and PRISMA-ScR guidelines. A search was conducted through seven electronic databases using a peer-reviewed search strategy. Five studies were yielded through two-level screenings. The extracted data were synthesized using conventional data analysis and reported using tables and narrative summaries. Four categories were found: *Awareness and Knowledge*, *Stigma*, *Healthcare Service*, and *Psychological Responses*. The studies were conducted in Australia, UK, and US published between 2014 to 2018. A total of 19 participant characteristics were extracted to contextualize their experiences. The World Health Organization's definition of accessibility should be defined through the guidance of the constructed truths of the individuals in the current context. The lack of demographic data and connection to client quotes further exacerbates the inequities among the population through overlooking their intragroup identities.

Key words: people who use injection drugs, accessibility, hepatitis C testing and diagnosis, Western countries, scoping review study

Acknowledgement

Gratitude means to demonstrate appreciation or be thankful for receiving kindness. Here, I attempt to express my feelings of gratitude in words to thank the people who helped me make it through this graduate journey.

I would first like to thank my thesis supervisor, Dr. Patrick O’Byrne, whose guidance was invaluable. You fostered an environment that made it easy for me to grow and I am extremely fortunate to have you as my thesis supervisor. Your work is impactful, and I am elated to continue learning from someone with such high standards.

I would like to thank Dr. Amanda Vandyk, a committee member who has been with me since the inception of this thesis. You have taught me the most about the methodology and your feedback surely challenged me to understand research to great depths.

I would also like to thank Tali Cahill for contributing to the screening and extraction of my study. You promptly helped with my thesis despite having your own work. I cannot thank you enough for allowing me to bug you throughout these years and am grateful for meeting you during our studies.

Thank you, Cynthia Horvath, for being a part of my committee during this difficult time.

Finally, I would like to thank my family and friends. Thank you, Mom, for being one of my biggest supports and for being the most important person in my life. Wilmer Santos, thank you for being my soundboard, late-night study buddy, and a bright light in my life. Thank you to my close family and friends for the overwhelming and nonconditional support throughout this graduate journey. I promise to make up for my absence in the past two years.

Table of Contents

Preface.....	ii
Abstract.....	iv
Acknowledgement.....	v
Table of Contents	vi
List of Figures.....	x
List of Tables	xi
Legend.....	xii
Chapter One: Introduction	1
Introduction.....	1
Hepatitis C Testing and Diagnosis.....	1
Hepatitis C Virus and People Who Use(d) Injection Drugs	3
Existing Synthesis Reviews	4
Problem Statement.....	6
Research Questions	7
Paradigmatic Stance.....	7
References	10
Chapter Two: Literature Review	19
Hepatitis C Virus.....	19
Natural History and Sequelae	19
Transmission	21
Care Continuum and Testing of Hepatitis C Virus.....	21
Diagnosis of Hepatitis C Virus and National Case Definitions	24
Treatment	25

People Who Use(d) Injection Drugs	26
Countries	28
Literature Search	28
Individual-Level Factors	29
Individual-Level Gaps in Practice	30
Sociocultural-Level Factors	31
Sociocultural-Level Gaps in Practice.....	32
Structural-Level Factors.....	32
Structural-Level Gaps in Practice	34
Relationships between Accessibility Factors.....	35
Summary	36
References	38
Chapter Three: Framework.....	51
Primary Health Care Theory	51
Gap in Accessibility	53
References	55
Chapter Four: Methodology	58
Methodological Overview	58
Study Design.....	60
Stage 1: Identifying the Research Question.....	61
Stage 2: Identifying the Literature	62
Electronic Databases	62
Search Terms	64
Search Process	67
Screening Process	68
PRISMA Flow Chart.....	69
Stage 4: Charting the Data	69
Data Extraction Items	70
Data Charting Process.....	72
Critical Appraisal	72

Stage 5: Summarizing and Reporting Results	73
Data Analysis Process	73
Conventional Content Analysis	74
Rigour	75
Ethics.....	77
References	78
Chapter Five: Results	83
PRISMA Flow Diagram	83
Critical Appraisal	85
Study Characteristics	85
Participant Characteristics	87
Client Experiences Content Analysis.....	92
Client Experiences Narrative Summary.....	96
Category 1: Awareness and Knowledge	96
Category 2: Stigma	98
Category 3: Health Service	100
Category 4: Psychological Responses	101
Client-Identified Barriers: Content Analysis	102
Client-Identified Barriers Narrative Summary	103
Category 1: Awareness and Knowledge	103
Category 2: Stigma	104
Category 3: Health Service	106
Category 4: Psychological Responses	107
Client-Identified Facilitators	111
Client-Identified Facilitators Narrative Summaries.....	111
Category 1: Awareness and Knowledge	111
Category 2: Health Service	112
References	116
Chapter Six: Discussion.....	118

How do PWID describe their experiences of seeking and receiving HCV testing and diagnosis in high-income, Western countries?.....	118
What are client-identified barriers and facilitators to HCV testing and diagnosis in high-income, Western countries?.....	119
Critiquing the Current Definition of Accessibility	119
Trajectories of Accessibility	120
Number of Interventions and Barriers to Testing	122
Flexible Pathways	124
Insufficient Client Demographics	127
Future Directions	128
Nursing Education	128
Nursing Practice.....	129
Research.....	129
Nursing Administration	130
Policy	130
State of Science.....	130
Limitations	132
Limitations of the Included Primary Studies	132
Limitations of the Critical Appraisal	133
Limitations of the Scoping Review.....	133
Conclusion	134
References	136
Appendix A.....	147
Appendix B	171

List of Figures

Figure 1 Natural History of HCV	20
Figure 2 The 2016 Global Care Continuum for HCV	23
Figure 3 The Model of Accessibility in Primary Health Care	53
Figure 4 PRISMA Flow Diagram	84
Figure 5 Client Experiences with Seeking or Receiving HCV Testing and Diagnosis	95
Figure 6 Client-Identified Barriers with Seeking or Receiving HCV Testing and Diagnosis....	110
Figure 7 Client-Identified Facilitators with Seeking or Receiving HCV Testing and Diagnosis	115
Figure 8 Multi-Dimensional Perspective of Accessibility.....	122
Figure 9 Client's Trajectory through the Dimensions of Accessibility	124
Figure 10 Flexible Pathways for Clients.....	125

List of Tables

Table 1 Electronic Database Names, Descriptions, and Rationales for Inclusion.....	63
Table 2 Key Search Terms, Search Limits, and Rationales for Criteria.....	65
Table 3 Extraction Items for the Scoping Review	71
Table 4 Counts and Reasons for Excluding Full-Text Citations	83
Table 5 Critical Appraisal Summary	85
Table 6 Study Characteristics	86
Table 7 Synthesis of Participant Characteristics.....	89
Table 8 Participant Characteristics Display Table.....	91
Table 9 Client Experiences Content Analysis	93
Table 10 Client-Identified Barriers Glossary.....	108
Table 11 Client-Identified Facilitators Glossary.....	114
Table A1 Sample of Search Strategy on MEDLINE	147
Table A2 Full Search Strategies	148
Table A3 Critical Appraisal Results	163
Table A4 Client-Identified Barriers Content Analysis	164
Table A5 Client-Identified Facilitators Content Analysis	166
Table A6 ENTREQ Checklist.....	167
Table A7 PRISMA-ScR Checklist.....	169

Legend

CDC	Centers for Disease Control and Prevention
CNA	Canadian Nurses Association
CNO	College of Nurses of Ontario
DAA	Direct-Acting Antiviral
ENTREQ	Enhancing Transparency in Reporting the Synthesis of Qualitative Research
HCP	Healthcare Provider
HCV	Hepatitis C Virus
IDU	Injection Drug Use
JB	Joanna Briggs Institute
MeSH	Medical Subject Headings
PHC	Primary Health Care
PHAC	Public Health Agency of Canada
POC	Point-Of-Care
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Scoping Reviews
PRESS	Peer Review of Electronic Search Strategies
PWID	People who use(d) injection drugs
RNA	Ribonucleic Acid
SEP	Syringe Exchange Program
STBBI	Sexually Transmitted Blood-Borne Infection
SVR	Sustained Virologic Response
UNICEF	United Nations Children's Fund
WHO	World Health Organization

Chapter One: Introduction

Introduction

Hepatitis C virus (HCV) is an infection transmitted via blood that requires public health attention. In 2019, the global estimate of people living with chronic HCV was 58 million people and it was estimated that each year, the global estimate rises by an additional 1.5 million new people living with HCV (World Health Organization [WHO], 2021). Chronic HCV commonly advances to the morbidities of liver disease or cancer (WHO, 2017a). This assertion is supported by the WHO's (2021) hepatitis report, which estimated that 150,000 people developed hepatocellular carcinoma in 2018. While HCV-related mortality HCV is declining, it contributed to 1.1 million deaths globally in 2019. Evidence suggests that limited funding and access to HCV diagnosis and treatment contributes to such mortality (WHO, 2017a, 2021). While HCV affects many people, it most disproportionately affects people who use(d) injection drugs (Hajarizadeh et al., 2013; Public Health Agency of Canada [PHAC], 2014; WHO, 2019b).

Hepatitis C Testing and Diagnosis

HCV diagnosis and treatment are essential steps in the care continuum. The care continuum is a concept to describe how individuals living with HCV engage with health services from exposure to clearance of infection (WHO, 2017a). While the overall goal of the care continuum is to maintain or increase client engagement at each step of the cascade (Tsui et al., 2019; WHO, 2017a), the global care continuum for HCV infection in 2015 shows that there was a decrease in engagement between all steps of the continuum. Indeed, there was a 70% gap between individuals living with HCV and individuals diagnosed with HCV, and a 73% gap between individuals diagnosed with HCV and those on treatment (WHO, 2017a, p. 31). Thus, it

is crucial to investigate the steps of testing and diagnosis because they are the first steps in the care continuum (Jones et al., 2014).

Specifically, diagnosis of HCV involves testing for HCV antibodies (anti-HCV), hepatitis C ribonucleic acid (RNA), and clinical confirmation of the individual's HCV serostatus (PHAC, 2019b). A positive or detectable anti-HCV status signals that an individual has HCV antibodies due to a current or past HCV infection (Trubnikov et al., 2014). However, because approximately 25% of persons with HCV infection naturally clear the infection, RNA testing is required to determine active infection (PHAC, 2019b; Trubnikov et al., 2014). HCV testing is available through a variety of methods; but the WHO (2017a, 2021) described barriers in testing which leads to approximately 80% of individuals living with hepatitis from being aware of their HCV serostatuses. These barriers often lead to a delay in diagnosis, which could lead to or exacerbate the following complications: fibrosis, liver inflammation, and if left untreated, hepatocellular carcinoma, decompensated liver disease, and death (Centers for Disease Control and Prevention [CDC], 2020a, 2020b; Lauer & Walker, 2001; PHAC, 2018).

In response to ongoing HCV transmission and barriers to the care continuum, the World Health Assembly set the Global Viral Hepatitis Strategy in 2016 with the goal of eliminating HCV infection. The targets aim for a 30% increase in awareness in HCV serostatus of individuals infected with HCV by 2020 and a 90% increase by 2030 (WHO, 2016). Additionally, the 2030 target aims to reduce HCV mortality by 65% compared to 2015 statistics (WHO, 2016, 2017a). However, the 2020 targets were not met (WHO, 2021). A study published by the International Liver Congress (2019) found that 80% of the high-income countries will not likely meet the 2030 targets and it was predicted that 67% of the high-income countries would not meet

the 2030 targets until after 2050. The 2017 Global Hepatitis Report similarly found that only 31 to 36% of people living with HCV were diagnosed and only 5 to 11% started on treatment in high-income, Western regions (WHO, 2017a). The WHO found that high-income countries may not reach the global HCV targets because of the lack of funding for HCV services and the availability of services dedicated to persons who use(d) drugs. These issues serve as challenges to engaging clients in the HCV care continuum (WHO, 2017b, 2019a).

Hepatitis C Virus and People Who Use(d) Injection Drugs

People who use(d) injection drugs (PWID) are at risk for HCV acquisition because they engage(d) in practices that can transmit HCV within a context where the risk of HCV exposure is high due to elevated baseline HCV prevalence among this population (at 66%), compared to the entire Canadian population (at .96%) (PHAC, 2012; Trubnikov et al., 2014; WHO, 2019b).

Healthcare providers (HCPs) and clients could influence client engagement in the HCV care continuum to decrease transmission. HCPs engage clients through following screening guidelines to target at-risk individuals (WHO, 2017b, 2019a), whereas clients may engage through accessing healthcare services to request the diagnostics that they feel they need. However, marginalized populations, such as PWID, experience more barriers to accessing healthcare services such as HCV testing due to stigma related to their injection drug use and because of their vulnerability to systemic marginalization and criminalization (Global Commission on Drug Policy, 2011; Jürgens, 2008; Richardson et al., 2015).

Recognizing such vulnerability in PWID, harm reduction interventions are population-appropriate strategies that can be used to enhance inclusivity, promote equity, and minimize negative experiences. Examples of harm reduction approaches include reducing stigma at testing

centres relating to injection practice and HCV, offering less invasive HCV testing options, and integrative models of HCV care with outreach and at supervised injection sites (Biancarelli et al., 2019; Chikovani et al., 2019; Roose et al., 2014; Swan et al., 2018).

Many screening guidelines from Western countries include PWID as target populations and suggests multi-testing methods to accommodate the clients (Australian Government, 2004, 2015; Best Practice Advocacy Centre New Zealand [BPAC NZ], 2019; Bregenzer et al., 2017; Canadian Aids Treatment Information Exchange [CATIE], 2018; CDC, 2020c; European Centre for Disease Prevention and Control [ECDC], 2018; Gastroenterological Society of Australia, 2020; Ha et al., 2016; Health Protection Agency, 2011; Kileng et al., 2019; Lab tests online Australia, 2020; Löve & Stanzeit, 1994; Ministry of Health New Zealand, 2018; National Hepatitis Team, National Infection Service, Public Health England, 2019; Official Journal of the European Union, 2018; Olafsson et al., 2017, 2019; PHAC, 2018, 2019a). Despite the population-appropriate strategies such as inclusive screening guidelines and harm reduction strategies, most HCV infections are among PWID (Challacombe, 2019; WHO, 2017a), thus this will be the focus herein. Since PWID are susceptible to systemic marginalization, they may experience access to HCV testing and diagnosis differently compared to the other at-risk populations. Discussion about their experiences could reduce inequities and allow for more population-specific approaches (Biancarelli et al., 2019; Chikovani et al., 2019; Roose et al., 2014; Swan et al., 2018; WHO, 2017a).

Existing Synthesis Reviews

A preliminary search of the literature was conducted to screen for relevant synthesis studies that existed about PWID's experiences accessing HCV testing. The Health Sciences

librarian at the University of Ottawa reviewed the search process conducted on MEDLINE. The key search terms included the concepts of *PWID*, *HCV*, *testing*, *diagnosis*, and *synthesis study*. Search terms, synonyms, terms specific to each database, and Medical Subject Headings (MeSH) terms were searched in the multipurpose set of fields. Searches were conducted in the online databases Google Scholar, MEDLINE, Embase, Figshare, and the Open Science Framework (OSF) from June 2020 to August 2020, and one qualitative systematic review about PWID's views and experiences with HCV testing and diagnosis was identified (Jones et al., 2014). The review included 28 studies published between 2003 to 2010 from 14 databases. The studies originated from high-income Western countries such as Australia, Canada, Hungary, Ireland, the United Kingdom (UK) and the United States (US). Despite being published in 2014, the review limited searches from 1990 to April 2011.

Jones and colleagues (2014) explored the perspectives of PWID and HCPs with HCV testing. While their review study included qualitative literature, which may contain information on the perspectives of PWID on HCV, their research questions were categorized into four specific fields, with one question focused on exploring the population's "knowledge, beliefs, and practices" (p. 205) relating to HCV and describing the population's opinions of changing their behaviours towards HCV testing (Jones et al., 2014). In addition, the study by Jones and colleagues (2014) is different in scope because they included HCP and inmates' perspectives about the phenomenon.

Compared to my study exploring the clients' organic access to testing and diagnosis in the community settings, the Jones and colleagues (2014) took interest in investigating a larger scope of the phenomenon through their inclusion of diverse populations (i.e., HCPs and inmates)

to broadly illustrate a similar phenomenon. Conducting an updated synthesis focusing on the experiences solely verbalized by the clients may provide more specific findings. As well, the updated synthesis search from 2014 onward will help ensure our understandings of the participants' reported experiences in the current context of more effective and tolerable HCV treatments (Goodyear et al., 2021; Torrens et al., 2020; Madden et al., 2018). Such an update regarding treatment is important because access to, and the tolerability of, treatment can influence persons' willingness to access testing (Bartlett et al., 2019). Combining the experiences about testing before 2014 would be inappropriate because of the different contexts in treatment. My scoping review study will not only shed light on findings from newer, more current research, it is also markedly different in scope

Problem Statement

Despite the implementation of harm reduction approaches, HCV infection among PWID continues to be a significant problem that causes long-term complications (Biancarelli et al., 2019; CDC, 2020b; Chikovani et al., 2019; PHAC, 2019b; Roose et al., 2014; Swan et al., 2018; Trubnikov et al., 2014; WHO, 2019a). PWID face considerable barriers because of the aforementioned reasons (Global Commission on Drug Policy, 2011; Jürgens, 2008; Richardson et al., 2015) which undermine their engagement with HCV-related services, thus supporting the assertion that there is decreased engagement in each step of the HCV care continuum. Low testing rates are problematic because testing is one of the initial steps to engaging individuals to HCV treatment, hence low testing rates would lead to lower treatment rates and onward transmission (Tsui et al., 2019; WHO 2017a).

Jones and colleagues (2014) started an important discussion regarding access to HCV testing which includes the client perspective, but there needs to be an updated review to scope the literature in the current context of newer and more effective treatment (Goodyear et al., 2021; Torrens et al., 2020; Madden et al., 2018).

Addressing this problem from their perspectives could give HCPs more insight into ways to develop more population-specific strategies, as well as a more nuanced understanding of current trends in PWID's access to HCV diagnosis. The findings could better inform clinical practice, research, policies, and administration which could ultimately address the population's unique needs (WHO, 2019a), including their quality of life as well as population-level morbidity and mortality.

Therefore, the following research questions were created to address this thesis:

Research Questions

1. Based on existing literature, how do PWID describe their experiences of seeking and receiving HCV testing and diagnosis in high-income, Western countries?
2. What are client-identified barriers and facilitators to HCV testing and diagnosis in high-income, Western countries?

Paradigmatic Stance

Philosophical paradigms are a set of “basic beliefs” (Guba & Lincoln, 1994, p. 107) that influence an individual's perspective of the world. Examples include positivism, constructivism, and postpositivism (Guba & Lincoln, 1994). Critical theory is another paradigm, with its aim of inquiry being to focus on the constraints individuals may face and empower individuals to overcome contextual barriers (Creswell, 2013; Guba & Lincoln, 1994; Weaver & Olson, 2006).

The historical roots of critical theory lie in the discipline of sociology, heavily inspired by Marx, Habermas, and Freire (Weaver & Olson, 2006). This worldview suggests advocating for social justice and equity, and the emancipation of oppressed groups (Denzin, 2017; Weaver & Olson, 2006). Due to this focus on social justice, critical theory will guide this study in viewing the realities of PWID in accessing HCV testing and diagnosis and will guide recommendations on how to counteract the oppression.

The basic beliefs that define a philosophical paradigm like critical theory are bound by ontological, epistemological, and methodological assumptions (Guba & Lincoln, 1994). Firstly, ontology is about the understanding of truth (Guba & Lincoln, 1994). Critical theory assumes a *historical realist* ontology, which accepts that realities are mouldable constructs that could be affected by an individual's external context, such as demographics and political factors (Guba & Lincoln, 1994). Secondly, epistemology explores what can be known about the truths and describes the relationships between persons trying to understand the individual(s) of interest, or researcher, and the individual(s) of interest, or participant(s) (Guba & Lincoln, 1994). Critical theory assumes a *subjective* and *transactional* epistemology, which accepts that the relationship between the researcher and participant(s) is dynamic and findings are throughout the investigation (Creswell, 2013; Guba & Lincoln, 1994). Critical theory relies on the participant(s)' perspective and positions knowledge created throughout the investigation, within the constraints and context of gender, sexuality, economics, history, race and ethnicity (Guba & Lincoln, 1994). Lastly, methodology reflects how the researcher can discover findings and what methods can be used to accomplish this (Guba & Lincoln, 1994). Critical theory assumes a *dialogic* and *dialectical* methodology, which aims to interpret the situation through engagement

to reveal how these constraints may lead to disadvantaged experiences, such as struggle, conflict, or suffering (Guba & Lincoln, 1994).

Within the critical theorist philosophy, my thesis will be conceptualized through a poststructuralist lens. Poststructuralism, as influenced by Derrida and Foucault, while created based on the philosophy of structuralism, rejects the tenet of absolute truths. The poststructuralist stance views ontology as co-constructed through social and historized meanings. Thus, ontological meanings are produced in language and are created through each person's interpretation, presenting new conceptualizations and meanings (Deleuze & Guattari, 1983; Foucault, 1954). These beliefs align with the nursing construct of client-centred care, recognizing that individuals are not to be homogenized, and signalling that individualized care plans with external considerations are required for each client (Jolley et al., 2017).

To preserve the uniqueness of an individual's perspective of the experiences, the scoping review methodology was used to collect client statements, which revealed the similarities and differences among these perspectives about the phenomenon of interest, as well as larger contextual issues the clients' experience to create a multifaceted interpretation of the phenomenon (Barnett-Page & Thomas, 2009; Paterson et al., 2007). The synthesis of participants' statements in the reviewed studies is not, however, understood in this thesis as a representation of an absolute truth, but rather, as one possibility within a multiplicity of truths. Hence, a scoping review situated in the critical theorist approach is appropriate for displaying the many and lived realities of PWID in this time and place in history.

References

- Australian Government. (2004). *Hepatitis c (unspecified) case definition*. Australian Government Department of Health.
https://www1.health.gov.au/internet/main/publishing.nsf/Content/cda-surveil-nndss-casedefs-cd_hepcun.htm
- Australian Government. (2015). *Hepatitis C (newly acquired) case definition*. Australian Government Department of Health.
https://www1.health.gov.au/internet/main/publishing.nsf/Content/cda-surveil-nndss-casedefs-cd_hepcnew.htm
- Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: A critical review. *BMC Medical Research Methodology*, 9(1), 59.
<https://doi.org/10.1186/1471-2288-9-59>
- Bartlett, S. R., Yu, A., Chapinal, N., Rossi, C., Butt, Z., Wong, S., Darvishian, M., Gilbert, M., Wong, J., Binka, M., Alvarez, M., Tyndall, M., Krajden, M., & Janjua, N. Z. (2019). The population level care cascade for hepatitis C in British Columbia, Canada as of 2018: Impact of direct acting antivirals. *Liver International*, 39(12), 2261–2272.
<https://doi.org/10.1111/liv.14227>
- Biancarelli, D. L., Biello, K. B., Childs, E., Drainoni, M., Salhaney, P., Edeza, A., Mimiaga, M. J., Saitz, R., & Bazzi, A. R. (2019). Strategies used by people who inject drugs to avoid stigma in healthcare settings. *Drug and Alcohol Dependence*, 198(Complete), 80–86.
<https://doi.org/10.1016/j.drugalcdep.2019.01.037>
- Best Practice Advocacy Centre New Zealand [BPAC NZ]. (2019, January). *Testing for hepatitis c virus (HCV) in patients at high risk of infection*. BPAC NZ Better Medicine.

Bregenzer, A., Conen, A., Knuchel, J., Friedl, A., Eigenmann, F., Näf, M., Ackle, P., Roth, M., & Fux, C. A. (2017). Management of hepatitis C in decentralised versus centralised drug substitution programmes and minimally invasive point-of-care tests to close gaps in the HCV cascade. *Swiss Medical Weekly*, 147(4748).

<https://doi.org/10.4414/smw.2017.14544>

CATIE. (2018). *Easy HCV-test*. Programming Connection. <https://www.catie.ca/en/pc/evidence-briefs/easy-hcv>

Centers for Disease Control and Prevention [CDC]. (2013). *Testing for HCV infection: An update of guidance for clinicians and laboratorians* (Morbidity and Mortality Weekly Report). <https://www-cdc-gov.proxy.bib.uottawa.ca/mmwr/pdf/wk/mm62e0507a2.pdf>

CDC. (2019). *Viral hepatitis surveillance United States, 2017*. <https://www-cdc-gov.proxy.bib.uottawa.ca/hepatitis/statistics/2017surveillance/pdfs/2017HepSurveillanceRpt.pdf>

CDC. (2020a). *Hepatitis C, acute. 2020 case definition*. National Notifiable Diseases Surveillance System (NNDSS). [/nndss/conditions/hepatitis-c-acute/case-definition/2020/](https://www.cdc.gov/nndss/conditions/hepatitis-c-acute/case-definition/2020/)

CDC. (2020b). *Hepatitis C, chronic. 2020 case definition*. National Notifiable Diseases Surveillance System (NNDSS). <https://wwwn.cdc.gov/nndss/conditions/hepatitis-c-chronic/case-definition/2020/>

CDC. (2020c, July 29). *Testing recommendations for hepatitis C virus infection*. Viral Hepatitis. <http://www.cdc.gov/hepatitis/hcv/guidelinesc.htm>

Challacombe, L. (2019). *The epidemiology of hepatitis C in Canada*. CATIE Canada's Source for HIV and Hepatitis C Information. <https://www.catie.ca/factsheets/epidemiology/epidemiology-hepatitis-c-canada>

- Chikovani, I., Ompad, D. C., Uchaneishvili, M., Sulaberidze, L., Sikharulidze, K., Hagan, H., & Van Devanter, N. L. (2019). On the way to Hepatitis C elimination in the Republic of Georgia—Barriers and facilitators for people who inject drugs for engaging in the treatment program: A formative qualitative study. *PLOS ONE*, *14*(4), e0216123. <https://doi.org/10.1371/journal.pone.0216123>
- Creswell, J. (2013). *Third edition qualitative inquiry and research design* (Third). Sage Publications, Inc. <http://www.ceil-conicet.gov.ar/wp-content/uploads/2018/04/CRESWELLQualitative-Inquiry-and-Research-Design-Creswell.pdf>
- Deleuze, G., & Guattari, F. (1983). *Anti-edupus capitalism and schizophrenia*. University of Minnesota Press.
- Denzin, N. K. (2017). Critical qualitative inquiry. *Qualitative Inquiry*, *23*(1), 8–16. <https://doi.org/10.1177/1077800416681864>
- European Centre for Disease Prevention and Control [ECDC]. (2018). *Public health guidance on HIV, hepatitis B and C testing in the EU/EEA – An integrated approach*. 111. <https://doi.org/10.2900/79127>
- Foucault, M. (1954). Structuralism et poststructuralisme. In *Dits et écrits*. Éditions Gallimard.
- Gastroenterological Society of Australia. (2020, June). *Screening and diagnosis*. Australian Recommendations for the Management of Hepatitis C Virus Infection: A Consensus Statement (June 2020). <https://www.hepcguidelines.org.au/screening-and-diagnosis/>
- Global Commission on Drug Policy. (2011). *War on drugs. Report of the Global Commission on drug policy*. https://www.globalcommissionondrugs.org/wp-content/themes/gcdp_v1/pdf/Global_Commission_Report_English.pdf

- Goodyear, T., Brown, H., Browne, A. J., Hoong, P., Ti, L., & Knight, R. (2021). “I want to get better, but...”: Identifying the perceptions and experiences of people who inject drugs with respect to evolving hepatitis C virus treatments. *International Journal for Equity in Health*, 20(1), 81. <https://doi.org/10.1186/s12939-021-01420-7>
- Guba, E., & Lincoln, Y. (1994). Chapter 6 competing paradigms in qualitative research. In *Handbook of qualitative research* (pp. 105–117). N.K. Denzin & Y. S. Lincoln.
- Ha, S., Totten, S., Pogany, L., Wu, J., & Gale-Rowe, M. (2016). Hepatitis C in Canada and the importance of risk-based screening. *PHAC*, 42(3), 57–62.
<https://doi.org/10.14745/ccdr.v42i03a02>
- Hajarizadeh, B., Grebely, J., & Dore, G. J. (2013). Epidemiology and natural history of HCV infection. *Nature Reviews Gastroenterology & Hepatology*, 10(9), 553–562.
<https://doi.org/10.1038/nrgastro.2013.107>
- Health Protection Agency. (2011). *Standards for local surveillance and follow up of hepatitis B and C*. Health Protection Agency.
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/324052/Standards_surveillance_follow_up_hep_B_and_C__final_.pdf
- Jolley, R. J., Lorenzetti, D. L., Manalili, K., Lu, M., Quan, H., & Santana, M. J. (2017). Protocol for a scoping review study to identify and classify patient-centred quality indicators. *BMJ Open*, 7(1), e013632. <https://doi.org/10.1136/bmjopen-2016-013632>
- Jones, L., Atkinson, A., Bates, G., McCoy, E., Porcellato, L., Beynon, C., McVeigh, J., & Bellis, M. A. (2014). Views and experiences of hepatitis C testing and diagnosis among people who inject drugs: Systematic review of qualitative research. [Review]. *Journal of Drug Policy*, 25(2), 204–211. <https://doi.org/10.1016/j.drugpo.2013.11.004>

Jürgens, R. (2008). “*Nothing about us without us*” greater, meaningful involvement of people who use illegal drugs: A public health, ethical and human rights imperative.

(International ed.). Canadian HIV/AIDS Legal Network, Canadian HIV/AIDS Legal Network : International HIV/AIDS Alliance : Open Society Institute.

<https://login.proxy.bib.uottawa.ca/login?url=http://www.deslibris.ca/ID/213091>

Kileng, H., Gutteberg, T., Goll, R., & Paulssen, E. J. (2019). Screening for hepatitis C in a general adult population in a low-prevalence area: The Tromsø study. *BMC Infectious Diseases*, 19. <https://doi.org/10.1186/s12879-019-3832-7>

Lab tests online Australia. (2020, April). *Hepatitis C virus*. Hepatitis C Virus.

<https://labtestsonline.org.au/learning/test-index/hepatitis-c>

Lauer, G. M., & Walker, B. D. (2001). Hepatitis C virus infection. *The New England Journal of Medicine*; Boston, 345(1), 41–52.

Löve, A., & Stanzeit, B. (1994). Hepatitis C virus infection in Iceland: A recently introduced bloodborne disease. *Epidemiology and Infection*, 113(3), 529–536.

<https://doi.org/10.1017/S0950268800068540>

Madden, A., Hopwood, M., Neale, J., & Treloar, C. (2018). Beyond interferon side effects: What residual barriers exist to DAA hepatitis C treatment for people who inject drugs? *PLoS ONE*, 13(11), 1–10. <https://doi.org/10.1371/journal.pone.0207226>

Ministry of Health NZ. (2018, April). *Hepatitis C*. Ministry of Health NZ.

<https://www.health.govt.nz/our-work/diseases-and-conditions/communicable-disease-control-manual/hepatitis-c>

National Hepatitis Team, National Infection Service, Public Health England. (2019). Hepatitis C: interventions for patient case-finding and linkage to care Evidence review. *Public Health England*, 99.

Official Journal of the European Union. (2018). *Commission implementing decision (EU)*.

Official Journal of the European Union. <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32018D0945&from=EN#page=23>

Olafsson, S., Fridriksdottir, R., Tyrfingsson, T., Runarsdottir, V., Hansdottir, I., Bergmann, O., Bjornsson, E., Johannsson, B., Sigurdardottir, B., Love, A., Baldvinsdottir, G., Love, T., Sigmundsdottir, G., Josefsdottir, K., Hernandez, U., Heimisdottir, M., Gottfredsson, M., & TRAP HEP C working group. (2019). Iceland may already have reached the WHO 2030 targets for diagnosis and treatment of hepatitis C virus infection. Results from the Treatment as Prevention for Hepatitis C (TrapHepC) program. *The International Liver Congress*, 10–14.

Olafsson, S., Tyrfingsson, T., Runarsdottir, V., Bergmann, O. M., Björnsson, E. S., Johannsson, B., Sigurdardottir, B., Fridriksdottir, R. H., Löve, A., Löve, T. J., Sigmundsdottir, G., Heimisdottir, M., & Gottfredsson, M. (2017). Treatment as prevention for hepatitis C in Iceland (TRAP HEP C). A real-world experience from a nationwide elimination program using direct acting antiviral agents. *Journal of Hepatology*, 66(1), S72–S72. [https://doi.org/10.1016/S0168-8278\(17\)30405-1](https://doi.org/10.1016/S0168-8278(17)30405-1)

Paterson, B. L., Backmund, M., Hirsch, G., & Yim, C. (2007). The depiction of stigmatization in research about hepatitis C. *International Journal of Drug Policy*, 18(5), 364–373. <https://doi.org/10.1016/j.drugpo.2007.02.004>

- PHAC. (2012). *Hepatitis C in Canada: 2005-2010 Surveillance Report*. Public Health Agency of Canada. https://epe.lac-bac.gc.ca/100/201/301/weekly_checklist/2012/internet/w12-16-U-E.html/collections/collection_2012/aspc-phac/HP40-70-2012-eng.pdf
- PHAC. (2014). *Summary of key findings from I-Track Phase 3 (2010-2012)* (I-Track). Public Health Agency of Canada. <https://www.canada.ca/en/public-health/services/diseases/hiv-aids/surveillance-hiv-aids/itrack-enhanced-surveillance-hiv-hepatitis-associated-risk-behaviours-people-who-inject-drugs-canada-phase-3.html>
- PHAC. (2018, December 12). *National case definition: Hepatitis C*. <https://www.canada.ca/en/public-health/services/diseases/hepatitis-c/health-professionals-hepatitis-c/national-case-definition.html>
- PHAC. (2019a). *Hepatitis C virus (HCV): Screening and testing for health professionals*. PHAC. <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/hepatitis-c-screening-testing-health-professionals.html>
- PHAC. (2019b, July 22). *For health professionals: Hepatitis C*. Government of Canada. <https://www.canada.ca/en/public-health/services/diseases/hepatitis-c/health-professionals-hepatitis-c.html>
- Richardson, L. A., Long, C., DeBeck, K., Nguyen, P., Milloy, M.-J. S., Wood, E., & Kerr, T. H. (2015). Socioeconomic marginalisation in the structural production of vulnerability to violence among people who use illicit drugs. *J Epidemiol Community Health*, 69(7), 686–692. <https://doi.org/10.1136/jech-2014-205079>
- Roose, R., Cockerham-Colas, L., Soloway, I., Batchelder, A., & Litwin, A. (2014). Reducing barriers to hepatitis C treatment among drug users: An integrated hepatitis C peer

- education and support program. *Journal of Health Care for the Poor and Underserved*, 25(2), 652–662. <https://doi.org/10.1353/hpu.2014.0096>
- Swan, D. M., McCombe, G., O'Connor, E., Murphy, C., Avramovic, G., Macias Sanchez, J., Oprea, C., Story, A., Surey, J., Vickerman, P., Ward, Z., Lambert, J. S., & Cullen, W. (2018). Integrating hepatitis C care for at risk groups: Findings from a multi-centre observational study in primary and community care. *International Journal of Integrated Care*, 18(s2), 360. <https://doi.org/10.5334/ijic.s2360>
- Torrens, M., Soyemi, T., Bowman, D., & Schatz, E. (2020). Beyond clinical outcomes: The social and healthcare system implications of hepatitis C treatment. *BMC Infectious Diseases*, 20(1), 702. <https://doi.org/10.1186/s12879-020-05426-4>
- Trubnikov, M., Yan, P., & Archibald, C. (2014). Estimated prevalence of Hepatitis C Virus infection in Canada, 2011. *Canada Communicable Disease Report*, 40(19), 429–436. <https://doi.org/10.14745/ccdr.v40i19a02>
- Tsui, J. I., Miller, C. M., Scott, J. D., Corcorran, M. A., Dombrowski, J. C., & Glick, S. N. (2019). Hepatitis C continuum of care and utilization of healthcare and harm reduction services among persons who inject drugs in Seattle. *Drug and Alcohol Dependence*, 195, 114–120. <https://doi.org/10.1016/j.drugalcdep.2018.11.026>
- Weaver, K., & Olson, J. K. (2006). Understanding paradigms used for nursing research. *Journal of Advanced Nursing*, 53(4), 459–469. <https://doi.org/10.1111/j.1365-2648.2006.03740.x>
- WHO. (2016). *Global Health Sector Strategy on Viral Hepatitis 2016-2021 Towards Ending Viral Hepatitis* (WHO/HIV/2016.06). <https://apps-who-int.proxy.bib.uottawa.ca/iris/bitstream/handle/10665/246177/WHO-HIV-2016.06-eng.pdf?sequence=1>

WHO. (2017a). *Global hepatitis report, 2017*.

<http://apps.who.int/iris/bitstream/10665/255016/1/9789241565455-eng.pdf?ua=1>

WHO. (2017b, July). *Eliminate hepatitis: WHO*. <https://www.who.int/news-room/detail/27-07-2017-eliminate-hepatitis-who>

WHO. (2019a). *Access to hepatitis C testing and treatment for people who inject drugs and people in prisons—A Global Perspective Policy Brief* (WHO/CDS/HIV/19.6).

<https://apps-who-int.proxy.bib.uottawa.ca/iris/bitstream/handle/10665/312116/WHO-CDS-HIV-19.6-eng.pdf>

WHO. (2019b, July 9). *Hepatitis C*. World Health Organization. <http://www.who.int/news-room/fact-sheets/detail/hepatitis-c>

WHO. (2021). *Global progress report on HIV, viral hepatitis and sexually transmitted infections, 2021* (p. 108). <https://www.who.int/publications/i/item/9789240027077>

Wilton, J., & Broeckeaert, L. (2013). *The HIV treatment cascade – patching the leaks to improve HIV prevention*. <https://www.catie.ca/en/pif/spring-2013/hiv-treatment-cascade-patching-leaks-improve-hiv-prevention>

Chapter Two: Literature Review

In this chapter, I describe the background that supports the main concepts from historical and current perspectives. I also describe the relationships between the main concepts, determine the current literature which speaks to the topic of interest, as well as reveal gaps with the literature describing the topic of interest.

Hepatitis C Virus

Viral hepatitis has climbed from the 10th leading cause of death worldwide in 2010 to the 6th leading cause of death in 2013, where 96% of the viral hepatitis-related deaths were caused by hepatitis B virus (HBV) and HCV (Wang et al., 2016). The Global Burden Disease Study found that in 2013, the viral hepatitis-related deaths in lower-income countries were comparable to those which occurred in higher-income countries (20.7 million and 21.7 million deaths respectively) (Stanaway et al., 2016). People are at higher risk of HCV acquisition due to many risk factors, with the most common including sharing of injection equipment, improper sterilization of medical equipment, transfusion of contaminated blood or blood products, and sexual practices involving exposure to blood (WHO, 2019). Despite the numerous risk factors, HCV-related statistics are underestimated because many people remain undiagnosed.

Natural History and Sequelae

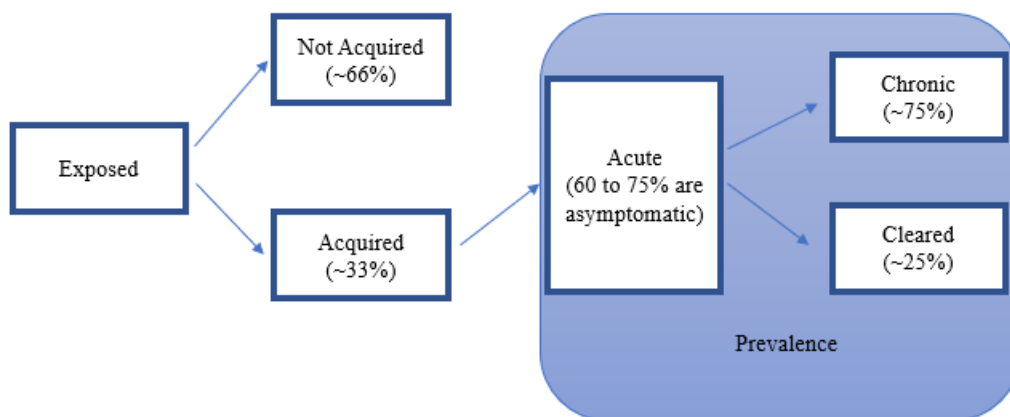
About 15 to 45% of HCV infections resolve within six months of exposure (defined as the acute period) without treatment (PHAC, 2018a; WHO, 2019). Clinical symptoms of acute infections often present within eight weeks of exposure (Lauer & Walker, 2001) as “anorexia, abdominal discomfort, nausea, vomiting, malaise, fatigue, dark urine, pale stools and jaundice” (PHAC, 2018a). Diagnosis of acute infection, however, is uncommon, as over 90% of cases are

unrecognized by clients and HCPs because symptoms are mild or non-existent (Lauer & Walker, 2001; PHAC, 2018a). Despite not being diagnosed, asymptomatic persons living with acute HCV can still transmit this infection to others (PHAC, 2018a).

Approximately 50 to 85% of acute infections persist for more than six months and become chronic (PHAC, 2019a). Chronic cases commonly cause fibrosis and hepatic inflammation, which can lead to hepatocellular carcinoma, decompensated liver disease, and premature death if left untreated (Lauer & Walker, 2001). Due to the comorbidities caused by HCV infection, it was the leading cause of liver transplants worldwide (Joshi, 2014). Of the individuals who acquire HCV and develop an acute infection, approximately 75% develop a chronic infection and about 25% spontaneously clear HCV (Micallef et al., 2006).

Figure 1

Natural History of HCV



Note. The data for the figure is from “[PHAC. (2019, July 22). *For health professionals: Hepatitis C*. Government of Canada. <https://www.canada.ca/en/public-health/services/diseases/hepatitis-c/health-professionals-hepatitis->

c.html]” and cross-checked on “[CDC. (2020, January 13). *Hepatitis C Questions and Answers for Health Professionals*. Centers for Disease Control and Prevention. <https://www.cdc.gov/hepatitis/hcv/hcvfaq.htm>]”.

Transmission

HCV is transmitted through blood and practices that pose a risk of exposure to blood. Sharing injection drug use equipment, reusing improperly sterilized medical equipment, transfusing contaminated blood, and sexual practices involving blood are the most common methods of transmission (WHO, 2019). Notably, sharing injection drug use equipment is the leading cause of HCV transmission in developed countries (Hajarizadeh et al., 2013; WHO, 2017). HCV has a high transmission rate of approximately 2 to 10% for needlestick exposures (The Official Website of New York State, 2005), thus making it 10 times more contagious than HIV (Page et al., 2013). Individuals can be susceptible to HCV more than once despite a successful treatment or natural clearance of HCV (Zein & Persing, 1996). HCV is thus easily transmitted.

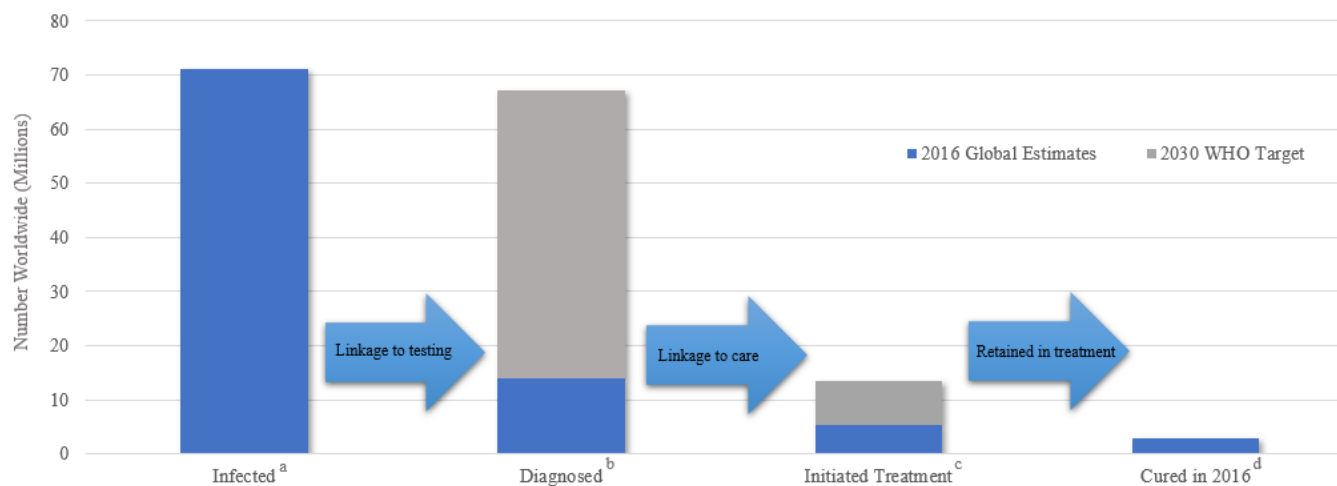
Care Continuum and Testing of Hepatitis C Virus

The care continuum, also known as the cascade of care, was created to display how people living with HIV engage with health services from exposure to screening and diagnosis to treatment to clearance of infection (WHO, 2017). A strong utility of the care continuum is that it shows where clients become disengaged from care throughout the cascade. Clients would ideally engage with all steps of the care continuum to ultimately meet their health and social needs (Andrews, 2017; Wilton & Broeckaert, 2013). However, engagement decreases at each step of the cascade and with each additional step in the cascade, there is a risk of losing more clients

(Wilton & Broeckeaert, 2013). See Figure 2 for the global care continuum for HCV with data from WHO (2016).

Figure 2

The 2016 Global Care Continuum for HCV



Note. The data from this figure is from “[WHO. (2017). *Global hepatitis report, 2017*. <http://apps.who.int/iris/bitstream/10665/255016/1/9789241565455-eng.pdf?ua=1>”].

Infected^a= estimated prevalence of chronic HCV (does not account for acute cases)

Diagnosed^b= could be further divided into steps describing the number of people receiving testing (anti-HCV and RNA testing, or just one test) and people who became aware of their serostatuses.

Treatment^c= could be further divided into steps describing liver function test, fibroscan, and genotype testing.

Cured^d= confirmation of suppressed viral load. After Cured, an option to include a step to describe follow-up and chronic care.

Summarizing the HCV care continuum, according to Thomas (2020), “among an estimated 71 million persons infected with HCV worldwide, approximately 20% were diagnosed and 7% successfully treated by 2015.” (p. 9), demonstrating a gradual decrease in engagement with each step of the cascade. Testing and diagnosis are one of the first steps in linking people into the HCV care continuum and could be further divided into steps describing the number of individuals engaged with receiving one of the steps of testing as well as the number who received a clinical diagnosis of HCV. Detection of HCV, particularly in the early stages helps promote prevention and reduces the risk of chronic HCV (PHAC, 2018b; WHO, 2017). As one of the first steps of the care continuum, the complexity of the step of diagnosis demonstrates the need to explore the recent experiences of PWID with accessing HCV testing and diagnosis. My thesis will focus on the experiences leading to the diagnosis step of the cascade with the acknowledgement that all steps are integral in decreasing HCV-related prevalence and mortality amongst PWID.

Diagnosis of Hepatitis C Virus and National Case Definitions

Diagnosis of HCV typically requires testing of hepatitis C antibody (anti-HCV) and hepatitis C ribonucleic acid (RNA) (PHAC, 2019b). A positive or detectable anti-HCV status identifies antibodies to HCV in the bloodstream due to a current or past HCV infection but does not provide insight relating to current infection (PHAC, 2019b; Trubnikov et al., 2014). With the confirmation of a reactive anti-HCV result, the secondary polymerase chain reaction (PCR or RNA) testing could be performed to confirm current infection and the amount of virus, or viral load, in the blood (PHAC, 2019b). Similarly, HCV core antigens testing is performed in replacement to HCV RNA in some countries (Fish, 2017). Rapid HCV testing, also known as

point-of-care (POC) HCV testing, provides the anti-HCV test results within the same visit, which allows for the implementation of both the anti-HCV test and the second test in one visit (Bajis et al., 2018). Currently, only the anti-HCV POC fingerstick blood test is available in Canada but other countries have anti-HCV POC testing with saliva and RNA POC testing (Bajis et al., 2018; Hosein, 2017; PHAC, 2019b). POC testing and methods of combining both tests for one visit eliminate one step in the HCV cascade to care, which may contribute to the retention of people across the cascade. It is now recommended to conduct reflex testing of HCV, which is a method of testing HCV where a reactive anti-HCV blood sample will be automatically tested for RNA (Action Hepatitis Canada, 2021). Diagnosis of active HCV infection is followed by a liver scan (FibroScan), alanine aminotransferase (ALT) testing, and genotype testing to determine the degree of fibrosis which thereby allows for the selection of proper HCV treatment (Harrison, 2015). This thesis will focus on any method of testing to lead to HCV diagnosis.

Treatment

Currently, while there is no vaccination available against HCV (Lauer & Walker, 2001), HCV is curable through medication, with clearance, also known as a sustained virologic response (SVR) being defined as undetectable HCV in the blood for either 12 or 24 weeks after treatment, depending on country (Dynamed, 2018). The direct-acting antiviral (DAA) oral medication is the treatment for HCV, and was released in Western countries in 2014 and has been proven highly effective, with SVR rates of over 95% (Seifert et al., 2015; WHO, 2016, 2019). Available in all Western, higher-income countries, medication regimens for HCV infection vary per country but the genotype and ALT testing is required to determine the appropriate DAA medication (Edwards et al., 2015; Robaeys et al., 2016). Treatment requires

daily administration of a combination of DAA medication for 8 to 12 weeks (CDC, 2019; Ozaras & Tahan, 2009). Before the global implementation of DAA treatment, interferon-based therapy was the main HCV treatment but had a longer treatment duration, more side effects, and lower rates of cure compared to DAAs (Madden et al., 2018). In the era of DAAs, there is evidence of PWID reporting positive outlooks on the new treatment as well as beneficial effects on their physical and mental wellbeing after successful completion of treatment (Goodyear et al., 2021; Torrens et al., 2020).

People Who Use(d) Injection Drugs

Practices of IDU along with sharing of injection-related equipment facilitates HCV transmission among this population with a high prevalence of HCV. Transmission of HCV through these practices could be minimized through harm reduction programs and needle exchange programs, where some programs could provide or link individuals to DAAs. However, PWID may have barriers in accessing appropriate services due to a series of unfavourable factors such as stigma, socioeconomic marginalization, and criminalization (Boyd et al., 2017; CDC, 2020).

PWID are commonly viewed as outcasts and inferior to the average person because of their IDU, which is often associated with criminal activity. Associated with the behaviour of IDU, HCV is often regarded as a stigmatized disease which, in a victim-blaming mentality, is seen as something PWID inflicted upon themselves (Goffman, 2009; WHO, 2001). The outcomes of such views of IDU and HCV enables a series of mistreatment towards PWID including discrimination, prejudice, and stereotypical attitudes such as physical and verbal violence, poverty, and crime (Economou et al., 2020; Jürgens, 2008; Keith, 2009; O’Keefe et al.,

2019; Ozaras & Tahan, 2009) from HCPs, families, peers, partners, employers, workmates, and themselves (Anti-Discrimination Board of New South Wales, 2001; Hopwood & Southgate, 2003). To avoid the anticipated and actual stigma that they may face at healthcare services, PWID may avoid or delay meeting their health and social needs (Biancarelli et al., 2019; Guise et al., 2018; Hopwood & Southgate, 2003), thus potentially enabling the continuation of HCV transmission (Etesam et al., 2014; Garvey & Jones, 2019; Keith, 2009; Ozaras & Tahan, 2009; PHAC, 2012; WHO, 2017, 2019).

The harm reduction approach has a goal of providing a supportive approach for marginalized populations to access medical and social services (Gagnon et al., 2019; Ministry of Health/Public Health Branch, 1997). The strategies of harm reduction are thus based on addressing inequity and social justice, welcoming all populations and creating an inclusive environment to benefit the client's overall health and wellbeing (Gagnon et al., 2019; Ministry of Health/Public Health Branch, 1997). In particular, the *Mandatory Health Programs and Services Guidelines* (1997) mandates and recognizes that PWID should have comprehensive access to a variety of health services, such as:

Sterile injection equipment by the provision of needle and syringe exchange programs as a strategy to prevent transmission of HIV, hepatitis B, hepatitis C and other blood-borne infections and other associated diseases in areas where drug use is recognized as a problem in the community. The strategy shall also include counselling and education and referral to primary health services and addiction/treatment services (Ministry of Health, 2018).

Harm reduction services include supervised consumption sites (SCS); distribution of naloxone; overdose prevention programs; STBBI treatment and counselling; safer injection and inhalation supply distribution programs in fixed and mobile sites and methadone treatment centres (Gagnon et al., 2019; Ottawa Public Health [OPH], 2019; Strike et al., 2015). As marginalized populations may not seek conventional healthcare, these services provide support and clinical services tailored to substance use, which has shown to improve clients' biopsychosocial needs by connecting clients with appropriate services or agencies (Ministry of Health/Public Health Branch, 1997; Pericàs et al., 2019; Stvilia et al., 2019).

Countries

Each country's approach to HCV was assessed for similarities in HCV approaches such as a national case definition of HCV, screening guidelines, and testing methods available. National case definitions are generally under national surveillance due to the risk of transmission and/or health complications to public health. The similarity in the national case definition demonstrates a similar understanding of communicable disease and the same public health attention to eliminating HCV.

Literature Search

The literature search was performed in June 2020. The key search terms included the concepts of *PWID*, *HCV*, *testing*, and, *diagnosis*. Search terms, synonyms, terms specific to each database, and Medical Subject Headings (MeSH) terms were searched in the multipurpose set of fields. No search limits were placed on the results however only English citations were included. The online databases CINAHL, Medline, Scopus, Google Scholar, WHO hepatitis database, Sociology Proquest, PsycInfo, Academic Source, and grey literature of PWID groups through Google were conducted. While people in the injection drug-using community hold differing

views about accessing HCV diagnosis in Western countries, the literature search revealed three dominant themes as perceived by PWID: individual, sociocultural, and structural factors.

Individual-Level Factors

Individual-level factors are subjective factors as described by the individual engaging with care. In the literature, individual factors were represented as concerns, knowledge, and having a sense of control.

First, the participants reported their motivations as individual-level facilitators of receiving a HCV diagnosis, describing a need to seek HCV testing due to concerns of possible health issues for themselves and people within their social circle (Barocas et al., 2014; Jones et al., 2014).

Similarly, participants described anxiety as another source of motivation in seeking HCV testing. The anxiety involved having an understanding of the health complications associated with HCV and the risk of HCV transmission to individuals within and outside their social circles (Barocas et al., 2014). The synthesis study by Jones and colleagues (2014) further revealed personal facilitators about receiving an HCV diagnosis. Participants described that their testing outcomes (i.e., positive or negative results) motivated them to investigate changing their injecting practices and adopt a healthier lifestyle.

Alternatively, there were several personal barriers involved with HCV testing. Participants recalled emotional expressions from their experiences such as panic or anxiety from receiving a positive result; participants stated that they had a lack of understanding of the results (Barocas et al., 2014; Guise et al., 2018).

In addition to the emotional barriers, participants described barriers of competing priorities with HCV testing and feeling a lack of control of their HCV status' despite actions or intentions of reducing the risk of receiving HCV (Jones et al., 2014). Perceptions of HCV diagnosis were largely related to a lack of understanding of the diagnosis and the health complications associated with it. In particular, there were reports of PWID who perceived themselves and their social circle as low risk of acquiring HCV (Jones et al., 2014). Other studies have found that individuals who perceived HIV as more severe than HCV were often misinformed (Jones et al., 2014). Indeed, many PWID described feeling confused and anxious when they received their HCV diagnosis because they did not recall requesting nor giving consent to receive HCV testing. Jones and colleagues (2014) explained that PWID are unlikely to seek testing themselves unless the practitioners offer it. However, a lack of explicit HCV testing consent in routine testing by practitioners could cause unpreparedness in clients receiving results.

Individual-Level Gaps in Practice

The literature search revealed participant-reported concerns of their lack of understanding of the results, inaccurate self-perceptions of their risk of HCV, and previous misinformation about the virus (Barocas et al., 2014; Guise et al., 2018; Jones et al., 2014). A closer look at these concerns shows that HCPs may not be providing sufficient information before, during, and/or after the test.

In a scoping review of knowledge of HCV among HCPs, Ha and Timmerman (2018) found that there was insufficient knowledge among the public and general practitioners. They found two Canadian studies that reported 83 to 90% of people living with HCV lack awareness of the disease

and one Canadian study where only 35% of physicians reported confidence about the symptoms of HCV. While specialists had more HCV knowledge than general practitioners, HCPs in the community setting are vital in providing accurate information about HCV to clients when the opportunity for screening, pre- or post- counselling occurs. However, the high unawareness of HCV among the general public and high level of insufficient knowledge about HCV symptoms among physicians suggest that HCPs are the initial barrier to allowing the general public to access HCV testing. This affects PWID because they face heightened barriers to accessing services as a result of the multi-layered marginalization (Biancarelli et al., 2019; Global Commission on Drug Policy, 2011; Guise et al., 2018; Hopwood & Southgate, 2003; Jürgens, 2008; Richardson et al., 2015).

Sociocultural-Level Factors

Sociocultural-level factors include barriers and facilitators of HCV diagnosis as influenced by the individual's circle of relationships, stigma, and treatment by HCPs. Stigma was pervasive in the literature relating to the population and the illness (Barocas et al., 2014; Guise et al., 2018; Jones et al., 2014; Latham et al., 2019). Specifically, Barocas and colleagues (2014) found that PWID experienced stigma and judgement from the HCPs, family, and from within the IDU community due to the stigma associated with HCV and with injection drug use. Guise and colleagues (2018) explained that this abuse and stigma faced may lead to a mistrust of healthcare systems, leading to avoidance or delay of seeking help for HCV testing as well as meeting health and social needs (Biancarelli et al., 2019; Guise et al., 2018; Hopwood & Southgate, 2003). The stigmatization impacts PWID's access to HCV testing and diagnosis, which can enable ongoing

HCV transmission within the community (Marshall et al., 2019). Evidently, stigma further complicates this populations' health status.

Sociocultural-Level Gaps in Practice

Stigma towards the IDU communities is a longstanding issue and remains to be an issue that PWID perceive from others, including from within the population (Barocas et al., 2014; Cama et al., 2016; Guise et al., 2018; Muncan et al., 2020; Paquette et al., 2018).

The participants in the study conducted by Muncan and colleagues (2020) reported they feared or felt judgement from HCPs due to concerns of their IDU status. Due to the anticipated or perceived judgement, PWID reported instances of poor treatment and avoidance of mainstream services despite the need to address medical concerns. PWID compensated for the anticipated judgement by avoiding syringe exchange programs (SEPs) for sterile needles or by adjusting their appearance to avoid being labelled as a 'junkie'.

There are reports of further concerns regarding individuals with the intersectionality of their IDU and HCV status'. PWID living with HCV reported feelings of shame when they were with individuals without HCV, leading to avoidance of non-diagnosed individuals in mainstream services or PWID without HCV (Goodyear et al., 2021). These reports of stigma demonstrate that better investigation and action are required to address this gap in practice.

Structural-Level Factors

Structural-level factors relate to available resources, facilities, and logistics associated with the facilities. There was evidence describing the perspectives about the different testing methods. For instance, participants appreciated the convenience of routine testing rather than

requesting the HCV test themselves. Additional structural facilitators included access to transportation, HCV testing offered at harm reduction programs, mobile testing centres or needle and syringe exchange programs, and no costs associated with the tests (Barocas et al., 2014).

Testing offered in a comfortable and safe environment facilitated individuals in receiving HCV testing (Barocas et al., 2014). Treloar and colleagues (2015) found many benefits of peer support workers in an integrated model of care regarding linking clients to HCV care as well as other services. The participants felt that peer support workers were mediators in the clinics, bridging the roles of the staff and clients. The participants reported the importance of the role of the peer support worker since they were relatable to the participants through their lived experiences and were not judgemental. The peer support workers were able to bridge the knowledge of HCV care in terms of providing anecdotal information about what to expect from the tests and diagnosis which the staff may not necessarily have insightful information about, hence they were perceived to be friendly, trustful, honest, respectful, and encouraging.

Similarly, participants preferred remote or self-testing, as it allowed for more control, autonomy, privacy, and immediate results (Guise et al., 2018). Specifically, the availability of POC RNA testing was perceived as convenient and advantageous in terms of time (Jones et al., 2014). Jones and colleagues (2014) found reports of preference for saliva testing over blood sampling, especially the method of oral swabs for self-testing. Venipunctures were a facilitator in testing if the blood obtained from the test could be tested for multiple STBBIs and if clients could perform self-venipuncture. Additional structural facilitators included: having regular access to a HCP, having a rapport with the HCP, no judgement from HCPs, and confidentiality in the HCV test results (Barocas et al., 2014; Treloar et al., 2015). The participants reported that

their relationships with their HCPs highly influenced their decisions of returning to the clinic, which is a common factor for any health and social service (Barocas et al., 2014; Treloar et al., 2015).

Some general findings relating to structural-level barriers of accessing HCV diagnosis included a lack of access to transportation, costs associated with HCV testing, and time constraints of clinics (Barocas et al., 2014). Guise and colleagues (2018) and Jones and colleagues (2014) found more specific structural barriers relating to HCV testing available to PWID which were identified as a facilitator to some; participants voiced that remote testing was not efficient as individuals would ultimately need to seek a doctor for the results regardless of where the test was performed.

Also, structural-level concerns included a need for proper pre-counselling for participants to understand the purpose of the test and having near support from practitioners or in outreach settings despite depending on self-testing (Guise et al., 2018). The study suggested that not many participants were willing to wait for the POC results, suggesting POC testing may not be as rapid as intended (i.e., more than two hours or not same-day results). However, receiving rapid results was not perceived as a barrier because participants identified that HCV is asymptomatic and has a slow nature of mortality (Jones et al., 2014).

Structural-Level Gaps in Practice

In addition to the forementioned concerns that PWID had regarding access to testing, there are gaps in practice. Addressing barriers of accessing transportation, the cost of tests, and constraints of medical service operation hours, PWID often report barriers to these traditional operations of healthcare services (Barocas et al., 2014; Jones et al., 2014). There are reports of

difficulty in obtaining legal employment because of their IDU status, stigma, their criminal records, limited skills, and/or chronic homelessness. To compensate, PWID have reported involvement in illegal employment such as drug dealing, sex work, street-based activities (i.e., panhandling, selling recycled items, cleaning car windows), and theft (Richardson et al., 2015). These nonconventional methods of generating income led to disadvantages to accessing HCV services with traditional operations in place, suggesting that there remains to be a lack of consideration to address the unique barriers of PWID.

Relationships between Accessibility Factors

There exist several relationships between the factors that influence accessibility, which culminate to affect PWID's experience with HCV diagnosis. The literature search revealed that sociocultural- and structural-level factors may inspire individual-level feelings which could act as motivators or barriers in receiving HCV testing. In addition, structural factors may intersect with sociocultural factors if the staff available at the location of HCV testing are considered as resources and have relationships with the clients, ultimately influencing the accessibility of HCV diagnosis. These factors assist to define the meaning of accessibility through the categorization of individual, sociocultural, structural, geographical, and systemic factors (Canadian Nurses Association [CNA], 2000). In particular, these external and contextual factors demonstrate alignment with the critical theorist perspective as they shape the realities and knowledge of individuals affected by such (Guba & Lincoln, 1994).

There have been improvements in linking PWID to testing however PWID remain at risk for HCV and high-income countries are not projected to meet the global HCV targets. The scarcity in the literature demonstrates a need for more effort into understanding the process of

accessing HCV testing amongst PWID as it should be perceived as equal terms with the outcome of getting tested and diagnosed for HCV. Relating to the concept of accessibility and manifesto of *Nothing About Us Without Us*, engagement of the communities and users is a crucial aspect (Jürgens, 2008; United Nations Children's Fund [UNICEF] et al., 1978). This shows that the importance of integrating their lived experiences of accessing HCV testing has been overlooked which risks contributing to the oppression of PWID.

Summary

There are relationships between the factors of the principle of accessibility and gaps in the current research of accessing HCV testing and diagnosis which require exploring. Defined here as internal factors shaped by external constraints and external societal factors which influence the individual's ability to engage with a needed health service, the PHC principle of accessibility (CNA, 2000) provides structure in understanding the phenomenon of PWID in accessing HCV diagnosis, hence there is value in evaluating the findings using this concept.

PWID may experience individual-, sociocultural-, and structural-level factors which impact their access to HCV diagnosis. Individual-level factors may be represented as the individual's values, a sense of HCV knowledge, and wanting a personal sense of control in the individual's HCV journey. These factors may cause internal conflict in an individual's desire to receive HCV testing (Barocas et al, 2014). Sociocultural-level factors are largely related to the stigma associated with HCV and to PWID. Stigma can have distressing effects on PWID, including avoidance or delay of seeking help for HCV testing as well as meeting health and social needs (Biancarelli et al., 2019; Guise et al., 2018; Hopwood & Southgate, 2003). Structural-level factors were represented as the HCV and harm reduction services that were offered to link individuals to HCV testing. There are few recent studies have explored the

experiences of PWID in accessing HCV testing and there exists more research describing the PWID experience with accessing HCV treatment (Alavi et al., 2014; Boucher et al., 2019; Butler et al., 2017, 2019; Childs et al., 2019; Garvey & Jones, 2019; Haley & Kreek, 2015; Henry, 2018; Keith, 2009; Madden et al., 2018; Marshall et al., 2019; Mason et al., 2015; Mukherjee et al., 2017; Phillips et al., 2020; Richardson et al., 2015; Roose et al., 2014; Souliotis et al., 2017; Wolfe et al., 2010).

The literature findings show that the outcomes of HCV testing do not meet the Global Viral Hepatitis Strategy goals for eliminating HCV (WHO, 2016), demonstrating a need for clinicians to change the system in order to improve. Exploration should begin with the initial step of the HCV cascade, testing and diagnosis. The experiences of PWID should continue to be investigated to address these interrelated issues of social oppression and the public health issue of HCV. Therefore, these findings support my study of conducting a qualitative scoping review of PWID experiences with accessing HCV diagnosis in Western countries to extract data specific to this step of the care continuum.

References

- Action Hepatitis Canada. (2021). *Progress towards viral hepatitis elimination in Canada 2021 report* (p. 45).
https://www.actionhepatitiscanada.ca/uploads/8/3/3/9/83398604/ahc_progress_report_2021.pdf
- Alavi, M., Raffa, J. D., Deans, G. D., Lai, C., Krajden, M., Dore, G. J., Tyndall, M. W., & Grebely, J. (2014). Continued low uptake of treatment for hepatitis C virus infection in a large community-based cohort of inner city residents. *Liver International*, 34(8), 1198–1206. <https://doi.org/10.1111/liv.12370>
- Andrews, S. (2017). *Focusing our efforts: Changing the course of the HIV prevention, engagement and care cascade in Ontario. HIV/AIDs Strategy to 2026*. Canadian AIDS Treatment Information Exchange.
- Anti-Discrimination Board of New South Wales. (2001). *Change report of the enquiry into hepatitis C related discrimination*. Anti-discrimination board of New South Wales.
<http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.612.7032&rep=rep1&type=pdf>
- Bajis, S., Maher, L., Treloar, C., Hajarizadeh, B., Lamoury, F. M. J., Mowat, Y., Schulz, M., Marshall, A. D., Cunningham, E. B., Cock, V., Ezard, N., Gorton, C., Hayllar, J., Smith, J., Whelan, M., Martinello, M., Applegate, T. L., Dore, G. J., & Grebely, J. (2018). Acceptability and preferences of point-of-care finger-stick whole-blood and venepuncture hepatitis C virus testing among people who inject drugs in Australia. *International Journal of Drug Policy*, 61, 23–30. <https://doi.org/10.1016/j.drugpo.2018.08.011>
- Barocas, J. A., Brennan, M. B., Hull, S. J., Stokes, S., Fangman, J. J., & Westergaard, R. P. (2014). Barriers and facilitators of hepatitis C screening among people who inject drugs:

- A multi-city, mixed-methods study. *Harm Reduction Journal*, 11(1), 1.
<https://doi.org/10.1186/1477-7517-11-1>
- Biancarelli, D. L., Biello, K. B., Childs, E., Drainoni, M., Salhaney, P., Edeza, A., Mimiaga, M. J., Saitz, R., & Bazzi, A. R. (2019). Strategies used by people who inject drugs to avoid stigma in healthcare settings. *Drug and Alcohol Dependence*, 198(Complete), 80–86.
<https://doi.org/10.1016/j.drugalcdep.2019.01.037>
- Boucher, L. M., Bayoumi, A. M., Mark, A. E., Cooper, C., Martin, A., Marshall, Z., Boyd, R., Oickle, P., Diliso, N., Pineau, D., Renaud, B., LeBlanc, S., Tyndall, M., Lee, O. M., & Kendall, C. E. (2019). Hepatitis C testing, status and treatment among marginalized people who use drugs in an inner city setting: An observational cohort study. *Substance Use & Misuse*, 54(1), 18–30. <https://doi.org/10.1080/10826084.2018.1485699>
- Boyd, J., Fast, D., Hobbins, M., McNeil, R., & Small, W. (2017). Social-structural factors influencing periods of injection cessation among marginalized youth who inject drugs in Vancouver, Canada: An ethno-epidemiological study. *Harm Reduction Journal*, 14.
<https://doi.org/10.1186/s12954-017-0159-9>
- Butler, K., Day, C., Sutherland, R., van Buskirk, J., Breen, C., Burns, L., & Larney, S. (2017). Hepatitis C testing in general practice settings: A cross-sectional study of people who inject drugs in Australia. *International Journal of Drug Policy*, 47, 102–106.
<https://doi.org/10.1016/j.drugpo.2017.07.008>
- Butler, K., Larney, S., Day, C. A., & Burns, L. (2019). Uptake of direct acting antiviral therapies for the treatment of hepatitis C virus among people who inject drugs in a universal health-care system. *Drug and Alcohol Review*, 38(3), 264–269.
<https://doi.org/10.1111/dar.12883>

- Cama, E., Brener, L., Wilson, H., & von Hippel, C. (2016). Internalized stigma among people who inject drugs. *Substance Use & Misuse*, 51(12), 1664–1668.
<https://doi.org/10.1080/10826084.2016.1188951>
- Canadian Nurses Association [CNA]. (2000). *Fact sheet—The Primary Health Care approach*.
https://www.cna-aiic.ca/-/media/cna/page-content/pdf-en/fs02_primary_health_care_approach_june_2000_e.pdf?la=en&hash=C31F23CD20366955F267C04D737B32163F7D5623
- CDC. (2019). *The ABCs of hepatitis—For health professionals*.
<https://www.cdc.gov/hepatitis/resources/professionals/pdfs/abctable.pdf>
- CDC. (2020, February 6). *HIV among people who inject drugs*.
<https://www.cdc.gov/hiv/group/hiv-idu.html>
- Childs, E., Assoumou, S. A., Biello, K. B., Biancarelli, D. L., Drainoni, M.-L., Edeza, A., Salhaney, P., Mimiaga, M. J., & Bazzi, A. R. (2019). Evidence-based and guideline-concurrent responses to narratives deferring HCV treatment among people who inject drugs. *Harm Reduction Journal*, 16(1), 1–10. <https://doi.org/10.1186/s12954-019-0286-6>
- Dynamed. (2018, December 4). *Chronic hepatitis C infection*. Dynamed.
<https://www.dynamed.com/topics/dmp~AN~T115157>
- Economou, M., Bechraki, A., & Charitsi, M. (2020). [The stigma of mental illness: A historical overview and conceptual approaches]. *Psychiatrike = Psychiatriki*, 31(1), 36–46.
<https://doi.org/10.22365/jpsych.2020.311.36>
- Edwards, D. J., Coppens, D. G., Prasad, T. L., Rook, L. A., & Iyer, J. K. (2015). Access to hepatitis C medicines. *World Health Organization*, 93, 799–805.
<http://dx.doi.org/10.2471/BLT.15.157784>

- Etesam, F., Assarian, F., Hosseini, H., & Ghoreishi, F. S. (2014). Stigma and its determinants among male drug dependents receiving methadone maintenance treatment. *Archives of Iranian Medicine*, 17(2), 0–0.
- Fish, S. (2017). *Hepatitis C point of care testing: What is its impact on testing and linkage to care?* CATIE Canada's Source for HIV and Hepatitis C Information.
<https://www.catie.ca/en/pif/spring-2017/hepatitis-c-point-care-testing-what-its-impact-testing-and-linkage-care>
- Gagnon, M., Gauthier, T., Adán, E., Bänninger, A., Cormier, L., Gregg, J. K., Gill, S., Horsburgh, K., Kreutzmann, P., Latimer, J., Bourhis, G. L., Livgard, C., Parker, D., Reiremo, T., Telegdi, E., Thorner, T., & White, M. (2019). International consensus statement on the role of nurses in supervised consumption sites. *Journal of Mental Health and Addiction Nursing*, 3(1), e22–e31. <https://doi.org/10.22374/jmhan.v3i1.35>
- Garvey, C. M., & Jones, R. (2019). The role of stigma and trauma in hepatitis C virus treatment in veterans: Applying the common-sense model. *Public Health Nursing*, 36(6), 829–835.
<https://doi.org/10.1111/phn.12665>
- Global Commission on Drug Policy. (2011). *War on drugs. Report of the Global Commission on drug policy*. https://www.globalcommissionondrugs.org/wp-content/themes/gcdp_v1/pdf/Global_Commission_Report_English.pdf
- Goffman, E. (2009). *Stigma: Notes on the Management of Spoiled Identity*. Simon and Schuster.
- Goodyear, T., Brown, H., Browne, A. J., Hoong, P., Ti, L., & Knight, R. (2021). “I want to get better, but...”: Identifying the perceptions and experiences of people who inject drugs with respect to evolving hepatitis C virus treatments. *International Journal for Equity in Health*, 20(1), 81. <https://doi.org/10.1186/s12939-021-01420-7>

- Guba, E., & Lincoln, Y. (1994). Chapter 6 competing paradigms in qualitative research. In *Handbook of qualitative research* (pp. 105–117). N.K. Denzin & Y. S. Lincoln.
- Guise, A., Witzel, T. C., Mandal, S., Sabin, C., Rhodes, T., Nardone, A., & Harris, M. (2018). A qualitative assessment of the acceptability of hepatitis C remote self-testing and self-sampling amongst people who use drugs in London, UK. *BMC Infectious Diseases*, 18(1), 281. <https://doi.org/10.1186/s12879-018-3185-7>
- Hajarizadeh, B., Grebely, J., & Dore, G. J. (2013). Epidemiology and natural history of HCV infection. *Nature Reviews Gastroenterology & Hepatology*, 10(9), 553–562. <https://doi.org/10.1038/nrgastro.2013.107>
- Haley, S. J., & Kreek, M. J. (2015). A window of opportunity: Maximizing the effectiveness of new HCV regimens in the United States with the expansion of the Affordable Care Act. *American Journal of Public Health*, 105(3), 457–463. <https://doi.org/10.2105/AJPH.2014.302327>
- Harm reduction services in Ottawa*. (2020, January 14). Ottawa Public Health. <https://www.ottawapublichealth.ca/en/public-health-topics/harm-reduction-services-in-ottawa.aspx>
- Harrison, S. A. (2015). Utilization of FibroScan testing in Hepatitis C Virus management. *Gastroenterology & Hepatology*, 11(3), 187–189.
- Henry, B. (2018). Drug pricing and challenges to hepatitis C treatment access. *Journal of Health & Biomedical Law*, 14, 265–283.
- Hopwood, M., & Southgate, E. (2003). Living with hepatitis C: A sociological review. *Critical Public Health*, 13(3), 251–267. <https://doi.org/10.1080/0958159032000114453>

- Hosein, S. R. (2017, February 8). *New point of care hepatitis C antibody test approved in Canada*. CATIE Canada's Source for HIV and Hepatitis C Information.
<https://www.catie.ca/en/catienews/2017-02-08/new-point-care-hepatitis-c-antibody-test-approved-canada>
- Jones, L., Atkinson, A., Bates, G., McCoy, E., Porcellato, L., Beynon, C., McVeigh, J., & Bellis, M. A. (2014). Views and experiences of hepatitis C testing and diagnosis among people who inject drugs: Systematic review of qualitative research. [Review]. *Journal of Drug Policy*, 25(2), 204–211. <https://doi.org/10.1016/j.drugpo.2013.11.004>
- Joshi, S. N. (2014). Hepatitis C Screening. *The Ochsner Journal*, 14(4), 664–668.
- Jürgens, R. (2008). *“Nothing about us without us” greater, meaningful involvement of people who use illegal drugs: A public health, ethical and human rights imperative*. (International ed.). Canadian HIV/AIDS Legal Network, Canadian HIV/AIDS Legal Network : International HIV/AIDS Alliance : Open Society Institute.
<https://login.proxy.bib.uottawa.ca/login?url=http://www.deslibris.ca/ID/213091>
- Keith, A. (2009, January). *Barriers to HCV treatment access from the drug user's point of view: Stigma, complex lives and damaged veins*. Aidsmap.Com.
<https://www.aidsmap.com/news/jan-2019/barriers-hcv-treatment-access-drug-users-point-view-stigma-complex-lives-and-damaged>
- Latham, N. H., Pedrana, A., Doyle, J. S., Howell, J., Williams, B., Higgs, P., Thompson, A. J., & Hellard, M. E. (2019). Community-based, point-of-care hepatitis C testing: Perspectives and preferences of people who inject drugs. *Journal of Viral Hepatitis*, jvh.13087.
<https://doi.org/10.1111/jvh.13087>

- Lauer, G. M., & Walker, B. D. (2001). Hepatitis C virus infection. *The New England Journal of Medicine; Boston*, 345(1), 41–52.
- Madden, A., Hopwood, M., Neale, J., & Treloar, C. (2018). Beyond interferon side effects: What residual barriers exist to DAA hepatitis C treatment for people who inject drugs? *PLoS ONE*, 13(11), 1–10. <https://doi.org/10.1371/journal.pone.0207226>
- Marshall, A. D., Madden, A., & Treloar, C. (2019). Enhancing engagement in hepatitis C care among people who inject drugs. *Addiction*, 114(12), 2104–2106. <https://doi.org/10.1111/add.14698>
- Mason, K., Dodd, Z., Sockalingam, S., Altenberg, J., Meaney, C., Millson, P., & Powis, J. (2015). Beyond viral response: A prospective evaluation of a community-based, multi-disciplinary, peer-driven model of HCV treatment and support. *International Journal of Drug Policy*, 26(10), 1007–1013. <https://doi.org/10.1016/j.drugpo.2015.04.012>
- Micallef, J. M., Kaldor, J. M., & Dore, G. J. (2006). Spontaneous viral clearance following acute hepatitis C infection: A systematic review of longitudinal studies. *Journal of Viral Hepatitis*, 13(1), 34–41. <https://doi.org/10.1111/j.1365-2893.2005.00651.x>
- Ministry of Health. (2018, October 22). *Review of supervised consumption services and overdose prevention sites—Key findings*. Ontario. <https://news.ontario.ca/mohltc/en/2018/10/review-of-supervised-consumption-services-and-overdose-prevention-sites---key-findings.html>
- Ministry of Health/Public Health Branch. (1997). *Mandatory health programs and services guidelines*. Ontario, Ministry of Health, Public Health Branch. <http://www.ontla.on.ca/library/repository/mon/6000/10270964.pdf>

Mukherjee, T. I., Pillai, V., Ali, S. H., Altice, F. L., Kamarulzaman, A., & Wickersham, J. A.

(2017). Evaluation of a hepatitis C education intervention with clients enrolled in methadone maintenance and needle/syringe programs in Malaysia. *The International Journal on Drug Policy*, 47, 144–152. <https://doi.org/10.1016/j.drugpo.2017.05.041>

Muncan, B., Walters, S. M., Ezell, J., & Ompad, D. C. (2020). “They look at us like junkies”:

Influences of drug use stigma on the healthcare engagement of people who inject drugs in New York City. *Harm Reduction Journal*, 17(1), 53. <https://doi.org/10.1186/s12954-020-00399-8>

O’Keefe, D., Bluthenthal, R., Kral, A., Aitken, C., McCormack, A., & Dietze, P. (2019).

Measures of harm reduction service provision for people who inject drugs. *Bulletin of the World Health Organization*, 97, 605–611. <http://dx.doi.org/10.2471/BLT.18.224089>

Ottawa Public Health [OPH]. (2019). *Site needle and syringe program*. Harm Reduction

Services in Ottawa. <https://www.ottawapublichealth.ca/en/public-health-topics/harm-reduction-services-in-ottawa.aspx#Program-goals>

Ozaras, R., & Tahan, V. (2009). Acute hepatitis C: Prevention and treatment. *Expert Review of*

Anti-Infective Therapy, 7(3), 351–361. <https://doi.org/10.1586/eri.09.8>

Page, K., Morris, M. D., Hahn, J. A., Maher, L., & Prins, M. (2013). Injection drug use and

Hepatitis C Virus infection in young adult injectors: Using evidence to inform comprehensive prevention. *Clinical Infectious Diseases: An Official Publication of the Infectious Diseases Society of America*, 57(Suppl 2), S32–S38.

<https://doi.org/10.1093/cid/cit300>

- Paquette, C. E., Syvertsen, J. L., & Pollini, R. A. (2018). Stigma at every turn: Health services experiences among people who inject drugs. *International Journal of Drug Policy*, 57, 104–110. <https://doi.org/10.1016/j.drugpo.2018.04.004>
- Pericàs, J. M., Bromberg, D. J., Ocampo, D., Schatz, E., Wawer, I., Wysocki, P., Safreed-Harmon, K., & Lazarus, J. V. (2019). Hepatitis C services at harm reduction centres in the European Union: A 28-country survey. *Harm Reduction Journal*, 16(1), 20. <https://doi.org/10.1186/s12954-019-0290-x>
- PHAC (2012). *Hepatitis C in Canada: 2005-2010 Surveillance Report*. http://publications.gc.ca/collections/collection_2012/aspc-phac/HP40-70-2012-eng.pdf
- PHAC. (2018a, December 12). *National case definition: Hepatitis C*. <https://www.canada.ca/en/public-health/services/diseases/hepatitis-c/health-professionals-hepatitis-c/national-case-definition.html>
- PHAC (2018b). *Reducing the health impact of sexually transmitted and blood-borne infections in Canada by 2030: A pan-Canadian STBBI framework for action* (p. 25) [Program descriptions]. PHAC. <https://www.canada.ca/en/public-health/services/infectious-diseases/sexual-health-sexually-transmitted-infections/reports-publications/sexually-transmitted-blood-borne-infections-action-framework.html>
- PHAC. (2019a). *Report on Hepatitis B and C in Canada: 2016* [Research]. <https://www.canada.ca/en/services/health/publications/diseases-conditions/report-hepatitis-b-c-canada-2016.html#ref40>
- PHAC. (2019b, July 22). *For health professionals: Hepatitis C*. Government of Canada. <https://www.canada.ca/en/public-health/services/diseases/hepatitis-c/health-professionals-hepatitis-c.html>

- Phillips, C., Schulkind, J., O'Sullivan, M., Edelman, N., Smith, H. E., Verma, S., & Jones, C. J. (2020). Improving access to care for people who inject drugs: Qualitative evaluation of project ITTREAT—An integrated community hepatitis C service. *Journal of Viral Hepatitis*, 27(2), 176–187. <https://doi.org/10.1111/jvh.13214>
- Richardson, L. A., Long, C., DeBeck, K., Nguyen, P., Milloy, M.-J. S., Wood, E., & Kerr, T. H. (2015). Socioeconomic marginalisation in the structural production of vulnerability to violence among people who use illicit drugs. *J Epidemiol Community Health*, 69(7), 686–692. <https://doi.org/10.1136/jech-2014-205079>
- Robaey, G., Bielen, R., Azar, D. G., Razavi, H., & Nevens, F. (2016). Global genotype distribution of hepatitis C viral infection among people who inject drugs. *Journal of Hepatology*, 65(6), 1094–1103. <https://doi.org/10.1016/j.jhep.2016.07.042>
- Roose, R., Cockerham-Colas, L., Soloway, I., Batchelder, A., & Litwin, A. (2014). Reducing barriers to hepatitis C treatment among drug users: An integrated Hepatitis C peer education and support program. *Journal of Health Care for the Poor and Underserved*, 25(2), 652–662. <https://doi.org/10.1353/hpu.2014.0096>
- Seifert, L. L., Perumpail, R. B., & Ahmed, A. (2015). Update on hepatitis C: Direct-acting antivirals. *World Journal of Hepatology*, 7(28), 2829–2833. <https://doi.org/10.4254/wjh.v7.i28.2829>
- Souliotis, K., Agapidaki, E., Papageorgiou, M., Voudouri, N., & Contiades, X. (2017). Access to treatment for Hepatitis C among injection drug users: Results from the cross-sectional HOPE IV study. *International Journal for Equity in Health*, 16. <https://doi.org/10.1186/s12939-017-0601-3>

- Stanaway, J. D., Flaxman, A. D., Naghavi, M., Fitzmaurice, C., Vos, T., Abubakar, I., Abu-Raddad, L. J., Assadi, R., Bhala, N., Cowie, B., Forouzanfour, M. H., Groeger, J., Hanafiah, K. M., Jacobsen, K. H., James, S. L., MacLachlan, J., Malekzadeh, R., Martin, N. K., Mokdad, A. A., ... Cooke, G. S. (2016). The global burden of viral hepatitis from 1990 to 2013: Findings from the Global Burden of Disease Study 2013. *Lancet (London, England)*, 388(10049), 1081–1088. [https://doi.org/10.1016/S0140-6736\(16\)30579-7](https://doi.org/10.1016/S0140-6736(16)30579-7)
- Strike, C., Watson, T. M., Gohil, H., Miskovic, M., Robinson, S., Arkell, C., Challacombe, L., Amlani, A., Buxton, J., Demel, G., Gutierrez, N., Heywood, D., Hopkins, S., Lampkin, H., Leonard, L., Lockie, L., Millson, P., Nielsen, D., Petersen, D., ... Zurba, N. (2015). *Best Practice Recommendations 2 for Canadian Harm Reduction Programs that provide service to people who use drugs and are at risk for HIV, HCV, and other harms*. Working Group on Best Practice for Harm Reduction Programs in Canada. <https://www.catie.ca/sites/default/files/bestpractice-harmreduction-part2.pdf>
- Stvilia, K., Spradling, P. R., Asatiani, A., Gogia, M., Kutateladze, K., Butsashvili, M., Zarkua, J., Tsertsvadze, T., Sharvadze, L., Japaridze, M., Kuchuloria, T., Gvinjilia, L., Tskhomelidze, I., Gamkrelidze, A., Khonelidze, I., Sergeenko, D., Shadaker, S., Averhoff, F., & Nasrullah, M. (2019). Progress in testing for and treatment of Hepatitis C Virus infection among persons who inject drugs—Georgia, 2018. *MMWR. Morbidity and Mortality Weekly Report*, 68(29), 637–641. <https://doi.org/10.15585/mmwr.mm6829a2>
- The Official Website of New York State. (2005). *Clinical guidelines for the medical management of hepatitis C*. Department of Health. <https://www.health.ny.gov/publications/1852/post.htm>

- Thomas, D. L. (2020). State of the Hepatitis C Virus care cascade. *Clinical Liver Disease*, 16(1), 8–11. <https://doi.org/10.1002/cld.915>
- Torrens, M., Soyemi, T., Bowman, D., & Schatz, E. (2020). Beyond clinical outcomes: The social and healthcare system implications of hepatitis C treatment. *BMC Infectious Diseases*, 20(1), 702. <https://doi.org/10.1186/s12879-020-05426-4>
- Treloar, C., Rance, J., Bath, N., Everingham, H., Micallef, M., Day, C., Hazelwood, S., Grebely, J., & Dore, G. J. (2015). Evaluation of two community-controlled peer support services for assessment and treatment of Hepatitis C Virus infection in opioid substitution treatment clinics: The ETHOS study, Australia. *International Journal of Drug Policy*, 26(10), 992–998. <https://doi.org/10.1016/j.drugpo.2015.01.005>
- Trubnikov, M., Yan, P., & Archibald, C. (2014). Estimated prevalence of Hepatitis C Virus infection in Canada, 2011. *Canada Communicable Disease Report*, 40(19), 429–436. <https://doi.org/10.14745/ccdr.v40i19a02>
- UNICEF, World Health Organization, & International Conference on Primary Health Care. (1978). *Declaration of Alma-Ata International Conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978*. World Health Organization. <http://link.springer.com/10.1057/palgrave.development.1100047>
- Wang, H., Naghavi, M., Allen, C., Barber, R. M., Bhutta, Z. A., Carter, A., Casey, D. C., Charlson, F. J., Chen, A. Z., Coates, M. M., Coggeshall, M., Dandona, L., Dicker, D. J., Erskine, H. E., Ferrari, A. J., Fitzmaurice, C., Foreman, K., Forouzanfar, M. H., Fraser, M. S., ... Murray, C. J. L. (2016). Global, regional, and national life expectancy, all-cause mortality, and cause-specific mortality for 249 causes of death, 1980–2015: A

- systematic analysis for the Global Burden of Disease Study 2015. *The Lancet*, 388(10053), 1459–1544. [https://doi.org/10.1016/S0140-6736\(16\)31012-1](https://doi.org/10.1016/S0140-6736(16)31012-1)
- WHO. (2001). *Mental health: A call for action by World Health Ministers 54th World Health Assembly* (Ministerial Round Tables).
- WHO. (2016). *Global Health Sector Strategy on viral hepatitis 2016-2021 towards ending viral hepatitis* (WHO/HIV/2016.06). <https://apps-who-int.proxy.bib.uottawa.ca/iris/bitstream/handle/10665/246177/WHO-HIV-2016.06-eng.pdf?sequence=1>
- WHO. (2017). *Global hepatitis report, 2017*. <http://apps.who.int/iris/bitstream/10665/255016/1/9789241565455-eng.pdf?ua=1>
- WHO. (2019, July 9). *Hepatitis C*. World Health Organization. <http://www.who.int/news-room/fact-sheets/detail/hepatitis-c>
- Wilton, J., & Broeckert, L. (2013). *The HIV treatment cascade – patching the leaks to improve HIV prevention*. <https://www.catie.ca/en/pif/spring-2013/hiv-treatment-cascade-patching-leaks-improve-hiv-prevention>
- Wolfe, D., Mr, Carrieri, M. P., & Shepard, D. (2010). Treatment and care for injecting drug users with HIV infection: A review of barriers and ways forward. *The Lancet*, 376(9738), 355–366. [https://doi.org/10.1016/S0140-6736\(10\)60832-X](https://doi.org/10.1016/S0140-6736(10)60832-X)
- Zein, N. N., & Persing, D. H. (1996). Hepatitis C genotypes: Current trends and future implications. *Mayo Clinic Proceedings*, 71(5), 458–462. <https://doi.org/10.4065/71.5.458>

Chapter Three: Framework

In this chapter, I explain the underpinning theory to this research, the Primary Health Care theory and the principle of Accessibility.

Primary Health Care Theory

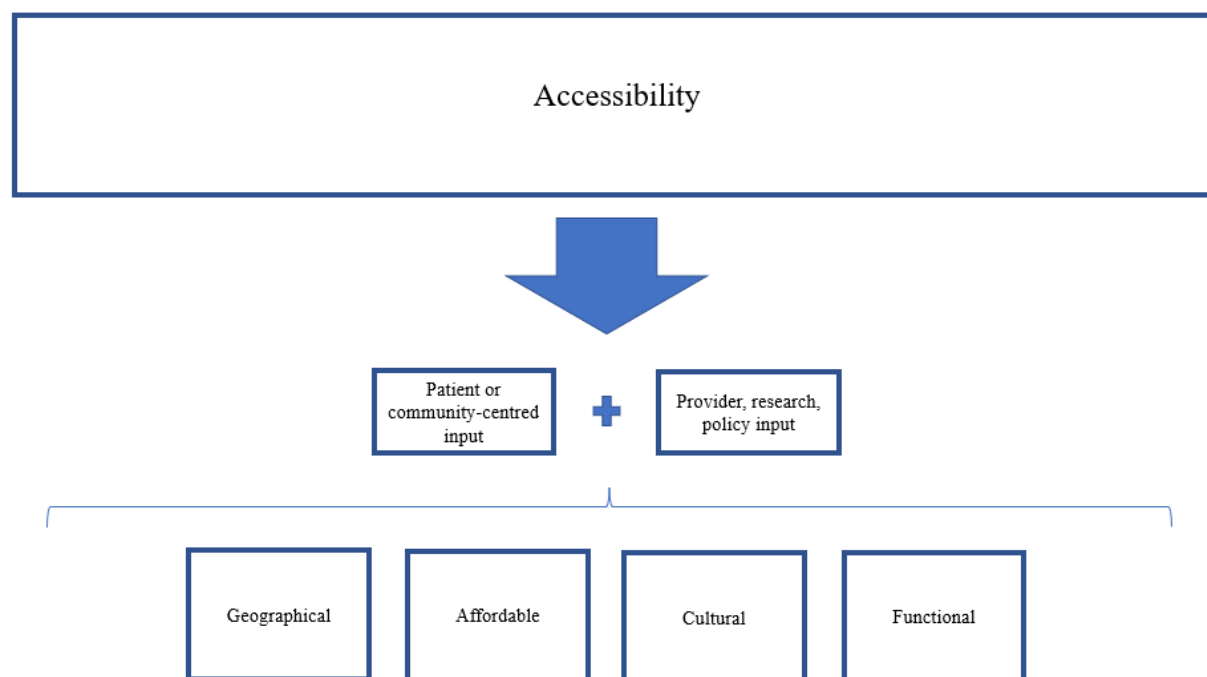
The World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) first promoted the need for Primary Health Care (PHC) in the Declaration of Alma-Ata in 1978, outlining PHC as a means of affirming health as an entity beyond mere physical health and addressing the considerable gap of inequitable distribution of health status between and within countries (UNICEF et al., 1978).

The WHO and UNICEF defined PHC as "...essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation..." (UNICEF et al., 1978, p. 3).

The Declaration outlines several operational components of PHC, one being coverage and accessibility. The component of coverage simply describes the availability of the number and types of healthcare services whereas accessibility further expands on the definition of coverage to include the client perspective of healthcare service delivery. It describes healthcare services that clients can reach, are needed by the community and can address the community's health needs. The WHO and UNICEF (1978) illustrated that the principle of accessibility should be 1) geographically appropriate to clients in terms of distance, travel time, and methods of transportation to the service, 2) affordable by the clients, 3) cultural, meaning the service incorporates cultural appropriate methods that evolve with the trends of the community and 4) functional, meaning community-specific care is provided to clients who need and want it. It was

acknowledged that the criteria for accessibility could be tailored towards each unique community to achieve a method of service delivery that is acceptable to the community and accessibility should be extended to consider the complex problems existing in the communities rather than merely assessing the coverage of such services (UNICEF et al., 1978).

The Canadian Nurses Association (CNA) (2005) encouraged nurses to adopt the PHC approach to all levels of nursing care and to reflect on both identifying barriers and addressing them effectively to allow clients to access the service. The CNA (2000, 2005) defined accessibility as part of providing effective healthcare to all through ensuring "...the right provider is offering the right care at the right time." (p. 1) with consideration of the client's social determinants of health that may affect their health status. Based on these definitions of accessibility, the system and nurses can provide the services, but the client input provides insight into how to provide the most client-centred (community-focused) care.

Figure 3*The Model of Accessibility in Primary Health Care*

Note. The criteria for accessibility could be tailored to each unique community in order to achieve a method of service delivery that is acceptable to the community(ies). The information from this figure is from “[UNICEF, World Health Organization, & International Conference on Primary Health Care. (1978). *Declaration of Alma-Ata International Conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978*. World Health Organization.

<http://link.springer.com/10.1057/palgrave.development.1100047>”, “[Canadian Nurses Association. (2000). *The Canada Health Act* [Fact sheet].]” and “[Canadian Nurses Association. (2005). *Primary Health Care: A summary of the issues* (CNA Backgrounder).]”.

Gap in Accessibility

It is important to note that the client's input about the methods of accessibility is only possible if the client decides to be engaged with providing their input, they feel that their feedback is valid and valuable and if they are offered the opportunity to provide feedback. The risk to engaging clients is the volunteers may not be representative of the whole community to

which the services are tailored and may instead be counteractive towards the subcommunities which exist, particularly those who may already have a difficult time with accessing services. Above all, the cost of the disenfranchisement that PWID face includes dismissing and invalidating their thoughts, preventing them from contributing to the services that ultimately affect them. Lastly, feedback can also only be incorporated into the program implementation when the service providers ask for it, meaning if it is not asked then the service users are less likely to give their input (Jürgens, 2008). The intrinsic nature of the uneven power dynamic that the clinician has is dominant through all of the processes and outcomes of the services that impact clients. Thus, being mindful of practice and systemic approaches affecting clients can better allow clients to express their opinions or self-advocate to improve access to the services that they need.

In light of the current understandings of accessibility and conversations on how to decrease HCV transmission and prevalence, there has been a rising discussion regarding the barriers, or factors that impact the accessibility of health services for PWID (Barocas et al., 2014; CDC, 2017; Guise et al., 2018; Jones et al., 2014; Latham et al., 2019; Levy, 2017; Souliotis et al., 2017a; Treloar et al., 2015). This literature search demonstrates that there is a lack of understanding of PWID experiences of accessing HCV testing. As such, the risks of this lack of engagement further disenfranchise the population by dismissing their opinions about the services that they need to access. Indeed, this calls for reconceptualizing the concept of accessibility to incorporate the perspectives of PWID, constructed through their contexts, which will therefore challenge the current understandings of accessibility (CNA 2000, 2005; Deleuze & Guattari, 1983; Foucault, 1954; UNICEF et al. 1978).

References

- Barocas, J. A., Brennan, M. B., Hull, S. J., Stokes, S., Fangman, J. J., & Westergaard, R. P. (2014). Barriers and facilitators of hepatitis C screening among people who inject drugs: A multi-city, mixed-methods study. *Harm Reduction Journal*, 11(1), 1. <https://doi.org/10.1186/1477-7517-11-1>
- CDC. (2017, December). *Increase in hepatitis C infections linked to worsening opioid crisis*. Centers for Disease Control and Prevention. <https://www.cdc.gov/nchhstp/newsroom/2017/hepatitis-c-and-opioid-injection-press-release.html>
- Canadian Nurses Association [CNA]. (2000). *The Canada Health Act* [Fact sheet].
- Deleuze, G., & Guattari, F. (1983). *Anti-edupus capitalism and schizophrenia*. University of Minnesota Press.
- CNA. (2005). *Primary Health Care: A summary of the issues* (CNA Backgrounder).
- Foucault, M. (1954). Structuralism et poststructuralisme. In *Dits et écrits*. Éditions Gallimard.
- Guisse, A., Witzel, T. C., Mandal, S., Sabin, C., Rhodes, T., Nardone, A., & Harris, M. (2018). A qualitative assessment of the acceptability of hepatitis C remote self-testing and self-sampling amongst people who use drugs in London, UK. *BMC Infectious Diseases*, 18(1), 281. <https://doi.org/10.1186/s12879-018-3185-7>
- Jones, L., Atkinson, A., Bates, G., McCoy, E., Porcellato, L., Beynon, C., McVeigh, J., & Bellis, M. A. (2014). Views and experiences of hepatitis C testing and diagnosis among people who inject drugs: Systematic review of qualitative research. [Review]. *Journal of Drug Policy*, 25(2), 204–211. <https://doi.org/10.1016/j.drugpo.2013.11.004>

- Jürgens, R. (2008). *“Nothing about us without us” greater, meaningful involvement of people who use illegal drugs: A public health, ethical and human rights imperative*. (International ed.). Canadian HIV/AIDS Legal Network, Canadian HIV/AIDS Legal Network : International HIV/AIDS Alliance : Open Society Institute.
<https://login.proxy.bib.uottawa.ca/login?url=http://www.deslibris.ca/ID/213091>
- Latham, N. H., Pedrana, A., Doyle, J. S., Howell, J., Williams, B., Higgs, P., Thompson, A. J., & Hellard, M. E. (2019). Community-based, point-of-care hepatitis C testing: Perspectives and preferences of people who inject drugs. *Journal of Viral Hepatitis*, jvh.13087.
<https://doi.org/10.1111/jvh.13087>
- Levy, I. (2017). *Harm reduction and overdose prevention – Status Report* (No. ACS2017-OPH-HPS-0002; Ottawa Board of Health).
- Souliotis, K., Agapidaki, E., Papageorgiou, M., Voudouri, N., & Contiades, X. (2017). Access to treatment for Hepatitis C among injection drug users: Results from the cross-sectional HOPE IV study. *International Journal for Equity in Health*, 16.
<https://doi.org/10.1186/s12939-017-0601-3>
- Treloar, C., Rance, J., Bath, N., Everingham, H., Micallef, M., Day, C., Hazelwood, S., Grebely, J., & Dore, G. J. (2015). Evaluation of two community-controlled peer support services for assessment and treatment of hepatitis C virus infection in opioid substitution treatment clinics: The ETHOS study, Australia. *International Journal of Drug Policy*, 26(10), 992–998. <https://doi.org/10.1016/j.drugpo.2015.01.005>
- UNICEF, World Health Organization, & International Conference on Primary Health Care. (1978). *Declaration of Alma-Ata International Conference on Primary Health Care*,

Alma-Ata, USSR, 6–12 September 1978. World Health Organization.

<http://link.springer.com/10.1057/palgrave.development.1100047>

Chapter Four: Methodology

In this chapter, I discuss the chosen methodology and explain the procedures involved with this research study.

Methodological Overview

As detailed in Chapter One, this scoping review is situated within the critical paradigm. Through this paradigm, data are valued to describe contextual and historical factors perceived by PWID (Mertens, 2012). The qualitative data collected through interviews and discussion could yield a diversity of opinions about the topic (Sandelowski et al., 2007). The qualitative data collected through quantitative instruments, such as questionnaires, may also contribute to the multiplicity of the topic (Saris & Gallhofer, 2007). Through the critical theory paradigm, the qualitative and quantitative data are viewed as subjective reports of an individual's experience, hence, the overall qualitative nature of this synthesis review with quantitative demographic information being used as a channel for displaying the client statements.

Synthesis studies or knowledge syntheses are collections of primary research studies which integrate bodies of evidence, research, or knowledge relating to a topic (Tong et al., 2012; Wyborn et al., 2018). Synthesis studies focus on increasing the accessibility of research results and facilitating the uptake of knowledge relating to a topic (Wyborn et al., 2018). There are several accepted synthesis methodologies, including systematic, scoping, narrative, and rapid reviews, among others. The two main types of synthesis studies are systematic reviews and scoping reviews.

Systematic reviews are defined as secondary sources of research which discern the most valid, feasible, or effective approach to supporting a gap in research (Munn et al., 2018).

Researchers who use this design often adopt a deductive approach to testing hypotheses, theories, or answering questions (Munn et al., 2018). This type of review typically informs research, policy, and practice (Munn et al., 2018). This type of review also has a strong emphasis on minimizing bias and ensuring the quality of review is maintained through adopting strict guidelines of conducting the review (Higgins et al., 2019; Munn et al., 2018). The strengths of a systematic review include producing trustworthy, reliable, and generalizable results to guide researchers, policymakers, and clinical leaders (Munn et al., 2018). However, systematic reviews are limited since they typically involve narrow or specific questions, often about intervention effectiveness (Munn et al., 2018).

Systematic reviews often look at the phenomenon based on the most evidence-based and efficient manner (Munn et al., 2018), which conflicts with the ontological perspective of the critical theories of differences in perspectives as a result of contextual factors (Guba & Lincoln, 1994). Research questions are used to guide the topic of interest rather than seeking absolute answers. The less common form of systematic reviews is qualitative in nature, which could adopt a critical theorist lens of presenting the voices of participants to explore the meaning of the intervention or topic of interest (JBI, 2020). However, systematic reviews overall have a methodological goal of providing a comprehensive study and suggest a linear approach to minimize challenges in the reporting criteria as indicated by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Booth, 2016; Moher et al., 2009). My scoping review study is not constrained to the systematic and linear nature of a systematic review. Instead, my scoping review study is explorative and sporadic, allowing the client's voices to guide the nature of the study.

Researchers Arksey and O'Malley (2005) encourage that the scoping review process is "...not linear but iterative" (p. 22). This type of synthesis study aims to broadly explore and map the available evidence on a topic (Munn et al., 2018), identify emerging topics, clarify concepts, explore the extent of research on the topic, and highlight research gaps (Tricco et al., 2016). The results from scoping reviews are often narrative or descriptive statements describing the extent of literature about a topic (Arksey & O'Malley, 2005; Peters et al., 2020; Tricco et al., 2016) and could be conducted as an independent study or as a preliminary study used to identify aspects of a topic amenable to systematic reviews (Munn et al., 2018; Pham et al., 2014; Tricco et al., 2016).

Unlike systematic reviews, scoping reviews also allows for adopting a variety of study types, including grey literature (Archibald et al., 2016; Arksey & O'Malley, 2005; Grant & Booth, 2009). Since social phenomena are sporadic and unpredictable, scoping reviews allow for promoting the participant's perspectives of the topic without the constraints of a rigid methodology and searching within certain study types. Hence, the scoping review methodology is considered the most appropriate for this thesis because it will be used to search the breadth of the literature and allow for summarizing patterns or themes in the descriptions of context, participants, or experiences. These qualitative findings will then be transferrable and disseminated to policy makers, researchers, and practitioners (Creswell, 2013).

Study Design

The design chosen for this study is a scoping review. The method as proposed by Arksey and O'Malley (2005) and elaborated upon by JBI (2020) was followed. Arksey and O'Malley (2005) were the first researchers to define the scoping review methodology and outline steps to

ensure rigour and consistency across studies. Scoping reviews are increasing in popularity and researchers have developed specific guidelines about how to conduct them to ensure transparency and replicability (Peters et al., 2020). The Arksey and O'Malley (2005) framework describe a strong structure for guiding the scoping review process. JBI (2020) elaborated on Arksey and O'Malley's (2005) work and provided specific, operational guidelines, detailing methods of ensuring rigour and providing information about how to complete each scoping review step (Peters et al., 2020). Aligning with these methodologies and the qualitative nature of this synthesis study (Sandelowski et al., 2007), the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) (Tong et al., 2012) and the Preferred Reporting Items for Systematic Review extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018) were also used.

The scoping review framework (Arksey and O'Malley, 2005) includes five stages:

Stage 1: Identifying the Research Question

This stage of the scoping review process involves identifying the research question(s). This is fundamental to guide the study, as the research question(s) must align with the aim of the study (Archibald et al., 2016; Arksey & O'Malley, 2005).

The structure of the research questions was guided by the Population, Concept, and Context (PCC) strategy (Peters et al. 2020). The JBI recommends the PCC strategy to guide the research questions to help readers understand the study of interest (Peters et al., 2020). The PCC components were the main concepts of my study: PWID, HCV testing and diagnosis, and high-income Western countries (See Appendix A).

The following research questions guided the research:

1. Based on existing literature, how do PWID describe their experiences of seeking and receiving HCV testing and diagnosis in high-income Western countries?
2. What are the client-identified barriers and facilitators to HCV testing and diagnosis in higher-income Western countries?

Stage 2: Identifying the Literature

This stage of the scoping review involved identifying relevant literature, and this stage was conducted in consultations with my thesis committee and the librarian from the University of Ottawa.

Electronic Databases

The electronic databases searched included MEDLINE, CINAHL (EBSCO), PsycInfo, Sociology ProQuest, Scopus, Nursing and Allied Health, and Web of Science. These databases were selected due to their broad nature, interdisciplinary recognition, and ability to provide sources of related disciplines (See Table 1).

Table 1*Electronic Database Names, Descriptions, and Rationales for Inclusion*

Electronic Database Names	Description of Database	Rationale for including Database
CINAHL EBSCOhost (Cumulative Index of Nursing and Allied Health Literature)	Database containing over 1,000,000 items for nursing, health sciences, and academics.	This database pertains to the discipline of health and fields of health practice, which are relevant to the concept of access to HCV diagnosis.
EMBASE Ovid	International database with over 3,500 journals for the disciplines of biomedical and pharmaceutical.	This database contains European articles which may be relevant to the context of Western countries.
MEDLINE Ovid	International database with over 3,900 journals for the disciplines of biomedicine, health sciences, humanities, medicine, and information science.	This is one of the largest and broadest interdisciplinary databases, which is beneficial for ensuring the most relevant literature is included in the search.
Nursing and Allied Health ProQuest	Nursing database with a wide range of health sources for nursing and health disciplines.	This database is specific to the discipline of nursing and will provide more comprehensive nursing searches.
PsycInfo Ovid	Database with psychology journals.	This psychology database is relevant to the population of focus.
Scopus	Database for the disciplines of science, technology, medicine, social sciences, arts and humanities.	This database may contain articles on the phenomenon of interest from other disciplinary journals.
Sociology Database ProQuest	International database relating to the sociological fields of policy, care, services, anthropology, gerontology, psychology, and population studies.	The population and phenomenon of interest have strong sociological underpinnings.

The search was created in collaboration with the health sciences librarian. The librarian also reviewed and critiqued the search process. The librarian and I (N.H.) also did preliminary searches using the key terms in the databases listed in Table 2 including Academic One Source and Sociological Abstracts. We also searched for PWID forums on Google for relevant data. These sources yielded no relevant data and were thus excluded from the scoping review. Lastly, the librarian conducted a peer review of the search strategy using the PRESS checklist on November 2, 2020, and I modified my search strategy as per the suggestions (McGowan et al., 2016). I searched from the selected electronic databases until November 20, 2020.

Search Terms

The key search terms included the concepts of *PWID*, *HCV*, *testing*, and *diagnosis*. Search terms, synonyms, terms specific to each database, and Medical Subject Headings (MeSH) terms were searched in the multipurpose set of fields. Excluded was the term, *access* because when combined with the population of interest, the search led to off-topic articles about accessing an injection site on the body (i.e., veins). Excluded were the terms, *perspectives*, *experiences*, *barriers*, and *facilitators* because when combined with the key search terms, the search led to a huge decline in the final number of searches. The research team decided it would be best to screen for these terms instead. Additional search terms were suggested by my thesis committee and the expert librarian.

Table 2*Key Search Terms, Search Limits, and Rationales for Criteria*

Search Terms	Inclusion criteria	Exclusion criteria
PWID	• Individuals with experience of intravenous drug use. • Individuals who were actively injecting drugs at the time of the study and peers with a history of injection drug use who are reflecting on the phenomenon of interest. • Individuals ≥ 18 years of age (young adults and adults). • Individuals belonging to any gender, ethnicity, socioeconomic class. • Community-dwelling individuals.	• Individuals < 18 years old since there are age restrictions and requirements for parental consent in accessing harm reduction services in some countries. • Hospitalized or incarcerated individuals.
HCV	• Acute or chronic STBBI • Regardless of symptoms expressed • New or recurrent infection	• Other STBBIs as the main focus of the study or when it was unclear whether individuals were sharing their experiences with HCV or other STBBI testing.
Testing	• Any phases of the testing process such as anti-HCV testing and/or HCV RNA testing administered from any route (ie. blood, oral). • Individuals with the intent of receiving HCV testing to receive a HCV diagnosis. • Individuals who are in process of receiving a clinical diagnosis or any phase of HCV testing. • Individuals recalling their experiences of accessing HCV testing.	• Treatment • Genotyping
Diagnosis	• A clinical confirmation of the absence or presence of an acute or chronic HCV dependent on the test result(s). • Individuals who believe they have HCV without receiving a clinical diagnosis and are describing their perspectives with seeking or experiencing HCV diagnosis.	

	• Individuals recalling their experiences of accessing HCV diagnosis.	
Limits	Inclusion	Exclusion
Date range	• Studies published from 2014 to present: 1) this avoided duplication in data (i.e. Including both Jones and colleagues (2014) and articles described in that article), and 2) 2014 marks the introduction of DAA HCV treatment.	
Language	• The language limit included English articles. Excluded were articles written in a language other than English.	
Type of literature	• The types of publication included were full-text, peer-reviewed, primary, secondary articles.	• Non full-text sources such as abstracts, conference proceedings, thesis', dissertations, books, letters, and editorials.
Screening criteria	Inclusion	Exclusion
Countries	• European microstates meeting the inclusion criterium of high-income countries, Western countries, countries with similar public health HCV case definitions and HCV screening guidelines as Canada.	
Study design	• Considered quantitative studies with survey or questionnaire data describing the perspectives of PWID with accessing HCV testing and/or diagnosis and their accompanying numerical frequencies (i.e. percentages, Likert scale). • Qualitative studies included interviewing PWID about their experiences with accessing HCV testing and/or diagnosis. • Mixed-methods studies were only considered if the quantitative and/or qualitative data as described can be clearly extracted.	• Intervention studies or studies where individuals were incentivized for their participation.

Search Process

I used the three-step strategy proposed by the JBI (2020). The search process involved the search terms, search limits, and databases as listed above. Target articles were chosen from the literature search for Chapter Two. I first followed the three-step strategy by conducting an initial search using the search strategy approved by the librarian. I searched on MEDLINE, where seven of eight target articles were identified from the results (Peters et al., 2020). I then translated the search strategy on CINAHL, where three of three target articles were identified from the results. The search strategies were then reviewed by the research team (P.O. and A.V.) and the expert librarian. I made revisions according to their feedback.

The initial search key terms included PWID, testing, diagnosis, and HCV. Synonyms and MeSH terms of each concept were searched, then the Boolean OR function combined the terms. The concepts were then combined using the Boolean AND function and the search limits were applied to the result to produce a full search strategy. I followed the second step of the three-step strategy by adapting the search strategy for each database and the search limits as listed above were applied when available. The following databases were searched: Embase, Nursing and Allied Health Proquest, PsycInfo, Scopus, and Sociology Database. The searches were saved in each database where appropriate and on a Microsoft Excel sheet. The Excel sheet documenting all searches was sent to the librarian for feedback. The searches for each database were reviewed and modified according to the feedback from the librarian. I followed the third step of the three-step strategy by conducting cited reference searching on articles included after the full-text screening through the database, Web of Science. The reference lists and citing articles of each search were hand-searched for relevant articles. The articles included from the cited reference

searching and forward citation search were searched through the database, Web of Science until data saturation was achieved. See Appendix A for a sample of the search strategy on MEDLINE and the search terms used for each database.

Stage 3: Identifying the Study Selection

This stage of the scoping review process involves developing eligibility criteria to gather the study sample (Arksey & O'Malley, 2005). I drafted the eligibility criteria in consultation with my thesis committee (P.O. and A.V.).

Screening Process

Two reviewers (N.H. and T.C.) met on November 29, 2020, to discuss each eligibility criteria and piloted screening 30 citations until all parties had a clear understanding of the eligibility criteria. (See stage 2 for eligibility criteria and limits). I created a screening questionnaire for each screening level to guide us through the reviewing process (See Appendix B). The results from each database were downloaded as RIS files and uploaded to Covidence, “an electronic programme designed for managing the screening process in systematic reviews” (Schmidt et al., 2018, p. 4). Covidence automatically removed duplicate citations. We used a two-level screening process by including citations based on the eligibility criteria (PHAC, 2018; CDC, 2017; Cousineau et al., 2020). The first-level screening was performed by independently screening for titles and abstracts. We read the abstracts then created notes explaining why an article was included, excluded, or undecided according to the eligibility criteria. The second-level screening was performed by independently screening full-text citations that were included during the first-level screening. The reviewers read the full texts to determine eligibility and articles were retained if there was a clear indication of the eligibility criteria. I additionally hand-

searched for articles and searched Web of Science for references that met the criteria for the aim of my study. A consensus of the screening process was reached between two reviewers (N.H. and T.C.). The research team (P.O. and A.V.) were involved to help resolve screening conflicts that were not able to be resolved by the two reviewers from the second-level screening.

PRISMA Flow Chart

The Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) is a flow diagram to illustrate the number of articles retained or excluded at each phase of screening (Liberati et al., 2009). This transparent method of reporting the screening process enhances the value of the synthesis review to readers (Liberati et al., 2009). The PRISMA diagram illustrated the citations identified in the searches from each database; the number of duplicates removed; the number of citations included in the first-level screening; the number of citations excluded from the first-level screening and the primary reasons for exclusion; the number of citations included in the second-level screening; the number of citations excluded from the second-level screening and the primary reasons for exclusion; the number of hand-searched citations; and the final number of citations screened-in from the second-level screening. There were several citations that did not have full-texts available. I emailed the primary authors twice starting in December 2020 with the second email sent a few weeks apart from the first. Citations without full-texts were not included if the authors did not respond by the first week of June 2021.

Stage 4: Charting the Data

This stage of the scoping review process involves charting the data; i.e., arranging and sorting pertinent data in preparation for analysis (Arksey & O'Malley, 2005). Data extraction

and a data charting tool were required to organize data for consistency of extraction across all the articles (Arksey & O'Malley, 2005).

Data Extraction Items

The following data were extracted from each citation and are displayed in Table 3. These extraction items were further labelled as the experience of seeking or receiving, and HCV testing or diagnosis as noted by the authors. This stage was performed iteratively. The participant characteristics data extraction criteria were reviewed and added as appropriate to the literature.

Client-identified barriers and facilitators were extracted using the principle of accessibility (UNICEF et al., 1979) and identifying key terms relating to barriers and facilitators. The key terms were compiled to guide extraction to ensure consistency in extracting related data across the literature and were reviewed by a second research member (T.C.) and new terms were added as appropriate.

Since there was one article with participants describing their experiences of accessing testing in different settings (i.e., hospital, incarceration facility, community settings) (Barocas et al., 2016). I scanned each quote and read the narrative summaries multiple times to understand the context described met the inclusion criteria.

Table 3*Extraction Items for the Scoping Review*

Data extraction categories	Extraction items
Study characteristics	Title, year, aim or objective, country of publication, study design, data collection method, data analysis method, recruitment source (as reported by author), setting or facility where the study was conducted.
Participant characteristics	Age, sex or gender, ethnicity or race, area of residence, living situation, education, employment, insurance, primary health provider status, current drug use, frequency of injection drug use, years injecting since initiation, injection equipment sharing, enrollment in opioid substitution therapy or methadone program, the primary drug injected, history of overdose on drugs, time since last HCV test, previous testing location, HCV diagnosis.
Qualitative findings	Themes, subthemes, categories, subcategories, excerpts and direct quotes in original texts, author explanations of the findings and their narrative interpretation.
Client-identified barriers and facilitators	Qualitative data collection method, client-identified barriers and facilitators from direct quotes, quantitative instrument(s) assessed, whether the instrument(s) were validated by the developer or in the present study, client-identified barriers and facilitators of measurement questions and associated outcomes/results of significance to research questions.

Data Charting Process

Data charting forms were created on Microsoft Excel based on 1) my research questions and 2) each data extraction category. Two reviewers (N.H. and T.C.) discussed the data charting form for a standardized approach to the process. I pre-filled a data extraction form to set an example of how the data extraction should look and explained each pre-filled category for the other reviewer (T.C.). The reviewers divided the data extraction for each citation meeting the inclusion criteria: T.C. performed data extraction for the study characteristics and participant characteristics for all articles while N.H. performed data extraction for the qualitative data, quantitative data, and barriers and facilitators for all articles. The reviewers cross-checked the extraction tables. Each article was reviewed and extracted the data meeting the inclusion criteria. The research team (A.V. and P.O.) were consulted for any unresolved discrepancies or disagreements.

Critical Appraisal

Critical appraisal is not typically conducted in scoping reviews (Arksey & O'Malley, 2005), but is recommended to assess the strength and quality of the citations included in this study (Peters et al., 2020). Unlike systematic reviews, scoping reviews retain all citations, regardless of critical appraisal scores (Peters et al., 2020). Critical appraisal of the final articles was used to assess the quality of the literature synthesized (Peters et al., 2020). The purpose of displaying the critical appraisal results was to allow readers to judge the sources included in this thesis, which ultimately facilitates their decisions to adopt the discussion to research, policymaking, or practice. As this scoping review includes citations of several study designs, the study design of each citation guided the choice of JBI critical appraisal checklists (JBI, 2020).

The JBI critical appraisal checklists are simple to understand and are comprehensive (Hannes et al., 2010). Two reviewers (N.H. and T.C.) independently conducted a critical appraisal of each citation. We assigned appropriate checklists to each citation according to the study design and reviewed the checklists to confirm a mutual understanding of each criterion listed. I pre-filled a critical appraisal form as an example for T.C. to refer to and we discussed our interpretations of the critical appraisal questions throughout the process. The reviewers independently appraised each article, created notes as appropriate, and documented the process in Microsoft Excel workbooks. Thereafter, the reviewers compared the critical appraisal results and discussed any discrepancies or disagreements to compile the final critical appraisal results. The two reviewers examined and revised the complete data charting forms for any disagreements or discrepancies. Then, the research team (P.O. and A.V.) were consulted for discrepancies, questions, or disputes about specific criteria which could not be resolved between the two reviewers. I created summary tables on Microsoft Word to present the final critical appraisal scores and reported the critical appraisal scores narratively, commenting on the critical appraisal scores in comparison with the total set of scores.

Stage 5: Summarizing and Reporting Results

This stage of the scoping review process involved presenting the results in a comprehensive method (Arksey & O'Malley, 2005). Conventional content analysis was used to develop categories for the data without preconceived categories (Hsieh & Shannon, 2005).

Data Analysis Process

The principal investigator (N.H.) independently performed data analysis and the research team (P.O. and A.V) reviewed the analysis. All participant characteristics were presented in

synthesized tables presenting frequencies and counts of the data. I then created a table to show the counts of characteristics each article presented.

Conventional Content Analysis

Data analysis was conducted inductive and iteratively with input from my supervisor and thesis committee (P.O. and A.V.). First, I aggregated all extracted qualitative data and then read and re-read the whole data to become familiar with the ideas presented in the original articles. Next, I identified concepts prevalent with the data and made comments to capture the main ideas.

The compiled data were transferred onto one Excel sheet and read repeatedly for content analysis (Hsieh & Shannon, 2005). The concepts, terms, or words were noted from the text that represented the major concepts of the citation and comments were made about significant data throughout the text. Labels, or codes, were then created from the highlighted terms and notes. The codes were categorized based on their relationships and differences. The categories were clustered and the subcategories were created for larger categories with more than 15 codes. Then, the subcategories were assessed whether they could be combined based on their relationships and differences.

I created summary tables of the content analysis and wrote definitions for each category and subcategory. Narrative summaries for each category represented patterns within the extracted findings, which were supported by participant quotes. When the content analysis was complete, I reviewed the quotes and counted the number of quotes that referenced barriers and facilitators about seeking or receiving and testing or diagnosis of HCV. Finally, I sorted the data based on if the participants were describing their experiences with *seeking HCV testing* or *diagnosis* or *receiving HCV testing* or *diagnosis*. This process was decided through analyzing the

participant's quotes of explicit or implicit statements about testing or diagnosis with a combination of reading the author's narrative summary of the quotes and identification through the title or aim of the study (See table in Appendix A).

Rigour

Rigour describes scholarly validity. I used two tools for establishing rigour: the ENTREQ (Tong et al., 2012) statement, as well as Guba (1981) and Lincoln's (1985) criteria of trustworthiness to validate the qualitative synthesis process. I used the PRISMA-ScR (Tricco et al., 2018) tool to guide the conduct and report of the scoping review process.

The ENTREQ statement (Tong et al., 2012) and Guba (1981) and Lincoln's (1985) criteria for trustworthiness were used as a means to establish rigour. This study lends to the qualitative design of exploring perceptions of the phenomenon of interest (Sandelowski, 2000) and the scoping review methodology (Arksey and O'Malley, 2005).

The four criteria of credibility, transferability, dependability, and confirmability were created (Guba, 1981; Lincoln, 1985). Tong and colleagues (2012) defined domain four of ENTREQ beyond the critical appraisal tool and recommended researchers appraise their studies based on Guba (1981) and Lincoln's (1985) four criteria for trustworthiness. The first of these criteria is credibility, which relates to ensuring there are a sufficient number of voices involved in the research and that there is representability of the diverse perspectives of the population within their contexts. Transferability ensures there is a sufficient amount of information for readers to determine the applicability of the findings from the participant's context to their population of interests' context (Guba, 1981; Hatch, 2007; Lincoln, 1985; Pozzebon et al., 2014). Dependability is the consistency and replicability of the research method. Confirmability helps to

enhance the transparency of the study (Guba, 1981; Pozzebon et al., 2014). Herein, credibility was operationalized through scoping the literature, not limited to a specific study type.

Transferability was demonstrated by scoping a diverse set of literature and databases, ensuring there is a sufficient amount of voices (Lincoln, 1985). I ensured this through data saturation in the articles in the searches and conducting the scoping review stages in an iterative manner (Lincoln, 1985). Domain five of the ENTREQ provides details on the documentation and analysis of findings, similar to stage 5 of the scoping review process (Arksey and O'Malley, 2005). Specifically, Tong and colleagues (2012) recommend clearly illustrating the section(s) of the article from which the findings were extracted and articulating the steps for the analysis. The transparency and confirmability of this synthesis study were further evidenced by a reflexive journal writing of all decision-making processes and notes of meeting discussions, explaining the rationale of any changes to the research process (Lincoln, 1985).

The ENTREQ statement was developed to guide researchers on conducting qualitative syntheses to enhance scholarly approval (Lincoln, 1985; Tong et al., 2012). Domains one and two of the ENTREQ statement pertain to the alignment between the introduction, methods, and methodology (Tong et al., 2012). These domains were met through careful selection of the scoping review methodology of critical interpretive synthesis to align with the three following items: the research question of describing the experiences of PWID with accessing a healthcare service, the qualitative methodology of Sandelowski (2000), and the philosophical position of critical theory. Domain three of the ENTREQ describes the transparency and fullness of the literature review (Tong et al., 2012). I fulfilled domain three by pre-planning all stages of the scoping review process by Arksey and O'Malley (2005) and the JBI (2020). The screening development was documented by an audit trail recording changes made, strengthening the

dependability and confirmability of this study (Lincoln, 1985). This included various Excel worksheets detailing specific moments of the research process and rationales for the decisions. Domain four of the ENTREQ pertains to the quality assessment of the qualitative sources included to provide transparency in the overall quality of the synthesis. This domain was fulfilled by two reviewers who independently completed the JBI critical appraisal tools on each citation. Please see Appendix A for a checklist demonstrating how each ENTREQ criteria were met.

Moreover, I used the PRISMA-ScR tool to report on the scoping review process and to ensure rigour in its conduct (Tricco et al., 2018). The PRISMA-ScR tool is a checklist comprised of 20 items and two optional items (Tricco et al., 2018). This study was reviewed for compliance with the PRISMA-ScR tool (Tricco et al., 2018), where details were amended as part of the iterative approach of the Arksey and O'Malley (2005) scoping review process. The protocol registration occurred on November 25, 2020, through the Center of Open Science (<https://osf.io/rgsfu/>). Please see Appendix A for a checklist describing how each PRISMA-ScR criteria were met.

Ethics

Using Public Health Ontario's Ethics Review Risk Screening Tool (Ondrusek et al., 2015), this scoping review received a minimal risk score. Research ethics board approval from the University of Ottawa was not required since synthesis studies and this review did not involve human participants.

References

- Archibald, D., Patterson, R., Haraldsdottir, E., Hazelwood, M., Fife, S., & Murray, S. A. (2016). Mapping the progress and impacts of public health approaches to palliative care: A scoping review protocol. *BMJ Open*, 6(7). <https://doi.org/10.1136/bmjopen-2016-012058>
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32. <https://doi.org/10.1080/1364557032000119616>
- Booth, A. (2016). Searching for qualitative research for inclusion in systematic reviews: A structured methodological review. *Systematic Reviews*, 5(1), 74. <https://doi.org/10.1186/s13643-016-0249-x>
- PHAC. (2018, January 4). *Awareness of hep C among health care providers* [Education and awareness]. Aem. <https://www.canada.ca/en/public-health/services/reports-publications/canada-communicable-disease-report-ccdr/monthly-issue/2018-44/issue-7-8-july-5-2018/article-2-awareness-hep-c-among-health-care-providers.html>
- CDC. (2017, December). *Increase in hepatitis C infections linked to worsening opioid crisis*. Centers for Disease Control and Prevention. <https://www.cdc.gov/nchhstp/newsroom/2017/hepatitis-c-and-opioid-injection-press-release.html>
- Cousineau, S. E., Erman, A., Liu, L., Saeed, S., Fradette, L., Feld, J. J., Grebely, J., MacParland, S. A., Shoukry, N. H., Sebastiani, G., Sagan, S. M., & C (CanHepC), on behalf of the C. N. on H. (2020). The 8th Canadian Symposium on Hepatitis C virus: “Improving diagnosis and linkage to care.” *Canadian Liver Journal*. <https://doi.org/10.3138/canlivj.2019-0032>

- Creswell, J. (2013). *Third edition qualitative inquiry and research design* (Third). Sage Publications, Inc. <http://www.ceil-conicet.gov.ar/wp-content/uploads/2018/04/CRESWELLQualitative-Inquary-and-Research-Design-Creswell.pdf>
- Grant, M. J., & Booth, A. (2009). A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal*, 26(2), 91–108. <https://doi.org/10.1111/j.1471-1842.2009.00848.x>
- Guba, E. (1981). ERIC/ECTJ Annual Review Paper: Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology*, 29(2), 75–91. JSTOR.
- Guba, E., & Lincoln, Y. (1994). Chapter 6 competing paradigms in qualitative research. In *Handbook of qualitative research* (pp. 105–117). N.K. Denzin & Y. S. Lincoln.
- Hannes, K., Lockwood, C., & Pearson, A. (2010). A comparative analysis of three online appraisal instruments' ability to assess validity in qualitative research. *Qualitative Health Research*, 20(12), 1736–1743. <https://doi.org/10.1177/1049732310378656>
- Hatch, J. A. (2007). Trustworthiness. In *The Blackwell Encyclopedia of Sociology*. American Cancer Society. <https://doi.org/10.1002/9781405165518.wbeost053>
- Higgins, J., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M., & Welch, V. (2019). *Cochrane Handbook for systematic reviews of interventions version 6.0*. Cochrane. www.training.cochrane.org/handbook
- Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288. <https://doi.org/10.1177/1049732305276687>

- JBI. (2020). *Critical appraisal tools*. JBI. <https://joannabriggs.org/critical-appraisal-tools>
- Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P. A., Clarke, M., Devereaux, P. J., Kleijnen, J., & Moher, D. (2009). The PRISMA Statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: Explanation and elaboration. *PLOS Medicine*, 6(7), e1000100. <https://doi.org/10.1371/journal.pmed.1000100>
- Lincoln, Y. S. (1985). *Naturalistic inquiry*. Sage Publications.
- McGowan, J., Sampson, M., Salzwedel, D. M., Cogo, E., Foerster, V., & Lefebvre, C. (2016). PRESS Peer Review of Electronic Search Strategies: 2015 Guideline Statement. *Journal of Clinical Epidemiology*, 75, 40–46. <https://doi.org/10.1016/j.jclinepi.2016.01.021>
- Mertens, D. M. (2012). Transformative mixed methods: Addressing inequities. *American Behavioral Scientist*, 56(6), 802–813. <https://doi.org/10.1177/0002764211433797>
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Group, T. P. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLOS Medicine*, 6(7), e1000097. <https://doi.org/10.1371/journal.pmed.1000097>
- Munn, Z., Peters, M. D. J., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology*, 18(1), 143. <https://doi.org/10.1186/s12874-018-0611-x>
- Ondrusek, N. K., Willison, D. J., Haroun, V., Bell, J. A. H., & Bornbaum, C. C. (2015). A risk screening tool for ethical appraisal of evidence-generating initiatives. *BMC Medical Ethics*, 16(1), 47. <https://doi.org/10.1186/s12910-015-0039-3>

- Peters, M., Godfrey, C., McInerney, P., Munn, Z., Tricco, A., & Khalil, H. (2020). Chapter 11: Scoping reviews. In *JBIM Manual for Evidence Synthesis*. JBI.
<https://doi.org/10.46658/JBIMES-20-12>
- Pham, M. T., Rajić, A., Greig, J. D., Sargeant, J. M., Papadopoulos, A., & McEwen, S. A. (2014). A scoping review of scoping reviews: Advancing the approach and enhancing the consistency. *Research Synthesis Methods*, 5(4), 371–385.
<https://doi.org/10.1002/jrsm.1123>
- Pozzebon, M., Rodriguez, C., & Petrini, M. (2014). Dialogical principles for qualitative inquiry: A nonfoundational path. *International Journal of Qualitative Methods*, 13(1), 293–317.
<https://doi.org/10.1177/160940691401300114>
- Sandelowski, M., Barroso, J., & Voils, C. I. (2007). Using Qualitative Metasummary to Synthesize qualitative and quantitative descriptive findings. *Research in Nursing & Health*, 30(1), 99–111. <https://doi.org/10.1002/nur.20176>
- Saris, W. E., & Gallhofer, I. N. (2007). Chapter 4 specific survey research features of requests for an answer. In *Design, Evaluation, and Analysis of Questionnaires for Survey Research* (1st ed., p. 83). Wiley-Interscience, John Wiley & Sons, Incorporated.
- Schmidt, B.-M., Colvin, C. J., Hohlfield, A., & Leon, N. (2018). Defining and conceptualising data harmonisation: A scoping review protocol. *Systematic Reviews*, 7(1), 226.
<https://doi.org/10.1186/s13643-018-0890-7>
- Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, 12(1), 181–181. <https://doi.org/10.1186/1471-2288-12-181>

- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K., Colquhoun, H., Kastner, M., Levac, D., Ng, C., Sharpe, J. P., Wilson, K., Kenny, M., Warren, R., Wilson, C., Stelfox, H. T., & Straus, S. E. (2016). A scoping review on the conduct and reporting of scoping reviews. *BMC Medical Research Methodology*, 16(1), 15–10. <https://doi.org/10.1186/s12874-016-0116-4>
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., ... Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467–473. <https://doi.org/10.7326/M18-0850>
- UNICEF, World Health Organization, & International Conference on Primary Health Care. (1978). Declaration of Alma-Ata International Conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978. World Health Organization. <http://link.springer.com/10.1057/palgrave.development.1100047>
- Wyborn, C., Louder, E., Harrison, J., Montambault, J., Montana, J., Ryan, M., Bednarek, A., Nesshöver, C., Pullin, A., Reed, M., Dellecker, E., Kramer, J., Boyd, J., Dellecker, A., & Hutton, J. (2018). Understanding the impacts of research synthesis. *Environmental Science & Policy*, 86, 72–84. <https://doi.org/10.1016/j.envsci.2018.04.013>

Chapter Five: Results

In this chapter, I present the findings of the scoping review.

PRISMA Flow Diagram

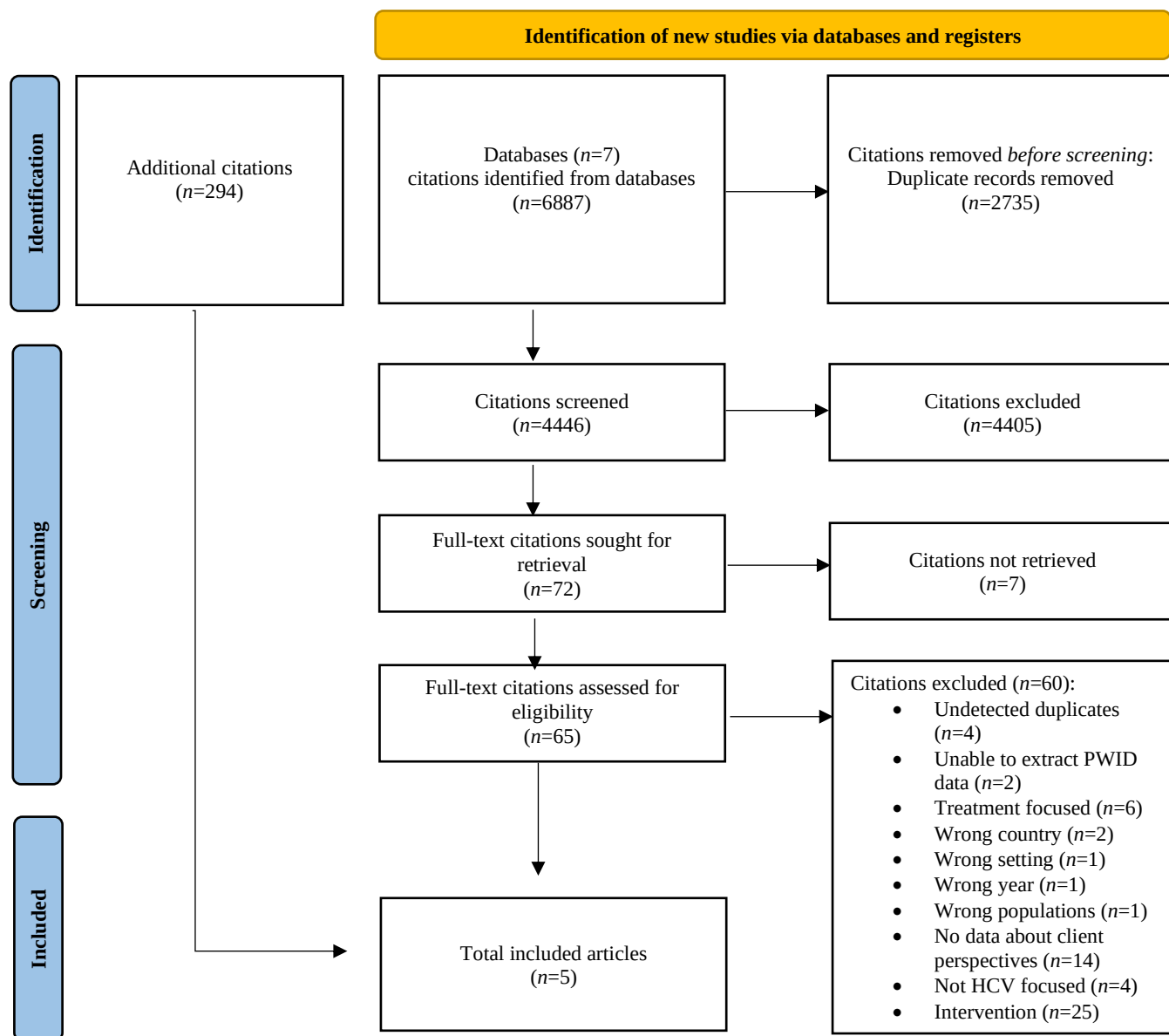
All citations were screened by June 4, 2021. The search strategy yielded 6887 citations from the chosen databases. 2735 citations were duplicates and 4446 citations were screened out from first-level screening. 72 citations were retained for second-level screening. 67 citations were excluded for the following reasons:

Table 4

Counts and Reasons for Excluding Full-Text Citations

Counts	Reason for exclusion
7	Did not have full-texts available.
4	Undetected duplicates.
2	Described multiple populations but PWID-related data was not distinct.
6	Aimed to describe the perspectives of PWID about the entire HCV continuum but was treatment-focused.
2	Were from low-income countries but had the correct data about describing the client's experiences of accessing HCV testing.
1	Only described the client's experience in an incarcerated facility.
1	Wrong year.
1	Wrong target population.
14	Had no data about client perspectives. Within the 14 citations, 3 citations had an aim to quantify PWID's access to testing and 11 were commentaries. The commentaries were hand searched for relevant citations.
4	Were not HCV-focused despite mentioning HCV in their titles and/or abstracts.
25	Were intervention studies which aimed to assess PWIDs' acceptance of several types of HCV testing and different models of care of distributing HCV testing.

Of the seven citations that did not have full-texts available, five were poster abstracts and did not meet the inclusion criteria for this study. Full-texts were requested from the primary authors of the two citations without full-text or poster abstracts through email with no success. Five articles met the inclusion criteria for this study. 294 additional citations were excluded, found through hand searching and backward forward-searching through Web of Science.

Figure 4*PRISMA Flow Diagram*

Note. The PRISMA flow diagram template is from [Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. DOI: 10.1136/bmj.n7]

Critical Appraisal

JBIs qualitative critical appraisal tool was used to assess the included articles ($N=5$). Out of a total score of 10, Barocas et al. (2014) scored six, Harris et al. (2014) scored seven, Harris et al. (2016) scored seven, Rance et al. (2017) scored six, and Skeer et al. (2018) scored seven. All studies were included in the scoping review regardless of the total score. All studies scored ‘unclear’ on their congruity between the stated philosophical perspective and the research methodology because the authors did not state their philosophical perspectives. All studies scored ‘Yes’ on their congruity between their qualitative methodology and chosen method of data collection, analysis of data, and interpretation of data. None of the authors described their influence on the research, and vice-versa. All studies scored ‘Yes’ to questions three, four, five, six, nine, and 10 of the JBI critical appraisal tool. Please see the following Table for a summary of the critical appraisal findings and see Appendix A for the full critical appraisal scores.

Table 5

Critical Appraisal Summary

JBIs Critical Appraisal Tool	References	Total Score
Qualitative research ($N=5$)	Barocas et al. 2014	6/10
	Harris et al. 2014	7/10
	Harris et al. 2016	7/10
	Rance et al. 2017	6/10
	Skeer et al. 2018	7/10

Study Characteristics

There were five articles included in scoping review. The included studies were published from 2014 to 2018. The studies were conducted in Australia ($n=1$), UK ($n=2$), and US ($n=2$). The studies had a qualitative methodology ($n=4$) and mixed-methods methodology ($n=1$). Interviews were conducted in all articles ($n=5$) and a survey was undertaken in the mixed-methods article to

retrieve participant characteristics. I extracted the frequencies and counts of the participant characteristics from the quantitative portion of the mixed-methods article, and I extracted the qualitative data from the interview portion of the mixed-methods article. All the studies included PWID ($N=5$), with the majority describing PWID as the only population of the study ($n=4$). Harris and colleagues (2016) interviewed a sample with PWID, individuals from endemic countries, individuals who sold blood, and people who received a blood transfusion prior to 1991. The PWID participants were distinguished through their interviews and the author's narrative summaries of mentioning IDU. The sample size of the studies ranged from 24 to 362 participants and they were mostly recruited through low barrier services in the community setting such as inner-city services, needle and syringe exchange programs, opioid substitution therapy clinics, shelters, and social service agencies ($n=4$). Studies were mostly conducted in PWID-related settings ($n=4$), with more than half of the studies offering more than one setting for individuals to attend ($n=3$). The authors of the included studies conducted analysis methods that aligned with qualitative methodologies such as thematic analysis ($n=3$) and grounded theory approach to analysis ($n=2$).

Table 6

Study Characteristics

Article # and Citation Author(s)	Country where the study took place	Recruitment source	Facility or setting(s) where the study was conducted	Study type	Data collection method	Sample size N
#1 Barocas et al. 2014	US	Community	Community	Mixed-methods	Open interviews	$N=362$ Qualitative, $N=520$ Quantitative
#2 Harris et al. 2016	UK	Hospitals or HCV organization	Community or participant's homes	Qualitative	Interviews and focus groups	$N=28$
#3 Harris et al. 2014	South East and North London (UK)	Community	Community or participant's homes	Qualitative	Interviews	$N=37$

#4 Rance et al. 2017	Two Australian states, New South Wales and Victoria	Community	NR	Qualitative	Semi-structured interviews	N=28
#5 Skeer et al. 2018	Boston, US	Community	University or community	Qualitative	Semi-structured interviews.	N=24

Note. In the article by Barocas and colleagues (2014), 553 participants agreed to complete the survey but only 520 responses were retained. Of the 520 participants who completed surveys, only 362 participants completed the interview.

Participant Characteristics

There were 18 participant characteristics in total, ranging from 3 to 15 participant characteristics per study. Barocas and colleagues (2014) reported the most participant characteristics ($n=15$ characteristics) while Rance and colleagues (2017) reported the least participant characteristics ($n=3$ characteristics). The participant's ages ranged from 22 to 67 years ($n=4$ articles). Most participants were men (64%) ($n=2$ articles specified gender, $n=3$ articles did not specify gender or sex). Most participants were white or Caucasian (78%), followed by unspecified non-white (13%). Most participants had a negative HCV status (62%, $n=4$ articles). In two articles, authors reported the diagnoses were self-identified by participants ($n=2$ articles) and in two articles, participants reported confirmation of the diagnoses through the study ($n=2$ articles). Participants from two articles reported having received HCV testing in the past 12 months of the study ($n=2$ articles). Of the HCV-related findings, authors from four articles reported the time since participants last received a HCV test ($n=4$ articles), authors from two articles reported their previous testing locations ($n=2$ articles), and authors from three articles confirmed their diagnoses ($n=3$ articles).

Barocas and colleagues (2014) were the only authors to collect and report the testing locations of participants who received testing in the past year (12 months). They reported that 10.3% ($n=34$) of the participants received HCV testing and diagnosis from correctional facilities while the rest of the clients received testing from community-health facilities: 12% ($n=64$)

received testing from syringe exchange and 21% ($n=107$) received testing from primary care medical clinics. 24% ($n=124$) of participants reported they received testing from other health care and public health venues.

Table 7*Synthesis of Participant Characteristics*

Participant socio-demographic characteristics	Number of studies (n) N=5	Total sample size (n) N=637	Counts, percentages, or ranges
Age	n=5	n=637	Range for 4 studies: 22 to 67
Sex or gender	n=4	n=609	Male: 386 (63) Female/women: 196 (32)
Ethnicity or race	n=4	n=609	White/Caucasian: 474 (78) (Anglo-Australian, Anglo-New Zealand, Greek-Italian, Hungarian, Scandanavian, Non-Hispanic white) Non-white (unspecified): 81 (13) Irish, black British, Latin American, Maltese, Polish, Portuguese, Armenian: 9 (<1) Aboriginal and Torres Strait Islander: 9 (<1) Australian-Armenian: 2 (<1) Indian: 1 (<1) African American/black: 2 (<1) Hispanic/Latino: 1 (<1) Mixed race: 1 (<1)
Area of residence	n=1	n=520	Rural: 80 (15) Suburban: 222 (43) Urban: 208 (40)
Living situation	n=1	n=520	Zip code: 279 (54) No zip code: 241 (46)
Education	n=1	n=520	Did not finish highschool: 77 (15) GED or high school diploma: 210 (40) Some college/technical school: 169 (33) Graduated college/technical school: 64 (12)
Employment	n=1	n=37	Social welfare: 21 (57) Full-time work 3 (8) Part-time work 2 (5) Dependent on partner's income 1 (<1) Prefer not to answer 1 (<1)
Insurance	n=1	n=520	No 276 (53) Yes 240 (46)
Clinical and injection characteristics	Number of studies N=5	Total sample size N=637	Mean, frequency, or range
Primary health provider status	n=1	n=520	No: 278 (53.5) Yes: 242 (46.5)
Current drug use	n=2	n=61	Yes: 49 (80) No: 12 (20)
Frequency injection use	n=2	n=557	Regular: 37 (7) One per week or less in the past 6 months: 50 (9)

			2-6 times/week in past 6 months: 112 (20) Once daily or more in the past 6 months: 354 (64)
Years injecting since initiation	n=2	n=557	Less than 2 years: 123 (22) 2-5 years: 211 (40) More than 5 years: 186 (33)
			Range <2 to 33 years
Injection equipment sharing	n=1	n=520	No in past 6 months: 220 (42) Yes in past 6 months: 300 (58)
Opioid substitution therapy or methadone program	n=2	n=65	Yes: 36 (55)
Primary drug injected	n=1	n=37	Heroin: 25, (68) Crack and heroin mix: 12 (32)
History of overdose on drugs	n=1	n=520	No: 364 (70) Yes: 152 (29)
HCV characteristics	Number of studies N=5	Total sample size N=637	Mean, frequency, or range
Time since last HCV test	n=2	n=520	Not tested in last 12 months 136 (26) Tested in last 12 months 384 (74)
Previous testing location	n=1	n=520	Syringe exchange program: 64 (19.5) Primary care medical clinic: 107 (32.5) Correctional facility: 34 (10.3) Other health care and public health venues: 124 (24)
HCV diagnosis	n=4	n=609	Negative: 377 (62) Positive: 96 (16)

Note. Previous testing locations reported by Barocas and colleagues (2014) only account for testing in the past year (12 months) of data collection.

Table 8*Participant Characteristics Display Table*

	Baseline sociodemographics									Injection practices and use							HCV related findings		
Reference	Age	Gender Or Sex	Ethnicity Or Race	Area of residence	Living situation	Education	Employment	Health insurance	Has primary health provider	Ongoing drug use	Years injecting since onset	Frequency of injection in the past	Sharing of injection-related	Enrolled in OST/MTD program	Drugs injected	History of overdose on drugs	Time since the last HCV test	Previous test location	Diagnosis
Barocas et al. 2014	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓			✓	✓	✓	
Harris et al. 2016	✓	✓		*										✓			✓		*
Harris et al. 2014	✓	✓	✓	*	*					✓	✓	✓		✓	✓		✓	✓	✓
Rance et al. 2017	✓	*	✓																✓
Skeer et al. 2018	✓	✓	✓							✓							✓		✓

Note. * = authors described the characteristics in the eligibility criteria but authors did not collect this data.

Client Experiences Content Analysis

Four categories were created through synthesizing the 54 instances of PWID describing their experiences with accessing HCV testing and diagnosis. Three studies had data about the participants' *Awareness and Knowledge* of HCV-related topics, four studies included data about *Stigma*, five studies included data about *Health Service Factors*, and four studies included data about *Psychological Responses*. I further striated the categories into two to three subcategories per category to demonstrate the variability in the data. I created two subcategories for the category, *Awareness and Knowledge*, three subcategories for *Stigma*, three subcategories for *Health Service Factors*, and two subcategories for *Psychological Responses*. Testing was identified in more than half of the data ($n=29$ data) and diagnosis was identified in the remaining data ($n=25$ data). Of the experiences about HCV testing, 24 quotes were about seeking testing and seven quotes were about receiving testing. Of the experiences about HCV diagnosis, 10 quotes were about seeking diagnosis and 17 quotes were about receiving the diagnosis.

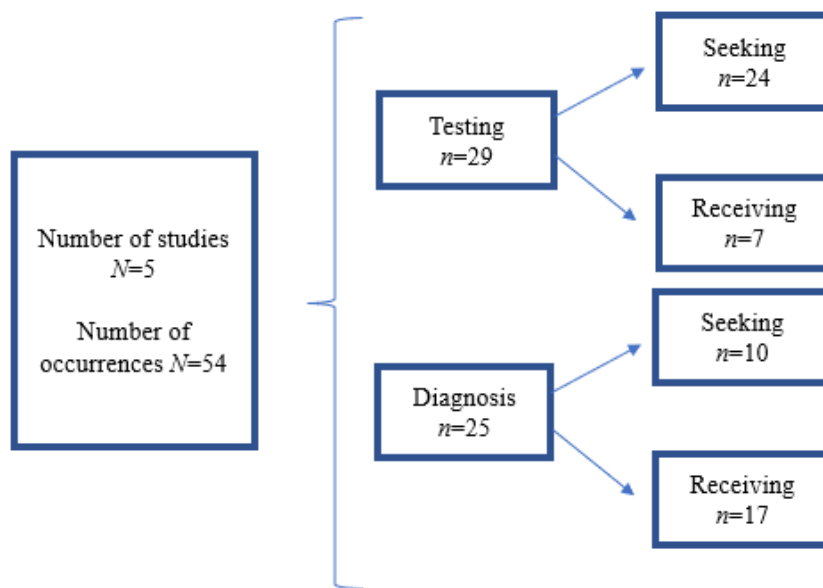
Table 9*Client Experiences Content Analysis*

Category	Definitions	Sample quote	Number of occurrences (N=54), Number of studies (N=5)	Subcategories	Definitions	Sample quote	Number of occurrences, Number of studies
Awareness and Knowledge	Understanding of Hep c related topics	I thought hepatitis was a generic illness and I remember saying to him [GP], 'But I can't have that I've been vaccinated against it', from having travelled, I assume I'd had a hep vaccine. I had to come off the phone and Google it, I didn't know what it was. (Helen) (Harris et al. 2016, p. 481).	n=11, n=3	Health	Knowledge and connection with HCV based on their state of health	Knowing [my HCV status] is something that I need to do to stay healthy. Knowing that I'll feel better about myself if the results are good makes it easier to get tested. (Barocas et al. 2014, p. 3).	n=7, n=3
				Clarification	Expressions of confusion of HCV diagnosis or testing	I'm going to die, oh my God, what is hepatitis C" (Marco) (Harris et al. 2014, p. 336).	n=4, n=3
Stigma	Rejection of a group or identity due to socially unacceptable attributes (Goffman, 2009)	I've never felt comfortable with any GP because, in the past, when you've gone to a GP, you say " I wonder if you can help me, I take heroin . . . " " (exclamation of horror) sorry, I don't deal with that here." (Fred) (Harris et al. 2014, p. 336).	n=11, n=4	Anticipated stigma	Feelings of fear or expectations that the individual may encounter stigma or judgement	'they [GP] know your family ... it was a small village and everybody knows everybody'. (Bella) (Harris et al. 2016, p. 481).	n=1, n=1
				Internal stigma	Perceived stigma of the self for identity	'I was ashamed of it, I didn't want people to know. Plus being a nurse I couldn't admit to being that other person that I had been for the decade before'. (Moir) (Harris et al. 2016, p. 482).	n=2, n=1

				Perceived Stigma	Feeling that there was an enactment of stigma towards the individual, the individual's behaviour, or disease	"I would be you know... out in like the suburbs or whatever other doctors I've been to where I say I'm an IV drug user and they don't respect me. I don't know they're just like not... educated about it." (Skeer et al. 2018, p. 20).	<i>n</i> =8, <i>n</i> =4
Health Service Factors	Structural factors that make up the service i.e., HCPs, cost, location, operation times, environment	"I can come here [SEP] and the staff does it for free and it's confidential." (Barocas 2014, p.5).	<i>n</i> =20, <i>n</i> =5	Provider	Interactions of or suggestions for provider offering test or diagnosis based on experiences of accessing	"Like if they were just like, 'here like you know like yeah you're positive, this is what you can go do about it, you know like, here's the numbers you need.' Like... give people more hope more than just like, 'Oh yeah, you have Hep C. See you later' you know, go figure it out." [30-year-old, white, non-Hispanic male; homeless; actively injecting heroin]. (Skeer et al. 2018, p. 9).	<i>n</i> =9, <i>n</i> =5
				Setting	Details about the testing and diagnosis location	"having a safe environment where people aren't going to 'notice you', such as here [SEP], where you know that other people are here for the same reason" (Barocas et al. 2014, p. 5).	<i>n</i> =5, <i>n</i> =2
				Test	Comments about the test itself	"[My GP] said it was really expensive" (Helen) (Harris et al. 2016, p. 481).	<i>n</i> =5, <i>n</i> =3
Psychological Responses	Expressions of reactions and methods of coping mechanisms to accessing testing and/or diagnosis, both as psychological responses	"No, they just said, 'Here you go, here's your uh thing' [handing him a pamphlet] ... I didn't know what to do, you know, and I didn't know what to think." (Skeer et al. 2018, p. 20).	<i>n</i> =12, <i>n</i> =4	Emotional Reactions	Emotional expressions in response to access to testing and/or diagnosis	"Oh it was fear.. ." (Andy). (Harris et al. 2014, p. 336).	<i>n</i> =6, <i>n</i> =3
				Coping Mechanisms	Behaviours in response to access to testing and/or diagnosis	"I'm in denial. I don't want to hear that I have it". (Barocas et al. 2014, p. 4).	<i>n</i> =6, <i>n</i> =3

Figure 5

Client Experiences with Seeking or Receiving HCV Testing and Diagnosis



Client Experiences Narrative Summary

Category 1: Awareness and Knowledge

This category was created to demonstrate the participants' experiences with accessing HCV testing through their *Awareness and Knowledge* about HCV-related topics. Three studies reported *Awareness and Knowledge* ($n=11$ data) about their own *Health Status* ($n=7$ data) and expressed a need for more *Clarification* about HCV ($n=4$ data).

Health Status. Participants demonstrated varying levels of awareness and knowledge about HCV through describing their health status'. The asymptomatic nature of HCV caused participants to think they were not living with HCV. For some, the absence of symptoms was discussed concurrently with feeling "well" to describe why they did not seek care sooner:

"I've spent the last 30 years of my life full of people with hep C and addiction problems. But I was fit and well ... The idea that if you have no symptoms you can't be ill is quite a powerful notion. And I didn't know anything about hep C really and I didn't know that it could sit dormant for decades." (Sam) (Harris et al. 2016, p. 481).

In the study by Harris and colleagues (2014), participants highlighted their lack of knowledge about HCV associated with their knowledge of a public figure in the UK. Anita Roddick, the founder of The Body Shop, was diagnosed with HCV and engaged in public awareness activities through her contribution to the Hepatitis C Trust (S. Jones, 2007). Participants spoke about their lack of connection with the diagnosis due to its asymptomatic nature and discussed the adverse health outcomes of the disease: "I'd heard of Anita Roddick ... there was no connection and I was so well ... I was totally disinterested, I just didn't think I was ill." (Helen) (Harris et al. 2016 p. 481).

Expanding on the asymptomatic nature of HCV, participants reported that they were only prompted to seek medical care when they started experiencing symptoms, although, even then, they were not initially interested in seeking care:

“A friend of mine was diagnosed in 2003 who I’d used drugs with, he suggested I get myself tested, cleverly I ignored him, just put it on the back burner.” They were “essentially symptom-free until 2012 when [they] started to feel weak...eventually had a battery of tests and [HCV] came up.” (Harris et al. 2016, p. 483).

Participants also described their health status’ as motivators for seeking and receiving HCV testing. Participants felt that knowing their HCV status will contribute to feeling “healthy” and “good”: “Knowing [my HCV status] is something that I need to do to stay healthy. Knowing that I’ll feel better about myself if the results are good makes it easier to get tested.” (Barocas et al. 2014, p. 3). Similarly, participants felt that the unknown status contributes to feelings of discomfort, relating to uncertainty: “Not knowing sucks. It doesn’t feel good when you don’t know if you have it or not.” (Barocas et al. 2014, pp. 3-4).

Finally, participants expressed concern about transmitting the virus to others such as their families. They knew that HCV is contagious and their concern for other people’s health statuses were motivators for getting tested: “Knowing that there’s an epidemic and that it can be passed on [makes it easier to get tested].” (Barocas et al. 2014, p. 4) and “if I knew I was positive, then I would take caution to not infect my family.” (Barocas et al. 2014, p. 4).

Clarification. Participants demonstrated a need for more awareness and knowledge about HCV through explicit expressions of confusion and asking questions about HCV. Most of the participants required clarification shortly after receiving their HCV diagnosis’:

“I thought hepatitis was a generic illness and I remember saying to him [GP], ‘But I can’t have that I’ve been vaccinated against it’, from having travelled, I assume I’d had a hep vaccine. I had to come off the phone and Google it, I didn’t know what it was.” (Helen) (Harris et al. 2016, p. 481).

“I got tested again and the second time, it was negative, but I’ve still got the paperwork, you know, that said that I’m hep C positive... And I’m thinking, well that can’t be right, what the fuck’s happening there? You know, nobody can really tell me.” (Tom) (Harris et al. 2014, pp. 337-338).

Finally, one article had a narrative summary of participants that identified “lack of knowledge surrounding testing.” (Barocas et al. 2014 p. 5). While participants did not specify which component of testing required more clarification, this suggests there may be a need for HCPs to re-evaluate the education involved with testing in general.

Category 2: Stigma

This category was created to represent the rejection of a group or identity due to socially unacceptable attributes (Goffman, 2009). As a result of *Perceiving* the stigma ($n=5$ data), some participants may *Anticipate* ($n=4$ data) stigma or *Internalize* ($n=2$ data) stigma.

Perceived Stigma. Participants felt stigma because of their drug use and visible marks from IDU. Most of the participants perceived stigma from their doctors:

“I’ve never felt comfortable with any GP because, in the past, when you’ve gone to a GP, you say ‘I wonder if you can help me, I take heroin ...’ ‘(exclamation of horror) sorry, I don’t deal with that here.’” (Fred) (Harris et al. 2014, p. 336).

“I would be you know... out in like the suburbs or whatever other doctors I’ve been to where I say I’m an IV drug user and they don’t respect me. I don’t know they’re just like not... educated about it.” (Skeer et al. 2018, p. 20).

“If a doctor wanted to examine us and I’d roll my sleeves up and I’ve got track marks, it was embarrassing man, it was horrible.” (Colin) (Harris et al. 2014, pp. 336-337).

Due to widespread stigma related to using injection drugs, participants described that most doctors were hesitant to ask the appropriate questions for screening for HCV: “No GP has ever said ‘Have you used drugs?’ Because there was a huge stigma and there still is a huge stigma.” (Harris et al. 2016, p. 481).

Lastly, participants described perceiving judgement from others when accessing HCV testing which led to having negative feelings about the experience. While the participants did not identify who they felt judgement from, they indicated having thoughts of “shame,” “embarrassment,” and “taboo” (Barocas et al. 2014, p. 5).

Anticipated Stigma. Participants had fears or expectations that they may be stigmatized for “both injection drug use as well as HCV” (Barocas et al. 2014, p. 5). Participants reported that they did not trust their doctors with their IDU status: “they [GP] know your family ... it was a small village and everybody knows everybody.” (Bella) (Harris et al. 2016, p. 481).

Internalized Stigma. Participants felt ashamed of their history of IDU. They had similar expressions of wanting to separate their identities from their behaviours through rationalizing that their behaviours occurred decades prior to their diagnosis:

“I don’t know whether I’d want to know. The shame of it... I think what I’d put my family through ... maybe I didn’t want to go back to it being so long ago, it was 30 years ago... I think it’s just if they’d screened me and then I have to face it, which is what I’ve done.” (Jane) (Harris et al. 2016 p. 482).

“I was ashamed of it, I didn’t want people to know. Plus being a nurse I couldn’t admit to being that other person that I had been for the decade before.” (Moirra) (Harris et al. 2016 p. 482).

Category 3: Health Service

This category was created to identify factors of *Health Services* which were reported as having influenced the client's experience with accessing HCV testing and obtaining a diagnosis. Participants made comments about their *Providers* offering the test or diagnosis ($n=9$ data), the *Setting* where the test or diagnosis was offered ($n=5$ data), and about the *Test* itself ($n=5$ data).

Providers. Participants described poor encounters with providers when asked about their experiences of HCV testing or diagnosis. Providers included doctors, SEP staff, and HCV counsellors:

“I think a lot of the older ones don’t have the knowledge because it wasn’t identified before 20 years ago was it? Also the attitude of the older GPs, they tend to ‘I’m the one who knows about this and I give you some drugs and you go away and take them’, whereas now they’re more sort of like ‘Well I don’t actually know anything about this but I can refer you to someone that does’.” (Matt) (Harris et al. 2016, p. 483).

Participants identified healthy relationships with their providers, which made the process of HCV testing “easy” (Barocas et al. 2014, p. 4): “I’m extremely honest with and have a very good relationship with my doctor.” (Barocas et al. 2014, pp. 4-5).

Setting. Many also described how the *Setting* of where HCV testing and diagnosis was offered influenced their experiences of accessibility. Some participants described factors that influenced their experiences such as having “access to transportation” (Barocas et al. 2014, p. 5) to travel to their HCV appointments and knowing where the “testing locations” exist (Barocas et al. 2014, p. 5). Moreover, participants described the importance of a client-centred location of “having a safe environment where people aren’t going to ‘notice you’, such as here [SEP], where you know that other people are here for the same reason” (Barocas et al. 2014, p. 5).

Test. Finally, concerns with the HCV *Test* itself were about cost and confidentiality: “[My GP] said it was really expensive” (Helen) (Harris et al. 2016, p. 481). Some participants reported their tests were “free and confidential” (Barocas et al. 2014, p. 5).

Category 4: Psychological Responses

This category was created to illustrate the *Psychological Responses* that the participants expressed while recalling their access to HCV testing or diagnosis. Participants had *Emotional Reactions* (n=6 data) and described *Coping Mechanisms* (n=6 data) from their experiences of accessing HCV testing and diagnosis.

Emotional Reactions. Participants conveyed a series of emotional reactions in response to their access to HCV testing or diagnosis. All of their reactions were negative responses, and most were fear-based in response to receiving their HCV diagnosis:

“Oh it was fear...” (Andy) (Harris et al. 2014, p. 336).

“I nearly died, I thought that was like really bad.” (Rebecca) (Harris et al. 2014, p. 336).

Upon receiving their HCV diagnosis, participants were in shock and did not know how to proceed with the information: “No, they just said, ‘Here you go, here’s your uh thing’ [handing him a pamphlet]... I didn’t know what to do, you know, and I didn’t know what to think.” (Skeer et al. 2018, p. 20).

Coping Mechanisms. Participants described behaviours they exhibited as a result of their discomfort with the idea of HCV testing and diagnosis. Many participants described their coping behaviours to explain why they delayed accessing HCV testing:

“I’d rather not know” (Andy). (Harris et al. 2014, p. 336).

Some were simply "not ready" (Barocas et al. 2014, p. 4) and “in denial. I don’t want to hear that I have it”. (Barocas et al. 2014, p. 4).

Others coped through disconnecting themselves from their IDU:

“It does [involve a disconnect] for me. I mean I have used some other softer, recreational drugs over the years, on and off, but I’ve never been involved in any injecting since that period so long ago and I didn’t really want to think about it.” (Matt) (Harris et al. 2016, p. 481).

Client-Identified Barriers: Content Analysis

All categories from the content analysis of client experiences ($n=4$ categories) were present in the barriers synthesis of experiences to accessing HCV testing and diagnosis. The categories ($n=4$) and subcategories ($n=10$) included 28 instances of PWID describing their

barriers with HCV testing and diagnosis from four articles. Two studies had data about the participants' *Awareness and Knowledge* of HCV-related topics, four studies reported on *Stigma*, two studies reported on *Health Service Factors*, and three studies reported *Psychological Responses*. I counted how many quotes referenced seeking or receiving, and testing or diagnosis of HCV and found that testing was identified in more than half of the data ($n=16$) and diagnosis was identified in the remaining data ($n=12$). Of the barriers to HCV testing, 16 quotes were about seeking testing and 0 quotes were about receiving testing. Of the barriers to HCV diagnosis, 12 quotes were about seeking diagnosis and four quotes were about receiving the diagnosis. See Table 10 for the terms and Table A4 for the content analysis categories reflecting the client-identified barriers to accessing HCV testing and diagnosis.

Client-Identified Barriers Narrative Summary

Category 1: Awareness and Knowledge

Clients identified barriers related to their *Understanding and Knowledge* of HCV prior to receiving HCV testing. Two studies reported on *Awareness and Knowledge* about the individual's *Health status* ($n=2$ data) and expressed a need for more *Clarification* about HCV ($n=1$ data).

Health status. Participants recalled that they initially did not think about HCV since they felt well and did not have symptoms. Their misunderstandings or lack of awareness of HCV in relation to their *Health Status*' were considered barriers to seeking HCV testing: "I'd heard of Anita Roddick ... there was no connection and I was so well ... I was totally disinterested, I just didn't think I was ill." (Helen) (Harris et al. 2016, p. 481).

Others reported an accurate understanding of the natural history of HCV at the time of the interview but did not think of HCV prior to receiving testing even though they knew people diagnosed with HCV and used drugs:

“I’ve spent the last 30 years of my life full of people with hep C and addiction problems. But I was fit and well ... The idea that if you have no symptoms you can’t be ill is quite a powerful notion. And I didn’t know anything about hep C really and I didn’t know that it could sit dormant for decades.” (Sam) (Harris et al. 2016, p. 481).

Clarification. Rather than having a misunderstanding of HCV and its natural history, some participants voiced that they did not have enough information about the testing itself. This suggests that they need more *Clarification* on the subject. Participants identified other tangible perceived barriers that were independent of past-year testing such as: “lack of transportation, time constraints, lack of knowledge surrounding testing, and cost of the test were identified barriers.” (Barocas et al. 2014, p. 5).

Category 2: Stigma

Many participants considered stigma as a barrier to accessing HCV testing. Four studies had reports of participants *Perceiving stigma* (n=5 data), *Anticipating stigma* (n=4 data), and *Internalizing* (n=2 data) the stigma.

Perceived. Stigma from providers acted as a barrier for several participants when they were seeking HCV testing. Due to the stigma, providers would not ask about drug use:

“I had as many as they deemed necessary to try and find out what it was, and it went on and on but obviously I didn’t get the hep C test then. No GP has ever said ‘Have you used

drugs?’ Because there was a huge stigma and there still is a huge stigma” (Bella) (Harris et al. 2016, p. 481).

Participants who disclosed their injection status’ to providers perceived disrespect and an overall lack of knowledge towards treating IDU:

“I would be you know... out in like the suburbs or whatever other doctors I’ve been to where I say I’m an IV drug user and they don’t respect me. I don’t know they’re just like not... educated about it.” (Skeer et al. 2018, p. 20).

“I’ve never felt comfortable with any GP because, in the past, when you’ve gone to a GP, you say ‘I wonder if you can help me, I take heroin . . . ‘ (exclamation of horror) sorry, I don’t deal with that here” (Fred) (Harris et al. 2014, p. 336).

Participants also recalled feeling judged by their providers, indicating they felt “shame”, “embarrassment”, and felt that it was “taboo” (Barocas et al. 2014, p. 5) when describing their experiences of accessing HCV testing. These experiences posed as barriers to receiving HCV testing: “If a doctor wanted to examine us and I’d roll my sleeves up and I’ve got track marks, it was embarrassing man, it was horrible.” (Colin). (Harris et al. 2014, pp. 336-337).

Anticipated. Participants expressed mistrust towards their GP, fearing that the information about their injection use will be disclosed to the entire village: “they [GP] know your family ... it was a small village and everybody knows everybody.” (Bella) (Harris et al. 2016, p. 481). This anticipated fear of breach in confidentiality led the participant to delay their search for HCV diagnosis.

Internal. Some participants voiced feelings of shame towards their current or past behaviours of injection drug use. It was particularly shameful for one participant who identified as a nurse, as they did not want to be associated with the “other person” (Harris et al. 2016, p. 482). While it is unclear how long the diagnosis was delayed, participants admitted to accepting the diagnosis once their provider screened them for testing:

“I don’t know whether I’d want to know. The shame of it... I think what I’d put my family through ... maybe I didn’t want to go back to it being so long ago, it was 30 years ago... I think it’s just if they’d screened me and then I have to face it, which is what I’ve done.”

(Jane) (Harris et al. 2016, p. 482).

Category 3: Health Service

This category was created to represent how patients identified *Health Services* as barriers to accessing HCV testing or diagnosis. Participants made comments about their *Providers* offering the test or diagnosis ($n=9$ data), the *Setting* where the test or diagnosis was offered ($n=5$ data), and about the *Test* itself ($n=5$ data).

Providers. Patient-identified barriers about *Providers* related to GPs having insufficient knowledge about HCV screening and testing. Participants self-advocated for testing from their GP and was frustrated at the lack of action on the GP’s part: “I keep telling her [GP], she ain’t done nothing, the stupid cow . . . I’m going to put my foot down, I want tests done and I want them done straightaway” (Bobby) (Harris et al. 2016, p. 482).

Another participant identified how because the recent discovery of HCV caused older GPs to not knowledgeable about it and were insufficient in addressing HCV:

“I think a lot of the older ones don’t have the knowledge because it wasn’t identified before 20 years ago was it? Also the attitude of the older GPs, they tend to ‘I’m the one who knows about this and I give you some drugs and you go away and take them’, whereas now they’re more sort of like ‘Well I don’t actually know anything about this but I can refer you to someone that does’.” (Matt) (Harris et al. 2016, p. 483).

Test. Client-identified barriers about the *Test* itself regarding the cost. Alike other participants (Barocas et al. 2014, p. 5), some participant’s GP told them the HCV test was “really expensive” (Helen) (Harris et al. 2016, p. 482), which deterred them from receiving the test at the time.

Category 4: Psychological Responses

Most participants identified *Coping Mechanisms* ($n=6$ data) as ways to avoid or delay seeking HCV testing. These *Coping Mechanisms* acted as initial barriers to seeking testing and helped participants to consolidate their fear of possibly being diagnosed with HCV: “I’d rather die of ignorance at that time” (Helene) (Harris et al. 2014, p. 336) and “I’m in denial. I don’t want to hear that I have it” (Barocas et al. 2014, p. 4)

Meanwhile, some participants coped through disconnecting themselves from IDU, which led to a delay in seeking testing:

“It does [involve a disconnect] for me. I mean I have used some other softer, recreational drugs over the years, on and off, but I’ve never been involved in any injecting since that period so long ago and I didn’t really want to think about it.” (Matt) (Harris et al. 2016, p. 481).

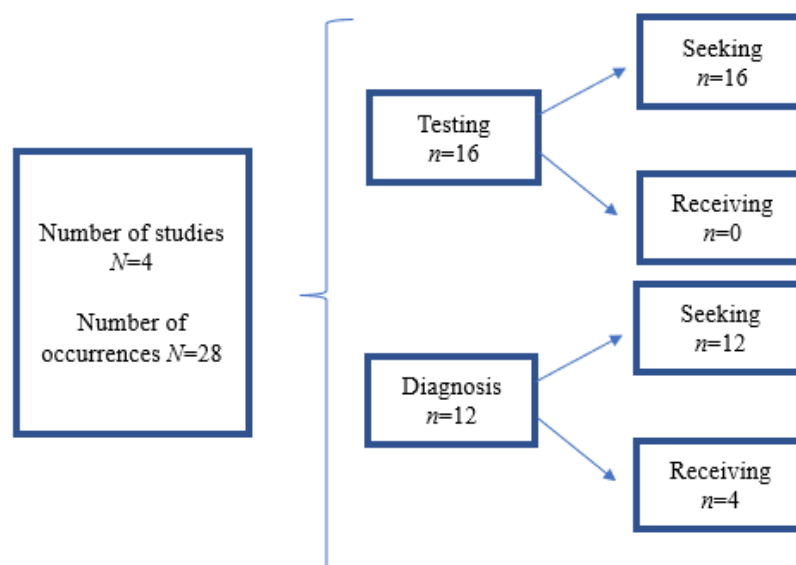
Table 10*Client-Identified Barriers Glossary*

Group	Barrier	Number of occurrences (N=28), Number of studies (N=4)
Knowledge	Disconnect with HCV	n=3, n=1
	Lack of knowledge about HCV	n=1, n=1
	No information about HCV	n=1, n=1
	Provider not knowing about HCV	n=1, n=1
	Lack of knowledge about testing	n=1, n=1
Stigma	Stigma from IDU status	n=6, n=4
	Shame	n=3, n=2
	Embarrassment	n=1, n=1
	Confidentiality	n=1, n=1
Structural Issues	Expensive	n=2, n=2
	Lack of transportation	n=1, n=1
	Time constraints	n=1, n=1
	Provider not acting	n=1, n=1

Results	Would rather not know about the result	$n=3, n=2$
	Not ready to know about the result	$n=1, n=1$
	Scared of the result	$n=1, n=1$

Figure 6

Client-Identified Barriers with Seeking or Receiving HCV Testing and Diagnosis



Client-Identified Facilitators

Two categories from the initial content analysis of client experiences ($n=2$ categories) were present in the categories describing client-identified facilitators to accessing testing. From the three articles which described facilitators, there were 14 instances of data where clients reported facilitators. Testing was identified in the majority of the data ($n=13$ data) and diagnosis was identified in the remaining data ($n=1$ data). Of the facilitators about HCV testing, eight quotes were about seeking testing and seven quotes were about receiving testing. Of the facilitators about HCV diagnosis, no quotes were about seeking diagnosis and one quote was about receiving the diagnosis. See Table 11 for the terms and Table A5 for the content analysis categories reflecting the client-identified facilitators to accessing HCV testing and diagnosis.

Client-Identified Facilitators Narrative Summaries

Category 1: Awareness and Knowledge

Participants reported that having an *Awareness and Knowledge* ($n=5$ data) of their *Health status* helped build their confidence in seeking and receiving HCV testing. Within this category, clients identified an understanding of their *Health* facilitated their access to HCV testing. One study had multiple participants expressing the need to know their status for their own and family's health and safety:

“if I knew I was positive, then I would take caution to not infect my family.” (Barocas et al. 2014, p. 4).

“Knowing [my HCV status] is something that I need to do to stay healthy. Knowing that I'll feel better about myself if the results are good makes it easier to get tested.” (Barocas et al. 2014, p. 3).

However, there were participants who stated they had only received testing because they were experiencing symptoms:

“I’ve been infected for over 30 years, I was essentially symptom free until 2012 when I started to feel weak . . . eventually had a battery of tests and it came up. A friend of mine was diagnosed in 2003 who I’d used drugs with, he suggested I get myself tested, cleverly I ignored him, just put it on the back burner.” (Sam) (Harris et al. 2016, p. 483).

Category 2: Health Service

Health Service Factors such as the *Providers*, *Setting*, and the *Test* contributed to reducing barriers to accessing testing and diagnosis. Participants described aspects of *Providers* ($n=2$ data), the *Setting* ($n=2$ data), and the *Test* itself ($n=2$ data) which facilitated their access to HCV testing and diagnosis.

Providers. Participants identified a healthy relationship with their *Providers* as a facilitator to accessing HCV testing. Most participants referred to providers as their doctors or GPs: “I’m extremely honest with and have a very good relationship with my doctor.” (Barocas et al. 2014, pp. 4-5).

The participants also shared their thoughts about SEP staff:

“They don’t think like any like lower or like higher, like you know what I mean, we’re all in the same – we’re all the same pretty much.” [29-year-old, mixed race, female; homeless, actively injecting heroin]. (Skeer et al. 2018, p. 9).”

There were also participants who shared that regular HCV screening facilitated their access to HCV testing. This was dependent on the *Provider’s* clinical judgement, action of

offering testing, and implementation of routine tests: “when it’s [HCV testing] offered to me on a regular basis [it makes it easier to get tested].” (Barocas et al. 2014, p. 5).

Setting. The participants highlighted several crucial points related to the *Setting* of where the HCV testing were offered: Knowing where to get tested and whether they were able to travel to the destination were facilitators to accessing HCV testing (Barocas et al. 2014, p. 5). Also, some participants identified the need for reducing the stigma of the environment where the testing is offered through designated location: “a safe environment where people aren’t going to ‘notice you’, such as here [SEP], where you know that other people are here for the same reason” (Barocas et al. 2014, p. 5).

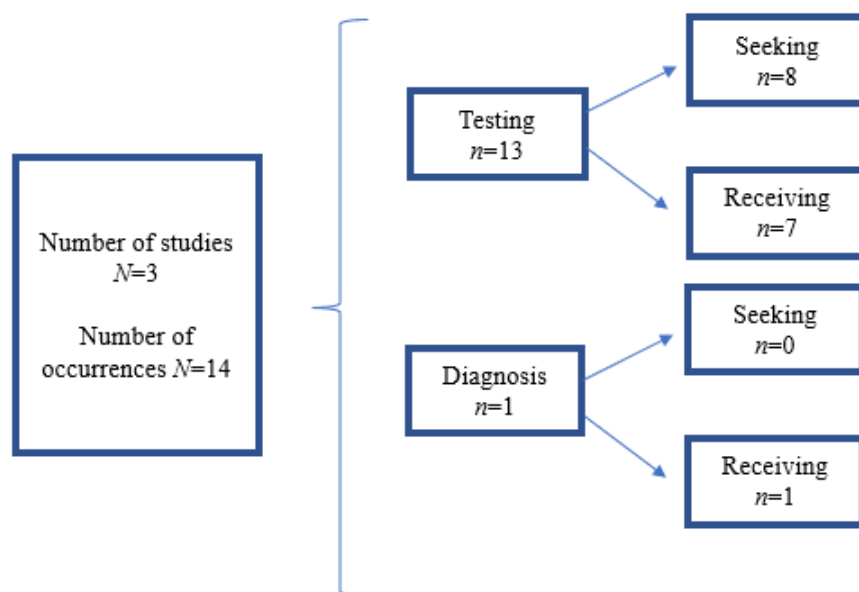
Test. Participants identified free *Testing* as a facilitator: “I can come here [SEP] and the staff does it for free and it’s confidential.” (Barocas et al. 2014, p. 5).

Table 11*Client-Identified Facilitators Glossary*

Group	Facilitator	Number of occurrences (N=14), Number of studies (N=3)
Individual	To stay healthy	n=1, n=1
	Not knowing does not feel good	n=1, n=1
	Concern of transmitting to others	n=2, n=1
	Feeling weak	n=1, n=1
Structural	Good relationship with provider	n=2, n=1
	Testing offered regularly	n=1, n=1
	Confidentiality	n=1, n=1
	Free testing	n=2, n=1
	Safe environment	n=1, n=1
	Access to transportation	n=1, n=1
	Awareness of testing locations	n=1, n=1
	Relatability with staff	n=1, n=1

Figure 7

Client-Identified Facilitators with Seeking or Receiving HCV Testing and Diagnosis



References

- Barocas, J. A., Brennan, M. B., Hull, S. J., Stokes, S., Fangman, J. J., & Westergaard, R. P. (2014). Barriers and facilitators of hepatitis C screening among people who inject drugs: A multi-city, mixed-methods study. *Harm Reduction Journal*, 11(1), 1. <https://doi.org/10.1186/1477-7517-11-1>
- Harris, M., McDonald, B., & Rhodes, T. (2014). Hepatitis C testing for people who inject drugs in the United Kingdom: Why is uptake so low? *Drugs: Education, Prevention and Policy*, 21(4), 333–342. <https://doi.org/10.3109/09687637.2014.899988>
- Harris, M., Ward, E., & Gore, C. (2016). Finding the undiagnosed: A qualitative exploration of hepatitis C diagnosis delay in the United Kingdom. *Journal of Viral Hepatitis*, 23, 479–486. <https://doi.org/10.1111/jvh.12513>
- Goffman, E. (2009). *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.
- Jones, S. (2007, February 15). Anita Roddick reveals she has hepatitis C. *The Guardian*. <https://www.theguardian.com/uk/2007/feb/15/healthandwellbeing.society>
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., ... Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, 372, n71. <https://doi.org/10.1136/bmj.n71>
- Rance, J., Treloar, C., Fraser, S., Bryant, J., & Rhodes, T. (2017). “Don’t think I’m going to leave you over it”: Accounts of changing hepatitis C status among couples who inject drugs. *Drug and Alcohol Dependence*, 173, 78–84. <https://doi.org/10.1016/j.drugalcdep.2016.12.020>

Skeer, M. R., Ladin, K., Wilkins, L. E., Landy, D. M., & Stopka, T. J. (2018). 'Hep C's like the common cold': Understanding barriers along the HCV care continuum among young people who inject drugs. *Drug and Alcohol Dependence*, 190, 246–254.
<https://doi.org/10.1016/j.drugalcdep.2018.06.013>

Chapter Six: Discussion

In this chapter, I summarize my findings, compare these findings to the available literature, present limitations of my synthesis study and the primary studies included in my synthesis study, discuss the state of science, and provide recommendations.

The research questions of this scoping review were:

1. Based on existing literature, how do PWID describe their experiences of seeking and receiving HCV testing and diagnosis in high-income, Western countries?
2. What are client-identified barriers and facilitators to HCV testing and diagnosis in high-income, Western countries?

Five studies were included in the review, where one article was mixed-methods in nature and four articles were qualitative. The articles were conducted in Australia ($n=1$), UK ($n=2$), and US ($n=2$). I extracted 19 participant characteristics relevant to contextualizing their experiences, where all the articles ($N=5$) reported on two characteristics; Age and Gender or Sex. I conducted a critical appraisal of the articles using JBI's qualitative critical appraisal checklist (JBI, 2020) and yielded scores ranging from six to seven.

How do PWID describe their experiences of seeking and receiving HCV testing and diagnosis in high-income, Western countries?

From the 54 instances of client quotes describing their experiences of accessing testing, I found four core categories describing client experiences of accessing testing: *Awareness and Knowledge*, *Stigma*, *Health Service Factors*, and *Psychological Responses* to seeking or receiving the testing. The category, *Awareness and Knowledge* ($n=3$ articles) is defined as the client's understanding of HCV-related topics and encompassed the subcategories of connecting the knowledge to their state of *Health* ($n=3$) and requiring *Clarification* ($n=3$) about HCV. The

category, *Stigma* ($n=4$) is defined as the rejection of a group or identity due to socially unacceptable attributes (Goffman, 2009). The category encompassed the subcategories of *Anticipated stigma* ($n=1$), *Internal stigma* ($n=2$), and *Perceived stigma* ($n=4$). The category, *Health Service Factors* ($n=5$) is defined as the structural-level factors affecting the service. It includes the subcategories about the *Provider* conducting the tests ($n=5$), the *Setting* of the service ($n=2$), and comments about the *HCV Test* ($n=3$). Lastly, the category, *Psychological Responses* ($n=4$) is defined as expressions of reactions and methods of coping. It includes the subcategories, *Emotional Reactions* ($n=3$) and *Coping Mechanisms* ($n=3$) in response to accessing testing.

What are client-identified barriers and facilitators to HCV testing and diagnosis in high-income, Western countries?

Client statements describing barriers to accessing HCV testing were identified in four studies. The following categories consisted of client-identified barriers: *Awareness and Knowledge* ($n=2$ articles), *Stigma* ($n=4$), *Health Service Factors* ($n=2$), and *Psychological Responses* ($n=3$). Client statements describing facilitators to accessing HCV testing were identified in three studies. The following categories consisted of client-identified facilitators: *Awareness and Knowledge* ($n=2$ articles) and *Health Service Factors* ($n=2$). These findings illustrate PWID's experiences with accessing HCV testing and diagnosis, confirming that they perceive facilitators and ongoing barriers.

Critiquing the Current Definition of Accessibility

Through the poststructuralist lens, reported findings and illustrative quotes provided insight into participants' perceptions of accessing HCV testing and these constructed truths were then displayed through my scoping review study (Guba & Lincoln, 1994). Recognizing how the

current structures in place are not absolute truths (Deleuze & Guattari, 1983; Foucault, 1954; Holmes & Gagnon, 2018), I suggest an alternative to the WHO (1978) definition of accessibility with the guidance of the constructed truths of these clients. Critiquing the current definition of accessibility (UNICEF et al., 1978) through the participant's perspective serves as a reminder to be attentive to the process of the phenomenon of accessing HCV testing rather than focusing on the outcome.

The revised WHO (1978) definition of accessibility suggested criteria that affect an individual's access such as cost, location, the functionality of the program, and culture of the population. The WHO (1978) later revised the definition to encompass complex issues that the population may face. The revision of the definition allows for adapting to different communities for a client-centred approach. However, it may be limited in providing a sustainable insight into accessibility because of differences in external factors that affect each individual. While the WHO (1978) and CNA (2000, 2005) provided a good structure for the definition of accessibility, this study defines accessibility of HCV testing and diagnosis for PWID that extends beyond the original definition to meet their unique needs.

Trajectories of Accessibility

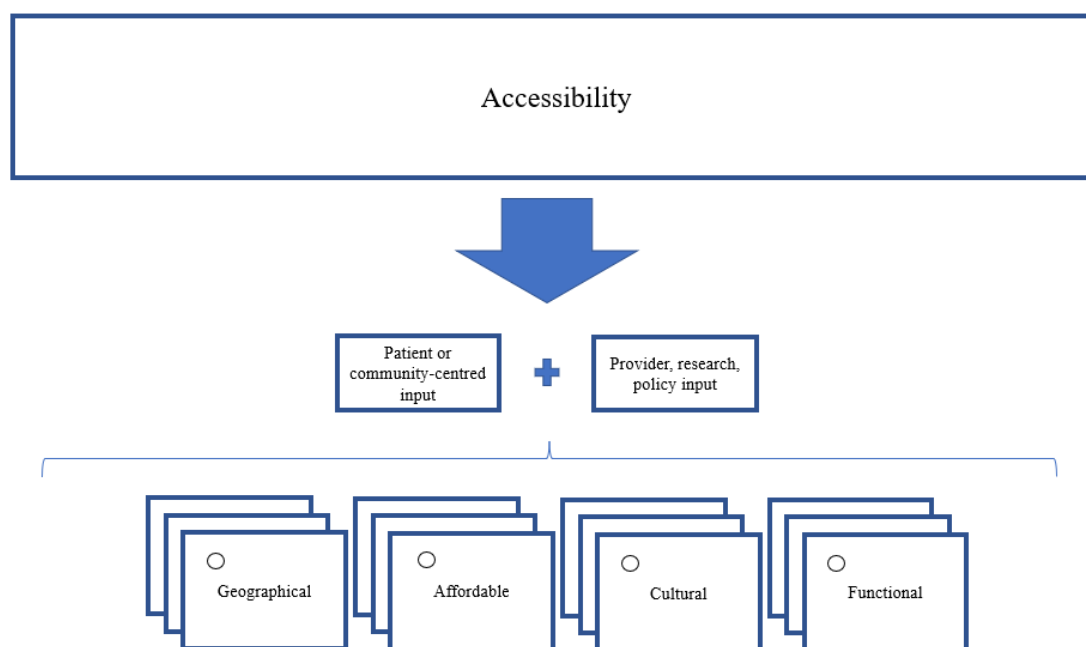
Firstly, these findings demonstrate the need to critique services as clinicians, researchers, and policymakers, as clients may have different perspective about access.

In this thesis, access was initially defined as receiving a service such as HCV testing and diagnosis, which encompassed the client seeking and receiving the test for a positive or negative result. However, my findings show that clients recalled their experiences of receiving HCV testing and diagnosis that demonstrates there is a trajectory within each criterion that clients need

to stay engaged with to wholly access testing. Herein, trajectories are defined as pathways that clients need to experience which may be unique to HCV testing, despite their individual contextual differences.

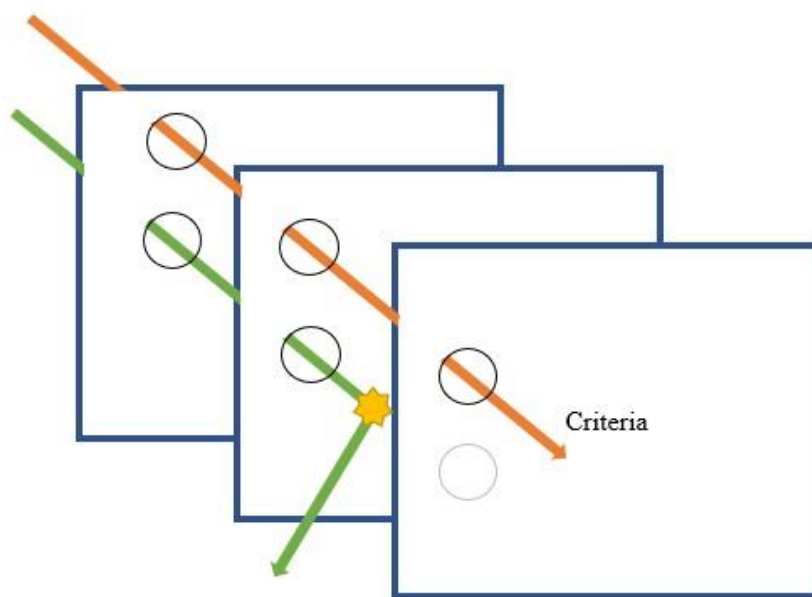
From my findings, the category of *Knowledge and Awareness* could serve as a criterion of accessibility. The trajectories of accessing testing included presenting HCV-related information to clients in terms of 1) the awareness or accuracy of knowledge of HCV to seek testing (Barocas et al., 2014; Harris et al., 2014, 2016), 2) whether the client has enough information to make an informed decision about the test (Barocas et al., 2014; Harris et al., 2014, 2016), and 3) whether the client understood the post-test counselling (Rance et al., 2017; Skeer et al., 2018). This is a notable finding due to the natural sequelae of HCV, particularly with the possibility of reinfection after treatment hence requiring the client to revisit the HCV care cascade starting with testing and diagnosis (Zein & Persing, 1996). From my findings, clients described feelings of confusion after receiving their diagnosis (Rance et al., 2017; Skeer et al., 2018). This confusion could further perpetuate the barrier that prevents clients from receiving HCV testing in the future. Thus, the goal of accessibility of HCV testing and diagnosis for PWID should be conceptualized in a multi-dimensional way and to understand that clients should remain engaged with the trajectories of 1) seeking, 2) receiving, and 3) having received the HCV test to wholly experience accessing testing for improved retention within the cascade of care.

As seen in the following Figure, the multi-dimensions of accessing HCV testing and diagnosis are represented by the layered criteria that could be tailored to each community rather than a one-dimensional perspective of each criterion.

Figure 8*Multi-Dimensional Perspective of Accessibility**Number of Interventions and Barriers to Testing*

A closer look at a newly defined model of accessibility in the following Figure shows that an individual will need to be successfully facilitated through the multi-dimensional trajectory to remain engaged with accessing HCV testing and diagnosis. Providers and policymakers should encourage clients to reach the final moment of accessing HCV testing and diagnosis. Notably, the Figure illustrates that insufficient interventions to facilitate accessibility, or disruptions of the care cascade will likely cause clients to face barriers or be dropped from this step of the care continuum. This concept lends to my findings which demonstrate that PWID experience more barriers than facilitators to accessing HCV testing and diagnosis. In addition to actual barriers in place, a client who experiences invalidating experiences could develop a sense of rejection and may avoid or delay seeking care (Biancarelli et al., 2019; Goodyear et al., 2021;

Guise et al., 2018; Hopwood & Southgate, 2003). This reconceptualization of accessibility aligns with the findings and literature search from Chapter Two that PWID are vulnerable to chronic discrimination from all levels of society.

Figure 9*Client's Trajectory through the Dimensions of Accessibility*

Note. In this Figure, the arrows represent the clients being engaged with the multi-dimensional trajectory of accessing HCV testing and diagnosis. It is evident that the arrows, or clients, need to be facilitated, or to pass through the holes, to remain engaged with the trajectory to successfully ‘access’ HCV testing and diagnosis. However, the green arrow is faced with a barrier (yellow star). The barriers could occur anywhere along the trajectory. Due to the barrier, the green arrow will not be able to reach the last dimension of the criteria to experience accessibility in full.

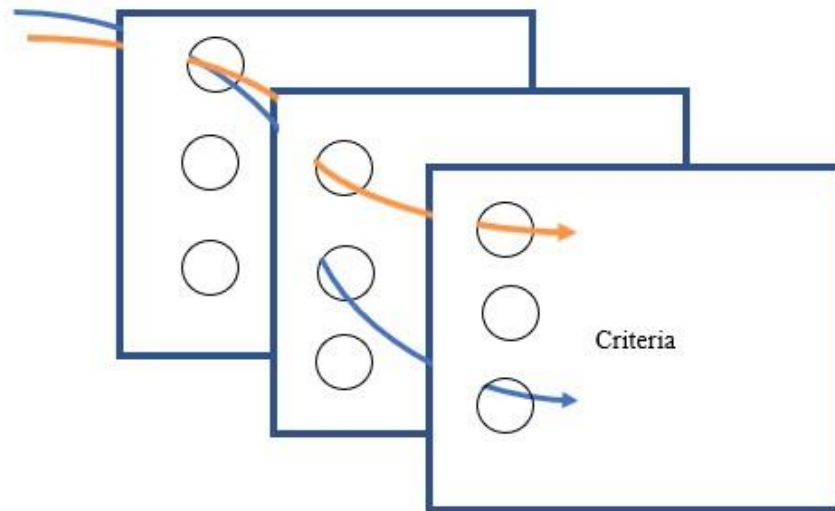
Flexible Pathways

In addition to creating enough interventions, or pathways, providers and policymakers need to be mindful of how a PWID experience each step of the care cascade.

This research demonstrates that PWID have historically faced more barriers in accessing healthcare because of social and societal marginalization. My findings highlight that PWID faced a lack of information about HCV even when diagnosed (Rance et al., 2017; Skeer et al., 2018), time constraints to accessing testing (Barocas et al., 2014), and poor interactions with providers (Barocas et al., 2014; Harris et al., 2014, 2016; Rance et al., 2017; Skeer et al., 2018). If providers and policymakers were more aware of how PWID experience each step of the care cascade, greater accessibility to outcomes could occur. One such method of reducing barriers includes creating flexible pathways to allow clients to remain engaged with accessing testing. This means that providers and policymakers must ensure there are multiple options for each dimension of the trajectory and despite which interventions clients choose, there is room to support them through the different interventions to reach the final moment of accessibility.

Flexible pathways have also been implemented for PWID in other areas of care, such as the distribution of injection and inhalation drug equipment and education on safer consumption techniques. For instance, needle exchange programs often operate through fixed locations and mobile for those who cannot access the sites (Gagnon et al., 2019; OPH, 2019; Strike et al., 2015). These flexible pathways allow for greater reach and accessibility for individuals with different contextual factors, thus providing benefits in the service provision.

Figure 10*Flexible Pathways for Clients*



Note. The clients are offered several interventions throughout each dimension of accessing HCV testing and diagnosis of that specific criteria. They could start with the same intervention in the first dimension of seeking testing and despite choosing different interventions for receiving and post-testing, both clients reach the same goal of experiencing accessibility. The flexibility in the pathways allows for each client to experience the dimensions in a client-centred way: simultaneously, concurrently, sequentially, iteratively, or with no pattern.

Further to access points for testing and diagnosis, PWID should have appropriate access to HCV testing especially because there is a possibility of reinfection after treatment (Zein & Persing, 1996). HCPs are unable to adequately address the quality of care when it is related to the experience of such care. Experiences of care must belong to the clients because their experiences are their realities, meaning for them, the experience was how they experienced it. Negative experiences and barriers in any moments of accessibility could cause mistrust and skepticism, which could deter clients from returning (Biancarelli et al., 2019; Guise et al., 2018; Hopwood & Southgate, 2003; Marshall et al., 2020). These specific dimensions are dependent on

the individual's contextual factors which shape their perceptions of the experience. Moreover, barriers in place will lead to clients being dropped from the step hence failing to engage with the overall HCV care continuum. Thus, providers and policymakers need to consider client perspectives of accessibility, remove potential barriers to ensure the clients reach the end goal of accessibility and provide multiple options as well as flexible pathways to cater to the needs of PWID.

Insufficient Client Demographics

My findings show that PWID may be faced with diverse barriers which could be a result of the layered systemic issues as discussed in Chapters Two and Three. There is insufficient demographic information, thus the contextual factors of the participants were not available. Findings from 80% of the included articles demonstrate that 63% of participants identified as men and 78% of participants identified as Caucasian. Nonetheless, only one article (Barocas et al., 2016) collected participant information about their area of residence, living situation, education, employment, health insurance, access to a primary health provider, and equipment sharing status. The article written by Barocas and colleagues (2016) was the only mixed-methods article in the included studies of this scoping review. While there was overlapping demographic information collected between Barocas and colleagues (2016) and the qualitative articles in this scoping review, the nature of the quantitative portion of the article allowed for a more comprehensive collection of demographic information to describe the target population.

Since the demographic data to illustrate the participants from the studies were unknown, it could be assumed that the dominant identifying characteristic is their IDU status. Similar issues have been discussed by Crenshaw (1980) who stated that intragroup identities are often

overlooked or merged in the realm of identity politics. The lack of supporting demographic data demonstrate that the focus is on their IDU status and other intergroup identities within the IDU community are unseen.

There are multiple implications to viewing the IDU status as a dominant identity. A lack of demographic data creates barriers in understanding who is represented in the data and whether practice suggestions truly meet the needs of PWID with intragroup identities. For instance, there were no trends suggesting there were sex and gender differences across the articles in my scoping review. While PWID are at risk of HCV transmission and can be a marginalized population, the literature demonstrates that women who use injection drugs experience additional unique barriers to accessing HCV testing (Canada FASD Research Network's Action Team, 2014; Deacon et al., 2013; For the Cedar Project Partnership et al., 2008; Kitson & O'Byrne, 2020; Wurcel et al., 2018). Harm reduction facilities may reflect the needs of people with an IDU status but the HCV testing services seldom reflect the needs of intragroups of people identifying of different sexes, races, or with different encounters with the criminal justice system. Thus, providers, researchers, and policymakers need to evaluate who they are reaching and how they are reaching the clients to minimize the exacerbation of inequities and to ensure intragroups within the IDU community are not overlooked.

Future Directions

Nursing Education

Nursing education recommendations include post-secondary nursing curriculums to incorporate or enhance topics such as substance use harm reduction, client-centred teachings for PWID, and the exceptionalism of STBBI testing (O'Byrne, 2021; O'Byrne & Orser, 2020). This

idea aligns with Principle One of the College of Nurses of Ontario (CNO) Code of Conduct (2019), nurses should treat clients with dignity and provide judgement-free care. However, my findings demonstrate that PWID continue to face a common barrier to care through experiencing multi-layered stigma. Exposing nursing students to the rippled effects from the systemic issue that marginalized populations face, may provoke change in the future generation of nursing practice, thus influencing policy, research, and administration.

Nursing Practice

Practice recommendations include creating flexible pathways for accessing HCV testing which cater to the needs of intragroups. As per Principle Two of the CNO Code of Conduct (2019) nurses should advocate to facilitate clients' access to care. Nurses should therefore work alongside PWID to advocate for flexible pathways to meet their needs and to implement the flexible pathways in the community setting (Jürgens, 2008). Flexible pathways include connecting several innovative, client-centred interventions to give PWID the power to choose between a set of options instead of being required to follow through a traditional streamline of the pathway. This will, in turn, help to reduce some barriers that PWID may face when accessing HCV testing and diagnosis.

Research

Research recommendations include a need to investigate each step of the cascade in-depth to determine the layered complexities within each step of the cascade. More insight into the barriers, facilitators, and overall experience of accessing each step of the cascade will shed light on how to reduce HCV within the IDU community and help to achieve the WHO hepatitis goals (WHO, 2016, 2017).

Nursing Administration

Nursing administration recommendations include the need to lead and implement policies with PWID (Jürgens, 2008). As per my findings of the structural barriers that PWID experienced, nursing administration could also address them through creating an inclusive environment and incorporating the needs of PWID such as adjusting the hours of operation, obtaining access to different types of tests and treatments, and strengthening community service networking for a smooth client linkage to care (Barocas et al., 2014).

Policy

Currently, PWID are key populations for HCV screening in many countries (CDC, 2020d; PHAC, 2018) due to their high prevalence of HCV. While this is an integral part of promoting the health status of PWID, mindfulness of exceptionalism in the community is required. This is needed to prevent the propagation of the disease, HCV, in the IDU community (O’Byrne, 2021; O’Byrne & Orser, 2020). Involving PWID in the design of policies to develop client-centred approaches to operationalize HCV screening is recommended (Jürgens, 2008).

State of Science

The findings from this review study are congruent with the other forms of evidence on the topic, including the qualitative systematic review conducted by Jones and colleagues (2014). Jones and colleagues (2014) found three major themes in their synthesis review: “...missed opportunities for the provision of information and knowledge; shifting priorities between HCV testing and other needs; and testing as unexpected and routine” (p. 208). The categories found in my scoping review were consistent with the themes from Jones and colleagues (2014), but there were distinctions between the findings of the studies.

I found client statements describing fear as an initial barrier in accessing testing, including individuals who reported they were “scared of the result” (Barocas et al., 2014 p. 4). These findings are consistent with Jones and colleagues’ (2014) findings, as these authors found client statements of being “frightened to get the test” (Khaw et al., 2007 p. 3) and their findings extended beyond the fear to rationalize that this is due to a lack of knowledge about HCV testing. However, my findings revealed six client statements describing their experiences of initial coping mechanisms in reaction to the thoughts of seeking or receiving testing, such as behaviors of avoidance, denial of the need for testing, and rejecting the identity of IDU (Barocas et al., 2014; M. Harris et al., 2014, 2016). Moreover, I found four client statements identifying their interactions with the *providers* as facilitators in accessing HCV testing. These findings are congruent with Jones and colleagues’ (2014) findings, as these authors found client reports of therapeutic relationships and support from staff at drug services (Munoz-Plaza et al., 2004; Strauss et al., 2008). However, my findings specify the types of providers including doctors ($n=2$ data) (Barocas et al., 2014) and harm reduction staff ($n=1$ data) (Skeer et al., 2018).

New findings are associated with the year, 2014, marking the introduction of a more successful and well-tolerated HCV treatment, which has proven to provide clients with heightened confidence in HCV care (Goodyear et al., 2021; Torrens et al., 2020). However, there was a paucity of literature about the client perspective about accessing HCV testing, suggesting there may be a shift of focus from organic client experiences (Jones et al., 2014). With the most recent article included in my review study published in 2018, there may be more interest in the structural-level innovations that target the cultural factors affecting marginalized clients since they are the clients most impacted by the disease and experience the most barriers to care (Bouzanis et al., 2021). Many authors of more recently published articles studying PWID are

interested in implementing structural-level innovations to address the PWID barriers to care such as convenient testing methods yielding immediate results or harm reduction and PWID-centered models of care (Bajis et al., 2017, 2018, 2020; Barocas et al., 2016; Bonnington & Harris, 2017; Chevaliez et al., 2020; Clements et al., 2015; Grebely et al., 2017, 2020; R. Harris et al., 2018; Harrison et al., 2019; Hayes et al., 2014; Lambert et al., 2019; Latham et al., 2019; Levine et al., 2015; Morano et al., 2014; Reynolds et al., 2017; Williams et al., 2019). However, investigating organic access to HCV testing could reflect the affected individual's lived experiences concerning their evolving context, thus allowing for the development of practice and policy recommendations that reflect their needs according to their perceptions of the phenomenon at that point in time.

Limitations

There were several limitations from this scoping review as well as the primary studies included in the review.

Limitations of the Included Primary Studies

A limitation to the primary studies included in my review is the heterogeneity in the context where participants accessed testing across studies. Barocas and colleagues (2014) reported that 10.3% ($n=34$) of their participants received HCV testing and diagnosis from correctional facilities and 24% ($n=124$) participants reported they received testing from “other health care and public health venues” (p. 3), while the rest of the participants received testing from community-health facilities. Acknowledging that I am excluding client perspectives of the phenomenon, accessing prison-based testing is different from community-based testing because of the nature of the closed setting, ability to self-select for testing, and provider's regard for

consent (Kronfli et al., 2020). Moreover, there was ambiguity with the reported location of “other health care venues” (Barocas et al., 2014, p. 3). To overcome this limitation, I assessed each quote to ensure that the experiences met the inclusion criteria.

Limitations of the Critical Appraisal

A limitation with the JBI critical appraisal question involved the question, “Are participants, and their voices, adequately represented?” (JBI, 2020, p. 3). My findings demonstrate that most of the included articles met this JBI critical appraisal criteria by narratively reporting the participant demographics or by providing demographic quantitative data. Attached to quotes were pseudonyms, which do not provide sufficient insight into whether the quotes represented the diversity of the demographics amongst the participants. Particularly, since the most common form of pseudonym used were fake names such as Colin, Helen, Andy, and Matt (M. Harris et al., 2014, 2016; Rance et al., 2017), readers are at risk of assuming the participant characteristics such as ethnicity, sex or gender of the individual based on the pseudonym that was chosen to be attached to the quote.

Limitations of the Scoping Review

A limitation to my scoping review is that I only searched for English citations, which may have led to a lack of diversity in the countries of publication of the primary articles. The included articles were limited to the US, UK, and Australia. I was, however, able to synthesize the results due to consistency across the literature (Tricco, 2016).

In addition, I identified more barriers ($n=4$ articles) than facilitators ($n=3$) in my review study. Categorizing the client statements into barriers and facilitators may have been affected by my experience of reading the literature thus gaining a biased lens that PWID have more

difficulties than facilitators with accessing care (Biancarelli et al., 2019; Global Commission on Drug Policy, 2011; Guise et al., 2018; Hopwood & Southgate, 2003; Jürgens, 2008; Richardson et al., 2015). To address this limitation, I involved a second reviewer to extract and review my data.

Another crucial limitation to this scoping review is the lack of involvement of a diverse group of PWID with lived experience of accessing HCV testing to participate in this research as committee members or as stakeholders. The lack of engagement could risk perpetuating their marginalization, creating inadequate recommendations to address their needs, and inaccurate interpretation of the collected client quotes (Jürgens, 2008).

Conclusion

My thesis provides an in-depth perspective of PWID's perspectives with accessing HCV testing and diagnosis. Categories representing the client experience, barriers, and facilitators to accessing HCV testing were identified. Testing remains an important part of the HCV cascade, especially since the WHO hepatitis goals have not been fulfilled (WHO, 2017, 2021). Client experiences contribute to the definition of accessibility (WHO, 1978). Without their input, they are further oppressed and systemically stigmatized through the implementation of paternalistic interventions. To create client-centred interventions, the topic needs to be framed in a poststructuralist stance. This stance supports the interventions and structures that are needed, but also advocates for the possibility of rewriting the structures by allowing individuals to describe their perspectives of the topic (Deleuze & Guattari, 1983; Foucault, 1954; Holmes & Gagnon, 2018).

In this thesis, accessibility has been re-conceptualized to include all criteria affecting an individual and ensure they remain engaged with the trajectory to wholly access HCV testing and diagnosis. A sufficient number of interventions and flexible pathways give clients a choice in directing their care and how the care should be implemented. Moreover, without demographic information, appropriate interventions to address the needs of PWID with intragroup identities are difficult to create. My findings demonstrate that PWID continue to perceive more barriers than facilitators with accessing HCV testing and diagnosis, as well as a general lack of research on the topic. Thus, more efforts to engage PWID in planning, practice, research, and policy levels of care are required to increase the validation of the targeted community in order to assess, plan, implement, and evaluate interventions to better testing rates.

References

- Bajis, S., Dore, G. J., Hajarizadeh, B., Cunningham, E. B., Maher, L., & Grebely, J. (2017). Interventions to enhance testing, linkage to care and treatment uptake for hepatitis C virus infection among people who inject drugs: A systematic review. *International Journal of Drug Policy*, 47, 34–46. <https://doi.org/10.1016/j.drugpo.2017.07.002>
- Bajis, S., Maher, L., Treloar, C., Hajarizadeh, B., Lamoury, F. M. J., Mowat, Y., Schulz, M., Marshall, A. D., Cunningham, E. B., Cock, V., Ezard, N., Gorton, C., Hayllar, J., Smith, J., Whelan, M., Martinello, M., Applegate, T. L., Dore, G. J., & Grebely, J. (2018). Acceptability and preferences of point-of-care finger-stick whole-blood and venepuncture hepatitis C virus testing among people who inject drugs in Australia. *International Journal of Drug Policy*, 61, 23–30. <https://doi.org/10.1016/j.drugpo.2018.08.011>
- Bajis, S., Grebely, J., Hajarizadeh, B., Applegate, T., Marshall, A. D., Ellen Harrod, M., Byrne, J., Bath, N., Read, P., Edwards, M., Gorton, C., Hayllar, J., Cock, V., Peterson, S., Thomson, C., Weltman, M., Jefferies, M., Wood, W., Haber, P., ... Clark, K. (2020). Hepatitis C Virus testing, liver disease assessment and treatment uptake among people who inject drugs pre- and post-universal access to direct-acting antiviral treatment in Australia: The LiveRLife study. *Journal of Viral Hepatitis*, 27(3), 281–293. <https://doi.org/10.1111/jvh.13233>
- Barocas, J. A., Brennan, M. B., Hull, S. J., Stokes, S., Fangman, J. J., & Westergaard, R. P. (2014). Barriers and facilitators of hepatitis C screening among people who inject drugs: A multi-city, mixed-methods study. *Harm Reduction Journal*, 11(1), 1. <https://doi.org/10.1186/1477-7517-11-1>

- Biancarelli, D. L., Biello, K. B., Childs, E., Drainoni, M., Salhaney, P., Edeza, A., Mimiaga, M. J., Saitz, R., & Bazzi, A. R. (2019). Strategies used by people who inject drugs to avoid stigma in healthcare settings. *Drug and Alcohol Dependence*, 198(Complete), 80–86. <https://doi.org/10.1016/j.drugalcdep.2019.01.037>
- Bonnington, O., & Harris, M. (2017). Tensions in relation: How peer support is experienced and received in a hepatitis C treatment intervention. *International Journal of Drug Policy*, 47, 221–229. <https://doi.org/10.1016/j.drugpo.2017.05.031>
- Bouzanis, K., Joshi, S., Lokker, C., Pavalagantharajah, S., Qiu, Y., Sidhu, H., Mbuagbaw, L., Qutob, M., Henedi, A., Levine, M. A. H., Lennox, R., Tarride, J.-E., Kalina, D., & Alvarez, E. (2021). Health programmes and services addressing the prevention and management of infectious diseases in people who inject drugs in Canada: A systematic integrative review. *BMJ Open*, 11(9), e047511. <https://doi.org/10.1136/bmjopen-2020-047511>
- Canada FASD Research Network's Action Team. (2014). *Substance use during pregnancy. An overview of key Canadian policy and practice areas*. <http://bccewh.bc.ca/wp-content/uploads/2014/09/Canadian.Policy-on.Subst-Use-+-Preg.Sept-2-2014web.pdf>
- CDC. (2020, July 29). *Testing recommendations for hepatitis C virus infection*. Viral Hepatitis. <http://www.cdc.gov/hepatitis/hcv/guidelinesc.htm>
- Chevaliez, S., Wlassow, M., Volant, J., Roudot-Thoraval, F., Bachelard, A., Poiteau, L., Trabut, J.-B., Hezode, C., Bourdel, A., & Dominguez, S. (2020). Assessing molecular point-of-care testing and dried blood spot for hepatitis C virus screening in people who inject drugs. *Open Forum Infectious Diseases*, 7(6), ofaa196. <https://doi.org/10.1093/ofid/ofaa196>

- Clements, A., Grose, J., & Skirton, H. (2015). Experiences of UK patients with hepatitis C virus infection accessing phlebotomy: A qualitative analysis. *Nursing & Health Sciences*, 17(2), 214–222. <https://doi.org/10.1111/nhs.12173>
- CNO. (2019). *Code of Conduct*. https://www.cno.org/globalassets/docs/prac/49040_code-of-conduct.pdf
- Coupland, H., White, B., Bates, A., Park, J. N., Iversen, J., & Maher, L. (2019). Engaging people who inject drugs in hepatitis C virus testing and prevention through community-based outreach, in Sydney, Australia: Increasing hepatitis C testing. *Drug and Alcohol Review*, 38(2), 177–184. <https://doi.org/10.1111/dar.12895>
- Crenshaw, K. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review*, 43(6), 1241–1299. <https://doi.org/10.2307/1229039>
- Deacon, R. M., Mooney-Somers, J., Treloar, C., & Maher, L. (2013). At the intersection of marginalised identities: Lesbian, gay, bisexual and transgender people’s experiences of injecting drug use and hepatitis C seroconversion. *Health & Social Care in the Community*, 21(4), 402–410. <https://doi.org/10.1111/hsc.12026>
- Deleuze, G., & Guattari, F. (1983). *Anti-edupus capitalism and schizophrenia*. University of Minnesota Press.
- For the Cedar Project Partnership, Mehrabadi, A., Paterson, K., Pearce, M., Patel, S., Craib, K. J. P., Moniruzzaman, A., Schechter, M. T., & Spittal, P. M. (2008). Gender differences in HIV and hepatitis C related vulnerabilities among Aboriginal young people who use street drugs in two Canadian cities. *Women & Health*, 48(3), 235–260. <https://doi.org/10.1080/03630240802463186>

- Foucault, M. (1954). Structuralism et poststructuralisme. In *Dits et écrits*. Éditions Gallimard.
- Gagnon, M., Gauthier, T., Adán, E., Bänninger, A., Cormier, L., Gregg, J. K., Gill, S., Horsburgh, K., Kreutzmann, P., Latimer, J., Bourhis, G. L., Livgard, C., Parker, D., Reiremo, T., Telegdi, E., Thorner, T., & White, M. (2019). International consensus statement on the role of nurses in supervised consumption sites. *Journal of Mental Health and Addiction Nursing*, 3(1), e22–e31. <https://doi.org/10.22374/jmhan.v3i1.35>
- Global Commission on Drug Policy. (2011). *War on drugs. Report of the Global Commission on drug policy*. https://www.globalcommissionondrugs.org/wp-content/themes/gcdp_v1/pdf/Global_Commission_Report_English.pdf
- Goffman, E. (2009). *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.
- Goodyear, T., Brown, H., Browne, A. J., Hoong, P., Ti, L., & Knight, R. (2021). “I want to get better, but...”: Identifying the perceptions and experiences of people who inject drugs with respect to evolving hepatitis C virus treatments. *International Journal for Equity in Health*, 20(1), 81. <https://doi.org/10.1186/s12939-021-01420-7>
- Grebely, J., Applegate, T. L., Cunningham, P., & Feld, J. J. (2017). Hepatitis C point-of-care diagnostics: In search of a single visit diagnosis. *Expert Review of Molecular Diagnostics*, 17(12), 1109–1115. <https://doi.org/10.1080/14737159.2017.1400385>
- Grebely, J., Catlett, B., Jayasinghe, I., Valerio, H., Hajarizadeh, B., Verich, A., Cunningham, P., Martinello, M., Tillakeratne, S., Silk, D., Dore, G. J., & Applegate, T. L. (2020). Time to detection of hepatitis C virus infection with the Xpert HCV viral load fingerstick point-of-care assay: Facilitating a more rapid time to diagnosis. *Journal of Infectious Diseases*, 221(12), 2043–2049. <https://doi.org/10.1093/infdis/jiaa037>

- Guba, E., & Lincoln, Y. (1994). Chapter 6 competing paradigms in qualitative research. In *Handbook of qualitative research* (pp. 105–117). N.K. Denzin & Y. S. Lincoln.
- Guise, A., Witzel, T. C., Mandal, S., Sabin, C., Rhodes, T., Nardone, A., & Harris, M. (2018). A qualitative assessment of the acceptability of hepatitis C remote self-testing and self-sampling amongst people who use drugs in London, UK. *BMC Infectious Diseases*, 18(1), 281. <https://doi.org/10.1186/s12879-018-3185-7>
- Harris, M., McDonald, B., & Rhodes, T. (2014). Hepatitis C testing for people who inject drugs in the United Kingdom: Why is uptake so low? *Drugs: Education, Prevention and Policy*, 21(4), 333–342. <https://doi.org/10.3109/09687637.2014.899988>
- Harris, M., Ward, E., & Gore, C. (2016). Finding the undiagnosed: A qualitative exploration of hepatitis C diagnosis delay in the United Kingdom. *Journal of Viral Hepatitis*, 23, 479–486. <https://doi.org/10.1111/jvh.12513>
- Harris, M., Bonnington, O., Harrison, G., Hickman, M., & Irving, W. (2018). Understanding hepatitis C intervention success: Qualitative findings from the HepCATT study. *Journal of Viral Hepatitis*, 25(7), 762–770. <https://doi.org/10.1111/jvh.12869>
- Harrison, G., Murray, K., Gore, R., Lee, P., Sreedharan, A., Richardson, P., Hughes, A. J., Wiselka, M., Gelson, W., Unitt, E., Ratcliff, K., Orton, A., Trinder, K., Simpson, C., Ryder, S. D., Oelbaum, S., Foster, G. R., Christian, A., Smith, S., ... Irving, W. L. (2019). The Hepatitis C Awareness Through to Treatment (HepCATT) study: Improving the cascade of care for hepatitis C virus-infected people who inject drugs in England. *Addiction*, 114(6), 1113–1122. <https://doi.org/10.1111/add.14569>
- Hayes, B., Briceno, A., Asher, A., Yu, M., Evans, J. L., Hahn, J. A., & Page, K. (2014). Preference, acceptability and implications of the rapid hepatitis C screening test among

- high-risk young people who inject drugs. *BMC Public Health*, 14(1), 645.
<https://doi.org/10.1186/1471-2458-14-645>
- Holmes, D., & Gagnon, M. (2018). Power, discourse, and resistance: Poststructuralist influences in nursing. *Nursing Philosophy*, 19(1), e12200. <https://doi.org/10.1111/nup.12200>
- Hopwood, M., & Southgate, E. (2003). Living with hepatitis C: A sociological review. *Critical Public Health*, 13(3), 251–267. <https://doi.org/10.1080/0958159032000114453>
- JB. (2020). *Critical appraisal tools*. JBI. <https://joannabriggs.org/critical-appraisal-tools>
- Jürgens, R. (2008). “*Nothing about us without us*” greater, meaningful involvement of people who use illegal drugs: A public health, ethical and human rights imperative. (International ed.). Canadian HIV/AIDS Legal Network, Canadian HIV/AIDS Legal Network : International HIV/AIDS Alliance : Open Society Institute.
<https://login.proxy.bib.uottawa.ca/login?url=http://www.deslibris.ca/ID/213091>
- Khaw, F.-M., Stobbart, L., & Murtagh, M. J. (2007). “I just keep thinking I haven’t got it because I’m not yellow”: A qualitative study of the factors that influence the uptake of Hepatitis C testing by prisoners. *Bmc Public Health*, 7, 98. <https://doi.org/10.1186/1471-2458-7-98>
- Kitson, C., & O’Byrne, P. (2020). The experience of violence against women who use injection drugs: An exploratory qualitative study. *Canadian Journal of Nursing Research*, 0844562120979577. <https://doi.org/10.1177/0844562120979577>
- Kronfli, N., Dussault, C., Chalifoux, S., Kavoukian, H., Klein, M. B., & Cox, J. (2020). A randomized pilot study assessing the acceptability of rapid point-of-care hepatitis C virus

- (HCV) testing among male inmates in Montreal, Canada. *International Journal of Drug Policy*, 85, 102921. <https://doi.org/10.1016/j.drugpo.2020.102921>
- Lambert, J. S., Murtagh, R., Menezes, D., O'Carroll, A., Murphy, C., Cullen, W., McHugh, T., Avramovic, G., Tinago, W., & Van Hout, M. C. (2019). "HepCheck Dublin": An intensified hepatitis C screening programme in a homeless population demonstrates the need for alternative models of care. *BMC Infectious Diseases*, 19(1), 128–128. <https://doi.org/10.1186/s12879-019-3748-2>
- Latham, N. H., Pedrana, A., Doyle, J. S., Howell, J., Williams, B., Higgs, P., Thompson, A. J., & Hellard, M. E. (2019). Community-based, point-of-care hepatitis C testing: Perspectives and preferences of people who inject drugs. *Journal of Viral Hepatitis*, jvh.13087. <https://doi.org/10.1111/jvh.13087>
- Levine, J. A., Cohen, S., Harkin, P., Guydish, J., Sorensen, J., & Masson, C. L. (2015). Acceptability of a mobile phone based hepatitis C intervention. *Drug and Alcohol Dependence*, 156, e127. <https://doi.org/10.1016/j.drugalcdep.2015.07.349>
- Marshall, A. D., Grebely, J., Dore, G. J., & Treloar, C. (2020). Barriers and facilitators to engaging in hepatitis C management and DAA therapy among general practitioners and drug and alcohol specialists-The practitioner experience. *Drug and Alcohol Dependence*, 206, 107705. <https://doi.org/10.1016/j.drugalcdep.2019.107705>
- Morano, J. P., Zelenev, A., Lombard, A., Marcus, R., Gibson, B. A., & Altice, F. L. (2014). Strategies for hepatitis C testing and linkage to care for vulnerable populations: Point-of-care and standard HCV testing in a mobile medical clinic. *Journal of Community Health*, 39(5), 922–934. <https://doi.org/10.1007/s10900-014-9932-9>

Munoz-Plaza, C. E., Strauss, S. M., Astone, J. M., Jarlms, D. C. D., & Hagan, H. (2004). Drug treatment programs as sites of opportunity for the delivery of hepatitis C prevention education: Client and staff perspectives. *Journal of Drug Issues*, 34(4), 861–878.

<https://doi.org/10.1177/002204260403400407>

O’Byrne, P. (2021). HIV self-testing: A review and analysis to guide HIV prevention policy.

Public Health Nursing. <https://doi.org/10.1111/phn.12917>

O’Byrne, P., & Orser, L. (2020). Avoiding missed opportunities to screen for HIV. *Journal of the American Association of Nurse Practitioners*, 32(5), 408–414.

<https://doi.org/10.1097/JXX.0000000000000274>

Ottawa Public Health [OPH]. (2019). *Site needle and syringe program*. Harm Reduction

Services in Ottawa. <https://www.ottawapublichealth.ca/en/public-health-topics/harm-reduction-services-in-ottawa.aspx#Program-goals>

PHAC. (2018, December 12). *National case definition: Hepatitis C*.

<https://www.canada.ca/en/public-health/services/diseases/hepatitis-c/health-professionals-hepatitis-c/national-case-definition.html>

Rance, J., Treloar, C., Fraser, S., Bryant, J., & Rhodes, T. (2017). “Don’t think I’m going to leave you over it”: Accounts of changing hepatitis C status among couples who inject drugs. *Drug and Alcohol Dependence*, 173, 78–84.

<https://doi.org/10.1016/j.drugalcdep.2016.12.020>

Reynolds, G. L., Fisher, D. G., Brocato, J., van Otterloo, L., Khahlil, K., & Huckabay, L. (2017). Stressful point-of-care rapid testing for human immunodeficiency virus, hepatitis C virus, and syphilis. *International Journal of STD & AIDS*, 28(10), 975–984.

<https://doi.org/10.1177/0956462416684460>

Richardson, L. A., Long, C., DeBeck, K., Nguyen, P., Milloy, M.-J. S., Wood, E., & Kerr, T. H.

(2015). Socioeconomic marginalisation in the structural production of vulnerability to violence among people who use illicit drugs. *J Epidemiol Community Health*, 69(7), 686–692. <https://doi.org/10.1136/jech-2014-205079>

Skeer, M. R., Ladin, K., Wilkins, L. E., Landy, D. M., & Stopka, T. J. (2018). ‘Hep C’s like the

common cold’: Understanding barriers along the HCV care continuum among young people who inject drugs. *Drug and Alcohol Dependence*, 190, 246–254.

<https://doi.org/10.1016/j.drugalcdep.2018.06.013>

Strauss, S. M., Munoz-Plaza, C., Tiburcio, N. J., Astone-Twerell, J., Des Jarlais, D. C., Gwadz,

M., Hagan, H., Osborne, A., & Rosenblum, A. (2008). Barriers and facilitators to undergoing hepatitis C virus (HCV) testing through drug treatment programs. *Journal of Drug Issues*, 38(4), 1161–1185. <https://doi.org/10.1177/002204260803800411>

Strike, C., Watson, T. M., Gohil, H., Miskovic, M., Robinson, S., Arkell, C., Challacombe, L.,

Amlani, A., Buxton, J., Demel, G., Gutierrez, N., Heywood, D., Hopkins, S., Lampkin, H., Leonard, L., Lockie, L., Millson, P., Nielsen, D., Petersen, D., ... Zurba, N. (2015).

Best practice recommendations 2 for Canadian harm reduction programs that provide service to people who use drugs and are at risk for HIV, HCV, and other harms. Working Group on Best Practice for Harm Reduction Programs in Canada.

<https://www.catie.ca/sites/default/files/bestpractice-harmreduction-part2.pdf>

Torrens, M., Soyemi, T., Bowman, D., & Schatz, E. (2020). Beyond clinical outcomes: The

social and healthcare system implications of hepatitis C treatment. *BMC Infectious Diseases*, 20(1), 702. <https://doi.org/10.1186/s12879-020-05426-4>

Tricco, A. C. (2016). *Barriers, facilitators, strategies and outcomes to engaging policy-makers, healthcare managers, and policy analysts in knowledge synthesis: A scoping review protocol*. St. Michael's Hospital. <https://osf.io/7y4e9/>

UNICEF, World Health Organization, & International Conference on Primary Health Care. (1978). *Declaration of Alma-Ata International Conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978*. World Health Organization. <http://link.springer.com/10.1057/palgrave.development.1100047>

WHO. (2016). *Global Health Sector Strategy on viral hepatitis 2016-2021 towards ending viral hepatitis* (WHO/HIV/2016.06). <https://apps-who-int.proxy.bib.uottawa.ca/iris/bitstream/handle/10665/246177/WHO-HIV-2016.06-eng.pdf?sequence=1>

WHO. (2017). *Global hepatitis report, 2017*. <http://apps.who.int/iris/bitstream/10665/255016/1/9789241565455-eng.pdf?ua=1>

WHO. (2021). *Global progress report on HIV, viral hepatitis and sexually transmitted infections, 2021* (p. 108). <https://www.who.int/publications/i/item/9789240027077>

Williams, B., Howell, J., Doyle, J., Thompson, A. J., Draper, B., Layton, C., Latham, N., Bramwell, F., Membrey, D., Mcpherson, M., Roney, J., Stoové, M., Hellard, M. E., & Pedrana, A. (2019). Point-of-care hepatitis C testing from needle and syringe programs: An Australian feasibility study. *International Journal of Drug Policy*, 72, 91–98. <https://doi.org/10.1016/j.drugpo.2019.05.012>

Wurcel, A. G., Burke, D., Skeer, M., Landy, D., Heimer, R., Wong, J. B., Chui, K. K. H., & Stopka, T. J. (2018). Sex work, injection drug use, and abscesses: Associations in

women, but not men. *Drug and Alcohol Dependence*, 185, 293–297.

<https://doi.org/10.1016/j.drugalcdep.2017.12.028>

Zein, N. N., & Persing, D. H. (1996). Hepatitis C genotypes: Current trends and future

implications. *Mayo Clinic Proceedings*, 71(5), 458–462. <https://doi.org/10.4065/71.5.458>

Appendix A

Tables

Table A1

Sample of Search Strategy on MEDLINE

Search for: limit 25 to (English language and yr="2014 -Current") Database: Ovid MEDLINE(R) ALL <1946 to November 13, 2020> Search Strategy:	
1	exp Substance Abuse, Intravenous/ or Drug Users/ (17565)
2	(intravenous drug use* or IVDU\$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (5307)
3	(intravenous adj2 drug* adj2 use*).mp. [mp=title, a
	abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (5555)
4	(injection drug use* or IDU\$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (12750)
5	(injection* adj2 drug* adj2 use*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (6715)
6	(people or person* or wom*n or m*n or peer* or LGBT* or GLBT* or gay* or lesbi* or bisexu#l* or transgender* or bicurious* or transpeople* or asexual* or transvestite or cross sex* or crosssex* or crossgender* or transperson* or transsexual* or homosexual* or intersex* or queer* or (trans adj2 (people or individual or individuals or person or persons or sexual* or male or female or m*n or wom*n or population* or gender))).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (10033917)
7	(who adj3 drug\$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (12630)
8	6 and 7 (9097)
9	(who adj3 substance\$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (1857)
10	6 and 9 (1310)
11	(PWID or PWUD or PWID).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (2038)
12	exp Hepatitis C/ (64732)
13	(hepatitis adj2 c).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (93929)
14	HCV.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (59160)
15	(Hep adj2 C).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (150)
16	hep-c.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (65)
17	(parenterally transmitted non a or non b hepatitis or pt-nanbh).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (2216)
18	exp Diagnosis/ or Diagnostic Services/ (8626517)
19	Point-of-Care Testing/ (2023)
20	diagnos*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (5084950)
21	test*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (4133614)
22	1 or 2 or 4 or 8 or 10 or 11 (35121)
23	12 or 13 or 14 or 15 or 16 or 17 (99591)
24	18 or 19 or 20 or 21 (12389842)
25	22 and 23 and 24 (3354)
26	limit 25 to (English language and yr="2014 -Current") (1297)

Table A2*Full Search Strategies*

Steps	Medline [n=1297]	Embase [n=2817]	Nursing and Allied Health [n=267]	CINAHL [n=1284]	PsycInfo [n=255]	Sociology Database Proquest [n=27]	Scopus [n=882]
1	exp Substance Abuse, Intravenous/ or Drug Users/ [n=17565]	injection drug user/ or intravenous drug abuse/ [n=12403]	noft(intravenous drug use* or IVDU*) [n=12321]	(MH "Substance Abuse, Intravenous") OR (MH "Intravenous Drug Users") [n=10801]	intravenous Drug Use/ [n=4017]	noft(intravenous drug use* or IVDU*) [n=719]	TITLE-ABS-KEY (intraveous W/2 use* OR ivd u*) [n=3]
2	(intravenous drug use* or IVDU\$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] [n=5307]	exp Substance Abuse, Intravenous/ or Drug Users/ [n=169383]	noft((injection drug use* or IDU*)) [n=15858]	intravenous drug use* or IVDU* [n=3142]	(intravenous drug use* or IVDU\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] [n=833]	noft(injection drug use* or IDU*) [n=1063]	TITLE-ABS-KEY (injection W/2 use* OR idu*) [n=27195]
3	(intravenous adj2 drug* adj2 use*).mp. [mp=title, abstract, original title, name of	(intravenous drug use* or IVDU\$).mp. [mp=title, abstract, heading word, drug trade name, original title, device	noft(injection* Near/2 drug* Near/2 use*) [n=2786]	intravenous N2 drug* N2 use* [n=53017]	(intravenous adj2 drug* adj2 use*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests &	noft(injection* Near/2 drug* Near/2 use*) [n=656]	TITLE-ABS KEY (people OR person* OR wom *n OR m*n OR peer* OR lgbt* O R glbt* OR gay* OR lesbi* OR bi sexu#l* OR transgender* OR bicuri ous* OR transpeople* OR asexual*

	substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] [n=5555]	manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] [n=7359]			measures, mesh] [n=837]		OR transvestite OR cross AND sex * OR crosssex* OR crossgender* OR transperson* OR transsexual* OR homosexual*) [n=1052780]
4	(injection drug use* or IDU\$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] [n=12750]	(intravenous adj2 drug* adj2 use*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] [n=7428]	noft(people or person* or wom*n or m*n or peer* or LGBT* or GLBT* or gay* or lesbi* or bisexu#l* or transgender* or bicurious* or transpeople* or asexual* or transvestite or cross sex* or crosssex* or crossgender* or transperson* or transsexual* or homosexual* or intersex* or queer*) [n=2347903]	injection drug use* or IDU* [n=4128]	(injection drug use* or IDU\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] [n=4177]	noft(people or person* or wom*n or m*n or peer* or LGBT* or GLBT* or gay* or lesbi* or bisexu#l* or transgender* or bicurious* or transpeople* or asexual* or transvestite or cross sex* or crosssex* or crossgender* or transperson* or transsexual* or homosexual* or intersex* or queer*) [n=305755]	TITLE-ABS-KEY (trans W/2 (people OR individual OR individuals OR person OR persons OR sexual* OR male OR female OR m*n OR wom*n OR population* OR gender)) [n=10480]

5	(injection* adj2 drug* adj2 use*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] [n=6715]	(people or person\$ or wom*n or m*n or peer\$ or LGBT* or GLBT* or gay\$ or lesbi* or bisexu#l* or transgender* or bicurious* or transpeople* or asexual* or transvestite or cross sex* or crosssex* or crossgender* or transperson* or transsexual* or homosexual* or intersex* or queer* or (trans adj2 (people or individual or individuals or person or persons or sexual* or male or female or m*n or wom*n or population* or gender))).mp. [n=14702651]	noft(trans NEAR/2 (people or individual or individuals or person or persons or sexual* or male or female or m*n or wom*n or population* or gender)) [n=505]	injection* N2 drug* N2 use [n=32342]	(people or person* or wom*n or m*n or peer* or LGBT* or GLBT* or gay* or lesbi* or bisexu#l* or transgender* or bicurious* or transpeople* or asexual* or transvestite or cross sex* or crosssex* or crossgender* or transperson* or transsexual* or homosexual* or intersex* or queer* or (trans adj2 (people or individual or individuals or person or persons or sexual* or male or female or m*n or wom*n or population* or gender))).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] [n=2348165]	noft(trans NEAR/2 (people or individual or individuals or person or persons or sexual* or male or female or m*n or wom*n or population* or gender)) [n306]	TITLE-ABS-KEY (who W/3 substance*) [n=3469]
6	(people or person* or wom*n or m*n or peer* or LGBT* or GLBT* or gay* or lesbi* or bisexu#l* or transgender* or bicurious* or transpeople* or asexual* or transvestite or	(who adj3 drug\$).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] [n=18017]	noft(who Near/3 substance*) [n=840]	(people or person* or wom*n or m*n or peer* or LGBT* or GLBT* or gay* or lesbi* or bisexu#l* or transgender* or bicurious* or transpeople* or asexual* or transvestite or cross sex* or crosssex* or crossgender* or	(who adj3 drug\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] [n=5351]	noft(who Near/3 substance*) [n=292]	TITLE-ABS-KEY (who W/3 drug*) [n=21046]

	cross sex* or crosssex* or crossgender* or transperson* or transsexual* or homosexual* or intersex* or queer* or (trans adj2 (people or individual or individuals or person or persons or sexual* or male or female or m*n or wom*n or population* or gender))).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] [n=10033917]			transperson* or transsexual* or homosexual* or intersex* or queer* or (trans N2 (people or individual or individuals or person or persons or sexual* or male or female or m*n or wom*n or population* or gender)) [n=5905493]			
7	(who adj3 drug\$).mp. [mp=title, abstract, original title, name of	5 and 6 [n=13259]	noft(who Near/3 drug*) [n=9714]	who N3 drug* [n=668]	5 and 6 [n=4071]	noft(who Near/3 drug*) [n=775]	TITLE-ABS- KEY (pwid* OR pwuid* OR pwud *) [n=2216]

	substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] [n=12630]						
8	6 and 7 [n=9097]	(who adj3 substance\$).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] [n=2366]	noft(PWID* OR PWUID* OR PWUD*) [n=600]	6 and 7 [n=6677]	(who adj3 substance\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] [n=2143]	noft(PWID* OR PWUID* OR PWUD*) [n=121]	(TITLE-ABS-KEY (people OR person* OR wom*n OR m*n OR peer* OR lgbt* O R glbt* OR gay* OR lesbi* OR bi sexu#l* OR transgender* OR bicuri ous* OR transpeople* OR asexual* OR transvestite OR cross AND sex * OR crossex* OR crossgender* OR transperson* OR transsexual* OR homosexual*)) OR (TITLE-ABS-KEY (trans W/2 (people OR indivi dual OR individuals OR person OR persons OR sexual* OR male OR female OR m*n OR wom*n OR p opulation* OR gender))) [n=10619 92]
9	(who adj3 substance\$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating	5 and 8 [n=1683]	5 and 6 [n=2347953]	who N3 substance* [n=1590]	5 and 8 [n=4071]	S4 OR S5 [n=305763]	((TITLE-ABS-KEY (people OR person* OR wom*n OR m*n OR peer* OR lgbt* O R glbt* OR gay* OR lesbi* OR bi sexu#l* OR transgender* OR bicuri ous* OR transpeople* OR asexual* OR transvestite OR cross AND sex * OR crossex* OR crossgender*

	sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] [n=1857]						OR transperson* OR transsexual* OR homosexual*)) OR (TITLE-ABS-KEY (trans W/2 (people OR individual OR individuals OR person OR persons OR sexual* OR male OR female OR m*n OR wom*n OR population* OR gender)))) AND (TITLE-ABS-KEY (who W/3 substance*)) [n=579]
10	6 and 9 [n=1310]	(PWID or PWUD or PWUID).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] [n=2921]	10 and 7 [n=571]	6 and 9 [n=1574]	(who adj3 substance\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] [n=979]	S9 AND S6 [n=212]	((TITLE-ABS-KEY (people OR person* OR wom*n OR m*n OR peer* OR lgbt* OR glbt* OR gay* OR lesbi* OR bisexual* OR transgender* OR bicurious* OR transpeople* OR asexual* OR transvestite OR cross AND sex* OR crossex* OR crossgender* OR transperson* OR transsexual* OR homosexual*)) OR (TITLE-ABS-KEY (trans W/2 (people OR individual OR individuals OR person OR persons OR sexual* OR male OR female OR m*n OR wom*n OR population* OR gender)))) AND (TITLE-ABS-KEY (who W/3 drug*)) [n=3631]
11	(PWID or PWUD or PWUID).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading	exp Hepatitis C/ [n=118471]	10 and 8 [n=4083]	PWID or PWUD or PWUID [n=2267]	(hepatitis adj2 c).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] [n=2962]	S9 AND S7 [n=593]	TITLE-ABS-KEY (hepatitis W/2 c) [n=131653]

	word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] [n=2038]						
12	exp Hepatitis C/ [n=64732]	(hepatitis adj2 c).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] [n=158051]	mainsubject.Exact ("hepatitis c virus" OR "hepatitis c" OR "chronic active hepatitis" OR "hepatitis c, chronic") [n=5370]	(MH "Hepatitis C+") OR (MH "Hepatitis C, Chronic") [n=15435]	hcv.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] [n=1942]	noft(hepatitis NEAR/2 C) [n=417]	TITLE-ABS- KEY ("HCV") [n=66798]
13	(hepatitis adj2 c).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier,	HCV.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] [n=100284]	noft(hepatitis NEAR/2 C) [n=25521]	hepatitis N2 C [n=19360]	(hep adj2 c).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] [n=5]	noft("HCV") [n=262]	TITLE-ABS-KEY (hep-c) [n=99]

	synonyms] [n=93929]						
14	HCV.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] [n=59160]	(Hep adj2 C).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] [n=456]	noft("HCV") [n=18480]	hcv [n=116552]	hep-c.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] [n=5]	noft(hep-c) [n=4]	TITLE-ABS- KEY (diagnos*) [n=5145264]
15	(Hep adj2 C).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier,	hep-c.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] [n=392]	noft(hep-c) [n=164]	hep N2 c [n=124]	Diagnosis/ [n=46457]	noft(diagnos*) [n=26501]	TITLE-ABS- KEY (test*) [n=9497724]

	synonyms] [n=150]						
16	hep-c.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] [n=65]	exp Diagnosis/ or Diagnostic Services/ [n=7393523]	mainsubject.Exact ("diagnosis, oral" OR "diagnosis") [n=13050]	hep-c [n=8777]	Testing/ [n=9194]	noft(test*) [n=50046]	TITLE-ABS- KEY (screen*) [n=1533496]
17	(parenterally transmitted non a or non b hepatitis or pt-nanbh).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary	Point-of-Care Testing/ [n=14304]	mainsubject.Exact ("testing" OR "testing procedures") [n=2652]	(MM "Diagnosis+") [n=693 142]	Screening/ [n=9727]	noft(screen*) [n=9491]	(TITLE-ABS- KEY (diagnos*)) AND (TITLE- ABS-KEY (screen*)) [n=338417]

	concept word, unique identifier, synonyms] [n=2216]						
18	exp Diagnosis/ or Diagnostic Services/ [n=8626517]	diagnos*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] [n=6911069]	mainsubject.Exact ("screening") [n=7490]	diagnos* [n=1066197]	diagnos*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] [n=377086]	S15 AND S17 [n=2637]	(TITLE-ABS- KEY (intravenous W/2 use* OR ivd u*)) OR (TITLE-ABS- KEY (injection W/2 use* OR idu*)) OR (TITLE-ABS- KEY (pwid* OR pwuid* OR pwud *)) OR (((TITLE-ABS- KEY (people OR person* OR wom *n OR m*n OR peer* OR lgbt* O R glbt* OR gay* OR lesbi* OR bi sexu#l* OR transgender* OR bicuri ous* OR transpeople* OR asexual* OR transvestite OR cross AND sex * OR crosssex* OR crossgender* OR transperson* OR transsexual* OR homosexual*))) OR (TITLE- ABS- KEY (trans W/2 (people OR indivi dual OR individuals OR person OR persons OR sexual* OR male OR female OR m*n OR wom*n OR p opulation* OR gender)))) AND (TITLE-ABS- KEY (who W/3 substance*))) OR (((TITLE-ABS- KEY (people OR person* OR wom *n OR m*n OR peer* OR lgbt* O R glbt* OR gay* OR lesbi* OR bi sexu#l* OR transgender* OR bicuri ous* OR transpeople* OR asexual* OR transvestite OR cross AND sex * OR crosssex* OR crossgender* OR transperson* OR transsexual* OR homosexual*))) OR (TITLE- ABS- KEY (trans W/2 (people OR indivi dual OR individuals OR person OR persons OR sexual* OR male OR

							female OR m*n OR wom*n OR population* OR gender)))) AND (TITLE-ABS-KEY (who W/3 drug*))).[n=31499]
19	Point-of-Care Testing/ [n=5084950]	test*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] [n=5592436]	noft(Diagnos*) [n=633312]	test* [n=1092519]	test*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] [n=986171]	S1 OR S2 OR S3 OR S8 OR S10 OR S11[n=2037]	(TITLE-ABS-KEY (hepatitis W/2 c)) OR (TITLE-ABS-KEY ("HCV")) OR (TITLE-ABS-KEY (hep-c)) [n=135588]
20	test*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] [n=4133614]	Screening/ [n=187668]	noft(test*) [n=652873]	Screen* [n=211399]	screen*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] [n=120808]	S12 OR S13 OR S14 [n=467]	(TITLE-ABS-KEY (diagnos*)) OR (TITLE-ABS-KEY (test*)) OR ((TITLE-ABS-KEY (diagnos*)) AND (TITLE-ABS-KEY (screen*))) [n=13428809]
21	1 or 2 or 4 or 8 or 10 or 11 [n=35121]	16 and 20 [n=80060]	noft(screen*) [n=222396]	(18 and 20) [n=93153]	18 and 20 [n=29928]	S15 OR S16 OR S18 [n=70507]	((TITLE-ABS-KEY (intravenous W/2 use* OR ivd u*)) OR (TITLE-ABS-KEY (injection W/2 use* OR idu*)) OR (TITLE-ABS-

							KEY (pwid* OR pwuid* OR pwud*)) OR (((TITLE-ABS-KEY (people OR person* OR wom*n OR m*n OR peer* OR lgbt* OR glbt* OR gay* OR lesbi* OR bisexual* OR transgender* OR bicurious* OR transpeople* OR asexual* OR transvestite OR cross AND sex* OR crosssex* OR crossgender* OR transperson* OR transsexual* OR homosexual*)) OR (TITLE-ABS-KEY (trans W/2 (people OR individual OR individuals OR person OR persons OR sexual* OR male OR female OR m*n OR wom*n OR population* OR gender)))) AND (TITLE-ABS-KEY (who W/3 substance*))) OR (((TITLE-ABS-KEY (people OR person* OR wom*n OR m*n OR peer* OR lgbt* OR glbt* OR gay* OR lesbi* OR bisexual* OR transgender* OR bicurious* OR transpeople* OR asexual* OR transvestite OR cross AND sex* OR crosssex* OR crossgender* OR transperson* OR transsexual* OR homosexual*)) OR (TITLE-ABS-KEY (trans W/2 (people OR individual OR individuals OR person OR persons OR sexual* OR male OR female OR m*n OR wom*n OR population* OR gender)))) AND (TITLE-ABS-KEY (who W/3 drug*)))) AND ((TITLE-ABS-KEY (hepatitis W/2 c)) OR (TITLE-ABS-KEY ("HCV")) OR (TITLE-ABS-KEY (hep-c))) AND ((TITLE-
--	--	--	--	--	--	--	---

							ABS- KEY (diagnos*)) OR (TITLE- ABS-KEY (test*)) OR ((TITLE- ABS- KEY (diagnos*)) AND (TITLE- ABS-KEY (screen*)))) ...View More [n=1551]
22	12 or 13 or 14 or 15 or 16 or 17 [n=99591]	screen*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] [n=1406143]	S17 AND S19 [n=369]	1 OR 2 OR 3 OR 4 OR 5 OR 8 OR 10 OR 11 [n=20137]	15 and 17 [n=672]	S19 AND S20 AND S21 [n=68]	(((TITLE-ABS- KEY (intravenous W/2 use* OR ivd u*)) OR (TITLE-ABS- KEY (injection W/2 use* OR idu*)) OR (TITLE-ABS- KEY (pwid* OR pwuid* OR pwud *)) OR (((TITLE-ABS- KEY (people OR person* OR wom *n OR m*n OR peer* OR lgbt* O R glbt* OR gay* OR lesbi* OR bi sexu#l* OR transgender* OR bicuri ous* OR transpeople* OR asexual* OR transvestite OR cross AND sex * OR crossex* OR crossgender* OR transperson* OR transsexual* OR homosexual*))) OR (TITLE- ABS- KEY (trans W/2 (people OR indivi dual OR individuals OR person OR persons OR sexual* OR male OR female OR m*n OR wom*n OR p opulation* OR gender)))) AND (TITLE-ABS- KEY (who W/3 substance*))) OR (((TITLE-ABS- KEY (people OR person* OR wom *n OR m*n OR peer* OR lgbt* O R glbt* OR gay* OR lesbi* OR bi sexu#l* OR transgender* OR bicuri ous* OR transpeople* OR asexual* OR transvestite OR cross AND sex * OR crossex* OR crossgender* OR transperson* OR transsexual* OR homosexual*))) OR (TITLE- ABS-

							KEY (trans W/2 (people OR individual OR individuals OR person OR persons OR sexual* OR male OR female OR m*n OR wom*n OR population* OR gender)))) AND (TITLE-ABS-KEY (who W/3 drug*)))) AND ((TITLE-ABS-KEY (hepatitis W/2 c)) OR (TITLE-ABS-KEY ("HCV")) OR (TITLE-ABS-KEY (hep-c))) AND ((TITLE-ABS-KEY (diagnos*)) OR (TITLE-ABS-KEY (test*)) OR ((TITLE-ABS-KEY (diagnos*)) AND (TITLE-ABS-KEY (screen*))))) AND (LIMIT-TO (PUBYEAR , 2021) OR LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014)) AND (LIMIT-TO (LANGUAGE , "English"))) ...View More [n=882]
23	18 or 19 or 20 or 21 [n=12389842]	18 and 22 [n=487650]	S20 AND S22 [n=83745]	17 OR 18 OR 19 OR 21 [n=2174931]	1 or 2 or 3 or 4 or 7 or 9 or 10 [n=10662]	S19 AND S20 AND S21Limits applied [n=68]	

24	22 and 23 and 24 [n=3354]	1 or 2 or 3 or 4 or 7 or 9 or 10 [n=194382]	S2 OR S3 OR S4 OR S9 OR S11 OR S12 [n=28600]	12 OR 13 OR 14 OR 15 OR 16 [n=20108]	11 or 12 or 13 or 14 [n=3299]	S19 AND S20 AND S21Limits applied [n=27]	
25	limit 25 to (english language and yr="2014 - Current") [n=1297]	11 or 12 or 13 or 14 or 15 [n=175416]	S13 OR S14 OR S15 OR S16 [n=29649]	22 AND 23 AND 24 [n=3437]	15 or 16 or 18 or 19 or 21 or 22 [n=1262538]	S19 AND S20 AND S21Limits applied [n=27]	
26		16 or 17 or 18 or 19 or 21 or 23 [n=13071944]	S17 OR S18 OR S20 or S21 OR S23 OR S24 [n=1144353]	Limiters - Peer Reviewed; Published Date: 20140101- 20211231; English Language [n=1284]	23 and 24 and 25 [n=541]		
27		24 and 25 and 26 [n=6094]	S25 AND S26 AND S27 [n=673]		limit 26 to (english language and yr="2014 -Current") [n=255]		
28		limit 27 to (english language and yr="2014 -Current") [n=2817]	S25 AND S26 AND S27 Limits applied [n=554]				
29			S25 AND S26 AND S27 Limits applied [n=267]				
30			S25 AND S26 AND S27 Limits applied [n=267]				

Table A3*Critical Appraisal Results*

Reference	1. Is there congruity between the stated philosophical position and the research objectives?	2. Is there congruity between the research objectives and the research questions?	3. Is there congruity between the research questions and the research hypotheses?	4. Is there congruity between the research hypotheses and the research objectives?	5. Is there congruity between the research objectives and the research questions?	6. Is there a statement locating the researcher subjectively?	7. Is the influence of the researcher on the research?	8. Are participant voices, and their experiences, adequately represented in the research?	9. Is the research ethical according to current standards?	10. Do the conclusions drawn in the research?	Overall appraisal
Barocas et al. 2014	Unclear	Yes	Yes	Yes	Yes	No	No	Unclear	Yes	Yes	6 Yes, 2 No, 2 Unclear
Harris et al. 2014	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	7 Yes, 2 No, 1 Unclear
Harris et al. 2016	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	7 Yes, 2 No, 1 Unclear
Rance et al. 2017	Unclear	Unclear	Yes	Yes	Yes	No	No	Yes	Yes	Yes	6 Yes, 2 No, 2 Unclear
Skeer et al. 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	7 Yes, 2 No, 1 Unclear

Table A4*Client-Identified Barriers Content Analysis*

Category	Definitions	Sample quote	Number of occurrences (N=28), Number of studies (N=4)	Subcategories	Definitions	Sample quote	Number of occurrences, Number of studies
Awareness and Knowledge	Understanding of Hep c related topics	“I thought hepatitis was a generic illness and I remember saying to him [GP], ‘But I can’t have that I’ve been vaccinated against it’, from having travelled, I assume I’d had a hep vaccine. I had to come off the phone and Google it, I didn’t know what it was”. (Helen) (Harris et al. 2016, p. 481).	N=3, n=2	Health	Knowledge and connection with HCV based on their state of health	“I’d heard of Anita Roddick ... there was no connection and I was so well ... I was totally disinterested, I just didn’t think I was ill”.(Helen) (Harris et al. 2016, p. 481).	N=2, n=1
				Clarification	Expressions of confusion of HCV diagnosis or testing	Participants identified other tangible perceived barriers and facilitators to testing. Independent of past-year testing, lack of transportation, time constraints, lack of knowledge surrounding testing , and cost of the test were identified barriers. (Barocas et al. 2014, p. 5).	N=1, n=1
Stigma	Rejection of a group or identity due to socially unacceptable attributes (Goffman, 2009)	“I’ve never felt comfortable with any GP because, in the past, when you’ve gone to a GP, you say “ I wonder if you can help me, I take heroin . . . ” “ (exclamation of horror) sorry, I don’t deal with that here.” (Fred) (Harris et al. 2014, p. 336).	N=11, n=4	Anticipated	Feelings of fear or expectations that the individual may encounter stigma or judgement	“they [GP] know your family ... it was a small village and everybody knows everybody.” (Bella) (Harris et al. 2016, p. 481).	N=1, n=1
				Internal	Perceived stigma of the self and acknowledgement of the negative beliefs	‘I was ashamed of it, I didn’t want people to know. Plus being a nurse I couldn’t admit to being that other person that I had been for the decade before’. (Harris et al. 2016, p. 482).	N=2, n=1

				Perceived	Feeling that there was an enactment of stigma towards the individual, the individual's behaviour, or disease	"I would be you know... out in like the suburbs or whatever other doctors I've been to where I say I'm an IV drug user and they don't respect me. I don't know they're just like not... educated about it." (Skeer et al. 2018, p. 20).	N=8, n=4
Health Service Factors	Structural factors that make up the service i.e., HCPs, cost, location, operation times, environment	"[My GP] said it was really expensive." (Helen) (Harris et al. 2016, p. 482).	N=7, n=2	Provider	Interactions of or suggestions for provider offering test or diagnosis based on experiences of accessing	"Like if they were just like, 'here like you know like yeah you're positive, this is what you can go do about it, you know like, here's the numbers you need.' Like... give people more hope more than just like, 'Oh yeah, you have Hep C. See you later' you know, go figure it out." [30-year-old, white, non-Hispanic male; homeless; actively injecting heroin]. (Skeer et al. 2018, p. 9).	N=2, n=1
				Setting	Details about the testing and diagnosis location	Participants identified other tangible perceived barriers and facilitators to testing. Independent of past-year testing, <i>lack of transportation</i> , time constraints, lack of knowledge surrounding testing, and cost of the test were identified barriers. (Barocas et al. 2014 p. 5).	N=2, n=1
				Test	Comments about the test itself	"[My GP] said it was really expensive" (Helen) (Harris et al. 2016, p. 481).	N=2, n=2
Psychological Responses	Expressions of reactions and methods of coping mechanisms to accessing testing and/or diagnosis, both as psychological responses	"No, they just said, 'Here you go, here's your uh thing' [handing him a pamphlet] ... I didn't know what to do, you know, and I didn't know what to think." (Skeer et al. 2018, p. 20)	n=7, n=3	Emotional Reactions	Emotional expressions in response to access to testing and/or diagnosis	"scared of the result" (Barocas et al. 2014, p. 4).	N=1, n=1
				Coping Mechanisms	Behaviours in response to access to testing and/or diagnosis	"I'm in denial. I don't want to hear that I have it". (Barocas et al. 2014, p. 4).	N=6, n=3

Table A5*Client-Identified Facilitators Content Analysis*

Category	Definitions	Sample quote	Number of occurrences (N=14), Number of studies (N=3)	Subcategories	Definitions	Sample quote	Number of occurrences, Number of studies
Awareness and Knowledge	Understanding of Hep c related topics	“Not knowing sucks. It doesn’t feel good when you don’t know if you have it or not.” (Barocas et al. 2014, pp. 3-4).	n=5, n=2	Health	Knowledge and connection with HCV based on their state of health	“Knowing [my HCV status] is something that I need to do to stay healthy. Knowing that I’ll feel better about myself if the results are good makes it easier to get tested.” (Barocas et al. 2014, p. 3).	n=5, n=2
Health Service Factors	Structural factors that make up the service i.e. HCPs, cost, location, operation times, environment	“I can come here [SEP] and the staff does it for free and it’s confidential.” (Barocas et al. 2014, p. 5).	n=9, n=2	Provider	Interactions or suggestions for provider offering test or diagnosis based on experiences of accessing	“I’m extremely honest with and have a very good relationship with my doctor.” (Barocas et al. 2014, pp. 4-5).	n=4, n=2
				Setting	Details about the testing and diagnosis location	“having a safe environment where people aren’t going to ‘notice you’, such as here [SEP], where you know that other people are here for the same reason” (Barocas et al. 2014, p. 5).	n=3, n=1
				Test	Comments about the test itself	“I can come here [SEP] and the staff does it for free and it’s confidential.” (Barocas et al. 2014, p. 5).	n=2, n=1

Table A6*ENTREQ Checklist*

No	Item	Guide and description	Reported on page number
1	Aim	State the research question the synthesis addresses.	7
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (<i>e.g., meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis</i>).	58 to 61
3	Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	62 to 68
4	Inclusion criteria	Specify the inclusion/exclusion criteria (<i>e.g., in terms of population, language, year limits, type of publication, study type</i>).	65
5	Data sources	Describe the information sources used (<i>e.g., electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists</i>) and when the searches conducted; provide the rationale for using the data sources.	62 to 68
6	Electronic Search strategy	Describe the literature search (<i>e.g., provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits</i>).	65, 140 to 141
7	Study screening methods	Describe the process of study screening and sifting (<i>e.g., title, abstract and full text review, number of independent reviewers who screened studies</i>).	68 to 69
8	Study characteristics	Present the characteristics of the included studies (<i>e.g., year of publication, country, population, number of participants, data collection, methodology, analysis, research questions</i>).	85 to 87
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (<i>e.g., for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development</i>).	83 to 84
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (<i>e.g., assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings</i>).	72 to 73

11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g., Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	72 to 73
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	72 to 73
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	85, 163
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g., all text under the headings “results /conclusions” were extracted electronically and entered into a computer software).	70 to 72
15	Software	State the computer software used, if any.	68
16	Number of reviewers	Identify who was involved in coding and analysis.	73 to 75
17	Coding	Describe the process for coding of data (e.g., line by line coding to search for concepts).	73 to 75
18	Study comparison	Describe how were comparisons made within and across studies (e.g., subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	73 to 75
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	74 to 75
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author’s interpretation.	92 to 113
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g., <i>new interpretation, models of evidence, conceptual models, analytical framework</i> ,	119 to 127

Note. Table from [Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, 12(1), 181–181. <https://doi.org/10.1186/1471-2288-12-181>]

Table A7*PRISMA-ScR Checklist*

Section	Item No	PRISMA-ScR Checklist Item	Reported on page number
TITLE			
Title	1	Identify the report as a scoping review.	Title page, iv, 61
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	iv
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	4 to 6, 28 to 37, 59 to 61
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	1 to 9
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	77
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	65
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	62 to 68
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	62 to 68
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	68 to 69
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	69 to 72
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	70 to 71
Critical appraisal of individual sources of evidence	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	72 to 73
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	73 to 75
RESULTS			

Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	83 to 84
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	83 to 84, 86 to 87
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	85
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	92 to 115
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	92 to 115
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	118 to 132
Limitations	20	Discuss the limitations of the scoping review process.	132 to 134
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	134 to 135
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	N/A

Note. Table from [Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA ScR): Checklist and Explanation. *Ann Intern Med.* 2018;169:467–473.doi: 10.7326/M18-0850.

Appendix B

Screening Questionnaires

Screening Tool for First-Level Screening

Overarching research question: **How do PWID describe their experiences of seeking and receiving HCV testing and diagnosis in Western countries?**

Sub question: **What are the client-identified barriers and facilitators to accessing HCV testing and diagnosis?**

Citation Screening

1. Was the study published on or after 2014?

- a. Yes: continue screening
- b. stop screening

2. Is the study written in English?

- a. Yes: continue screening
- b. stop screening

Title/Abstract Screening

3. Does the title/abstract mention people who use injection drugs (PWID) or peers who used injection drugs?

- a. Yes/Unclear: continue screening
 - Key terms: injection, intravenous
 - Can include multiple groups of people and PWUD (Second-level screening assess if we can extract eligible data and exclude this info)
- b. No: stop screening

- No mention of PWID

4. Does the title/abstract mention participants are > or = 18 years old at the time of the study?

- a. Yes/Unclear: continue screening
 - Key terms: adults, >= 18 years old
 - Can include youth (Second-level screening assess if we can extract eligible data and exclude this info)
- b. No: stop screening

- ONLY <18 years old

5. Does the title/abstract mention HCV?

- a. Yes or Unsure/Unclear: continue screening
 - can include other STBBIs and comorbidities (Second-level screening assess if we can extract eligible data and exclude this info)
 - can include cascade of care
- b. No: stop screening

-No mention of HCV at all

-For example: the study discussed HIV but does not mention HCV

6. Does the title/abstract mention (HCV) testing, diagnosis, or screening?

a. Yes or Unsure/Unclear: continue screening

-Key words: antibody HCV/anti-HCV testing, HCV RNA testing, clinical diagnosis, self-diagnosis, screening, point of care testing, dried blood spot testing, oral or blood testing

-can include genetic testing, treatment, entire cascade of care (Second-level screening assess if we can extract eligible data and exclude this info)

b. No: stop screening

-No mention of HCV testing, diagnosis, screening at all

-For example: the study discussed HCV treatment but does not mention testing

7. Does the title/abstract suggest the PWID are community-dwelling? Was the study conducted in a community setting?

a. Yes/Unclear: continue screening

-Key words: needle and syringe exchange programs, harm reduction site, homeless shelter, clinic, home, emergency department

- Could include prison and hospital (Second-level screening assess if we can extract eligible data and exclude this info)

b. No: stop screening

-No mention of community settings at all

-If entire sample of PWID were institutionalized: i.e. hospital, prison

8. Does the title/abstract indicate that the study was conducted in a Western country?

a. Yes/Unclear: continue screening

-For example: European countries/microcountries, Canada, USA, Australia, UK

-Can include Eastern countries (Second-level screening assess if we can extract eligible data and exclude this info)

b. No: stop screening

-For example: countries in Asia, Africa, South America

9. Does the title/abstract/**aim/results** assess the perspectives of PWID?

a. Yes/Unclear: continue screening

-Key terms: perspectives, experiences, acceptability, barriers, facilitators

-Through surveys or interviews

-Can include perspectives of clinicians and researchers (Second-level screening assess if we can extract eligible data and exclude this info)

b. No: stop screening

- No mention of PWID's perspectives

- Epidemiology, characterize

Decision: Should this article be included in Second-Level Screening?

a. **Yes**, all screening questions answered Yes or Unclear

b. **No**, at least one answers definitely “No”

Screening Tool for Second-Level Screening

1. Double check full-text for title/abstract screening questions
 - a. Check aim for population (PWID) and concept (their perception of accessing HCV testing/diagnosis)
 - b. Check eligibility criteria for population (PWID) and context (Western country)
 - c. Check methods for setting (community dwelling)
2. Are PWID describing organic access to HCV testing/diagnosis?
 - a. Yes/Unclear: continue screening
 - They chose to seek, receive, access testing/diagnosis on their own
 - b. No: stop screening
 - For example: intervention study where testing was given to PWID (Tag: inorganic experience)
3. Are the data we are interested in extractable?

Data we are interested in describes community-dwelling adult PWID perception with accessing HCV testing and diagnosis in Western countries.

 - a. If this is the only aim of the study and data aligns with my aim
 - Yes/Unclear: Include
 - No: continue to b
 - b. If eligibility criteria included other populations, concepts, or contexts - are we able to distinctly extract data that relates to my topic?
 - Yes: Include
 - No: Exclude
 - Unsure: discuss with each other, then with Patrick and Amanda if needed