

Experiences of governance in the context of community-based research:
Structures, problems and theory

Vivien Eileen Runnels

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Acronyms

CBOs	Community-based organizations
CBPR	Community-based Participatory Research
CBR	Community-based Research
CCPH	Community Campus Partnerships for Health
CES4Health	Community-Engaged Scholarship for Health
CHIS	California Health Interview Survey
CIHR	Canadian Institutes of Health Research

CURA(s)	Community-University Research Alliance(s)
DVD	Digital Video Disc or Digital Versatile Disc
ENACCT	Education Network to Advance Cancer Clinical Trials
GL	Grey literature
HIV/AIDS	Human- Immunodeficiency Virus/Acquired Auto-Immune Deficiency Syndrome
LOI	Letter of Intent
MeSH	medical subject headings
MOU	Memorandum of Understanding
NCL	non-conventional literature
NGOs	Non-governmental organizations
NHS	National Health Service
NSERC	Natural Sciences and Engineering Research Council
REB	Research Ethics Board
SDH	social determinants of health
SSHRC(C)	Social Sciences and Humanities Research Council (of Canada)
TCPS2	Tri-Council Policy Statement 2010
U.S.	United States
URC	Urban Research Center
WHO	World Health Organization
WoS	Web of Science

Thesis Abstract:
Experiences of governance in the context of community-based research:
Structures, problems and theory

Governance is a response to a recognition that traditional forms of decision-making have become inadequate to address complex societal and health problems generated by significant social and global changes (Chhotray & Stoker, 2009). The contributions of scientific and technical knowledge towards solving these complex problems have also been recognized as insufficient (Jasanoff, 2007). Community-based research (CBR) is an approach to research which is designed to make use of the knowledge of community and university members and their participation and collaboration “in all phases of the research process, with a shared goal of producing knowledge that will be translated into action or positive change for the community” (Lantz, Israel, Schulz & Reyes, 2006, p. 239). However, although the contributions of lay knowledge have been acknowledged, how governance or collaborative decision-making is arranged in the context of community-based research is not well described in the literature.

In order to address this knowledge gap, a study was undertaken in which in-depth interviews were conducted with community and university members of Canadian CBR collaborations to determine their governing experiences. Results are reported in a thesis by research papers. The first paper focuses on describing the governance structures that CBR collaborations used. In the second paper, the nature and content of problems which occurred in governing CBR collaborations, point to the importance of theory for conceptualizing and solving governance problems. To develop a theory of participation in governance of community-based research, the third paper uses Arnstein’s theory of participation to propose a grounded theoretical basis for implementing participation in governance of CBR collaborations (Arnstein, 1969).

Governance is a means of organizing, shaping and steering a course of decision-making. Governance is a critical component in the organization of knowledge production. Study and theory of governance in community-based research may help in improving understanding and implementation of a critical population health practice.

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been the springboard to a great deal of thinking about the governance of community-based research.

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CHAPTER 1.

SETTING THE CONTEXT: PUBLIC PARTICIPATION, KNOWLEDGE PRODUCTION AND GOVERNANCE OF COMMUNITY-BASED RESEARCH

From the post Second World War period through to the current, society's relationship with science, technology, health and medical research, reflects increasing acceptance and implementation of a view that public interests are better served through public participation (Petersen, 1984). Scientific work, teaching, research, and the development of health and science-related policies, were formerly set apart from the public, and science and technology were depicted as advancing along a trajectory determined by scientists and decision-makers alone (Irwin & Wynne, 1996; Ravetz, 1971). However, over the last sixty years, accounts of the public's exclusion from science, technology and health and medicine except as research subjects or patients, and descriptions of uninterested citizens, have been countered with stories of growing participation in decision-making, increased levels of public interest and scientific literacy, as well as public demonstrations of opposition to perceived health-threatening scientific developments (Ahearne, 2001; Petersen, 1984). These involvements display a variety of different forms of organization and levels of participation.

Public involvement and forms of social organization

There are a number of forms of organization that accommodate public participation and involvement within or as an extension of formal governmental or institutionalized settings. At the local level, local governments have devised means of increasing citizen participation through structures and processes such as thematic meetings and assemblies in participatory budgeting, citizen advisory and other ad hoc committees studying particular topics of interest, all allowing greater participation and contributions to decision-making beyond political choice-making (Cabannes, 2004; Lynn & Busenberg, 1995). Civil society broadly and NGOs (non-governmental organizations) as individual organizations or coalitions, are invited to participate in formal settings, in which representatives offer advice or consultation or contribute directly to decision-

making regarding research and policy (Ayres, 2004; Conference of NGOs in consultative relationship with the United Nations, 2006; Rootes, 1999). HIV/AIDS activism, for example, led to the creation and involvement of different HIV/AIDS associations pivotal for influencing the shape and directions of AIDS research and drug development (Epstein, 1996). The Global Fund to fight AIDS, Tuberculosis and Malaria, for example, has a governing board which includes representatives of affected communities, as well as donor and recipient governments, NGOs, and the corporate or private sector.¹ Outside these spaces for deliberation and governance, organizational forms include social movements, public interest groups, mutual self-help and advocacy groups, organized protests, and other forms of social and environmental activism, some of which may also be implicated in formal governance bodies. The Internet and different telecommunications technologies have also led to new forms of organization, in which the public uses social media to highlight public concerns to policy-making bodies.

Public participation and the ‘democratization’ of science

Increased democratic participation through citizens’ involvement in the governance of science and technology has been put forward so that people can choose between “alternative paths of societal development” (Felt & Wynne, 2007; Rogers, 2008, p. 3). However, citizen or public participation in making research and policy decisions to determine aspects of a society’s future is not only concerned with the presence of citizens when decisions are made. The public can be actively and meaningfully involved in shaping its own future by contributing to decision-making processes. To determine research and policy directions for finding solutions to complex societal problems is not only an exercise for scientific and expert knowledge, but requires normative choices and consideration of economic, ethical and moral interests (Jasanoff, 2007). ‘Objective’ knowledge alone is insufficient and other forms of knowledge are necessary (Dietz & Stern, 2008; Funtowicz, Ravetz, International Society for Ecological Economics (Content Partner), & Costanza, 2008). What has been referred to as the ‘democratization of

¹ <http://www.theglobalfund.org/en/howeare/?lang=en>

science’ or ‘civic science’ summarizes a phenomenon and an argument that scientific and technical knowledge by themselves, are insufficient for solving complex societal problems, and the democratic participation of citizens or ‘the public’, is necessary to transform society into something that is better, fairer and more sustainable (Bäckstrand, 2003; Rogers, 2008). The contributions that citizens and others make to decision-making processes include knowledge which comes from their own lives and contexts as they interpret it, referred to as lay or local knowledge. In order to access and make use of such forms of knowledge, certain processes and forms of organization for decision-making need to be in place. Participation in governance is one means by which lay or local knowledge is transferred.

Participation therefore has both pragmatic and political value. In democratic societies such as Canada, governments have started to formalize involvement of the public in different ways that includes their participation through governance in health and science policy-making (Abelson, Forest, Eyles, Smith, Martin, & Gauvin, 2003; Abelson, Giacomini & Gauvin, 2007). However, attitudes towards public participation and participation in governance, are equivocal. Some see it as valuable whilst others feel participation generates problems (Bruni, Laupacis, Martin & the University of Toronto Priority Setting in Health Care Research Group, 2008; Croft & Beresford, 1992). Some forms of public participation such as consumer consultation in Canadian health regulatory processes, are conditional on invitation or openings that are made available by official bodies (Phillips & Orsini, 2002). However, one view of public participation which is confined to certain points in decision-making processes, sees such approaches as undermining the expression of public concerns (Felt & Wynne, 2007, p. 11). Public participation in governance of research is also not without opposition. Moreover, whilst the research expertise of academics is important and a ‘given’ in regular science, even in the implementation of processes that intentionally seek to enable public participation, the substance of the public’s contributions, that is, their lay or local knowledge, are “modes of knowing that are often pushed aside” (Jasanoff, 2007, p. 33). Reconciling the democratic participation of the public in governance and acknowledging their knowledge contributions with expert knowledge and in the face of opposition, is not easily accomplished.

Issues of democratic participation and participation in governance, and questions concerning the standing of different types of knowledge that have been raised by the democratization of science, are also found in community-based research. Community-based research is understood as an approach to research in which people from universities and communities bring their different knowledge, experiences and skill sets, and make decisions collectively with the goal of generating new knowledge to address social and health problems (Green, George, Daniel, Frankish, Herbert, Bowie, et al., 1995; Israel, Schulz, Parker & Becker, 1998; Lantz, Israel, Schulz & Reyes, 2006). Participation of community members is a principle and an underpinning of community-based research. Combining local or lay knowledge with scientific and technical knowledge is also readily made in community-based research: indeed, the incorporation of local or lay modes of knowing is also a central principle and support of community-based research. By maintaining the centrality of lay knowledge and community members' participation, theory of community-based research proposes particular advantages by increasing the relevance and benefits of research for community members in comparison to traditional research (Reid, Brief & LeDrew, 2009; Viswanathan, Ammerman, Eng, Gartlehner, Lohr, Griffith, et al., 2004). However, just as participation in science and scientific research governance has its nay-sayers, participation of lay people in community-based research has also been criticized for its tokenism and lack of authenticity (Croft & Beresford, 1992; Rifkin, 1996).

Governance of community-based research

Governance is an encompassing term that is used to refer to the locus of decision-making, and structures, activities and actions generated from it. It refers to a space for making decisions of import that affect the direction of an organization or body, making values extant, and exposing and steering different kinds of knowledge in a joint mission. Community-based research is defined as “a collaborative approach to research that engages partners from a community - geographic or otherwise defined - in all phases of the research process, with a shared goal of producing knowledge that will be translated into action or positive change for the community” (Lantz et al., 2006, p. 239). It is based on a valuing of lay knowledge and notions of shared or collaborative decision-making as

a means of producing knowledge. However, although community-based research, its approach and methods are often well described, how governance is organized in the context of community-based research, is not clear. The kinds of problems that collaboration members face in governing community-based research are only hinted at in the literature. Although participation of citizens as research participants in community-based research is well described, specific accounts of their participation as participants in governance of community-based research are scarce.

The work of this thesis is therefore concerned with addressing these gaps by describing the arrangements of governance and problems associated with governing, and building grounded theory of governance from the experiences of members of community-university research collaborations working in the context of community-based research.

Thesis organization and contents

This thesis is organized by chapters. In accordance with departmental guidelines at the University of Ottawa, I have elected to write the thesis by papers. This means that three of the chapters are stand-alone research papers intended for publication as journal articles. The two early chapters of the thesis set the stage for the three research papers which are formatted as journal articles. Brief notes or links are inserted before each research paper, to help maintain continuity for the reader of the full thesis. The final chapter summarizes and concludes the thesis. The complete bibliography of the thesis is found at the end of the final chapter.

Following this introduction is an account of the methods, followed by a review of the literature. The literature review is organized using the components of a conceptual framework which links governance and democratic theory with knowledge production and the governance of community-based research.

The first research paper of the thesis is called “Arrangements of governance of community-based research collaborations: identification and experiences”. It describes the structures that a sample of community-based research collaborations used to govern. The research questions here are: What arrangements are used for governing community-based research collaborations, and what are collaborators’ experiences of them?

In the second research paper I turn from the arrangements that community-based research collaborations use in collaboration governance to the problems that occur in governing community-based research collaborations. What are these problems, and are there common themes and experiences? Whilst it may be important to alert participants and potential participants to problems, the identification of problems also raises some theoretical issues. In this paper, a critical theoretical approach is proposed for conceptualizing and solving problems arising from the governance of community-based research.

The third research paper builds from the two earlier descriptive research papers on arrangements of governance and problems arising from governance, and takes a closer look at the experiences of participation in governance of community-based research. “What are the participation experiences of community members in governing community-based research?” Using Arnstein’s theory of participation as a guide and grounded theory as an analytic approach, the third paper is an analysis of the experience of participation in governance in the context of community-based research (Arnstein, 1969). The research paper proposes a grounded theoretical basis for the implementation of participation in governance of community-based research collaborations.

The concluding chapter summarizes the research papers’ description of the arrangements of governance and the problems revealed through the experience of collaborators, and the third paper’s findings and steps taken towards building a grounded theory of participation in governance of community-based research. Some issues that arise from the research but that the papers do not address are discussed. The translation of the thesis findings into products that are practical and useable by community and university members governing community-based research collaborations is proposed. Contributions and limitations of the thesis study are suggested and potential future research directions are drawn.

In summary, the thesis describes and analyzes the governance of community-based research and its structures and problems and builds a theory of participation in governance of community-based research from the experiences of community and university members.

CHAPTER 2 METHODS

Introduction

In the introduction to his paper “Doing Interpretive Research” Walsham explains, “Authors of interpretive studies, and I am one of them, devote much of their allotted space to the substantive contents of their research topic, and only a little to their own research conduct and method” (Walsham, 2006, p. 321). In this chapter, I provide a detailed account of the research methods used in the thesis study and address methodological issues whose discussion and description are necessarily limited by the availability of space in journal articles.

I developed a study to collect evidence regarding the governance experience and practice of community and university members working in collaboration in the context of community-based health-related research in Canada. The first method I used in the study was a literature search and review of the topic. As there is little in the literature that pertains to the experiences of community and university members in governing community-based research, I designed the second method of the study to collect qualitative data from collaboration members through personal interviews focusing on their experiences and related from their personal perspectives. According to Miles and Huberman, qualitative data, “with their emphasis on people’s “lived experience” are fundamentally well suited for locating the meanings people place on the events, processes and structures of their lives:...and for connecting these meanings to the social world around them (Miles & Huberman, 1994, p. 10).

I begin with a description of research paradigms and the identification of the interpretive constructivist paradigm in which the study is located. Following this, I outline the methods used to approach the literature search and the development of the literature review, and I describe and discuss the empirical study design and its implementation. The chapter concludes with some reflections on my subjectivities over the period of the research and throughout the process of writing.

Research paradigms and the conduct of research

Research paradigms structure the beliefs of the qualitative researcher and his/her research actions, that is, they influence his/her approaches, implementation and recording of the research (Denzin & Lincoln, 2008; Kuhn, 1962). Each paradigm differs in its ontology which are theories about the nature of reality, or “what is the nature of reality and, by extension, truth?” (Mertens, 2003, p.140), epistemology (theories about the nature of knowledge and how we go about knowing), or, “what is the nature of knowledge and the relationship between the knower and the would-be known?” (Mertens, 2003, p. 140), and its methodology or “how can the inquirer (would-be knower) go about finding out whatever he or she believes can be known?” (Guba & Lincoln, 1998, p. 108). West and Turner add a fourth question concerning axiology asking what is worth knowing or what is valued (or not) in theory and research (West & Turner, 2003).

Scholars who focus their work on the study of paradigms have identified certain paradigms of relevance for qualitative research. Denzin and Lincoln’s handbook of qualitative research, for example, examines four major interpretive paradigms which structure the beliefs of the qualitative researcher and his/her research actions. These are positivist and postpositivist; constructivist-interpretive, critical theory (Marxist, emancipatory), and feminist-post-structural paradigms (Denzin & Lincoln, 2010, p. 31). Veenstra proposes three paradigms or ‘ideal-types’ of knowledge production, positivist social science, critical social science and interpretive social science for population health research (Veenstra, 1999). In this chapter I use Veenstra’s account to locate the work of the thesis.

Positivist social science uses exacting methods of empirical research to deduce causal relationships, and predict human activity. It takes an objectivist stance, meaning that there is a searchable ‘truth’ that exists apart from the researcher. An objectivist stance and a ‘truth’ that can be demonstrated repeatedly, suggests that theory can explain many different specific observations or experiences (West & Turner, 2003). Positivism typically employs quantitative methods to discover laws for prediction. Veenstra’s second paradigm of knowledge production, critical social science and critical theory, has its roots in Marxism (Fay, 1987; Sim & Van Loon, 2004). The goal of critical theory is to use theory to critique social organization and the science that studies it, and to offer a

theory of change to address the critiques (Carpiano & Daley, 2006). “Critical theory and critical researchers are less concerned with questions of *how* to do social research than with questions of *why* to do it and *who* is entitled to shape and control the research process. The purpose of all social inquiry, they argue, should not simply be to describe the world, but to change it” (Strand, 2000, p. 92). Critical theory does not only explain phenomena but also has a built-in emancipatory or action project (Strand, 2000). Once hidden structures of power that underlie problems are uncovered, also revealed are the routes to change the causes of oppression and its consequent effects.

Veenstra’s third paradigm, the interpretive social science paradigm, acknowledges that “the object of investigation—the web of language, symbol, and institutions that constitutes signification—and the tools by which investigation is carried out share inescapably the same pervasive content that is the human world” (Rabinow & Sullivan, 1987, p. 6). A constructivist interpretive paradigm’s epistemology is subjective, meaning that the researcher co-creates understanding with the subjects of the research. This epistemology also means that reality is socially constructed, i.e. “what people know and believe to be true about the world is constructed as people interact with one another over time in specific social settings” (Lecompte & Schensul, 1999, Book 1, p. 48; Berger & Luckmann, 1966). Interpretive social science places emphasis on context: in contrast to positivism there is no single comprehensive universally understandable ‘truth’. Realities are local and specifically constructed or ontologically relativist (Guba & Lincoln, 2005). Rabinow and Sullivan suggest that some discussants of the interpretive approach present interpretivism as almost exactly the opposite of positivism (Rabinow & Sullivan, 1987). To underscore their points about the interpretive paradigm, Lecompte and Schensul consistently compare it with the positivist paradigm (Lecompte & Schensul, 1999).²

The study for this thesis lies within the interpretive/constructivist subjective paradigm which is largely found in sociological and anthropological work and other disciplines which make use of certain qualitative research approaches (See for example,

² A number of authors have provided comparison tables of the defining characteristics of research paradigms. Two of these are Lecompte & Schensul, 1999 (pp. 59 –60), and Lather, 2006 (pp. 8-9).

Walsham, 2006). Methodologically, this means that “individual constructions can be elicited and refined only through interaction *between and among* investigator and respondents” with the aim of understanding (Guba & Lincoln, 2005, p.111-112). I designed the study and deployed the methods in keeping with this paradigm to build responses to two general research questions, “What are the arrangements of governance of community- based research collaborations?” and “What are the experiences of community-based research collaboration members with respect to governing community-based research collaborations?” These general questions were refined at a later date based on the findings and to adjust the focus of the enquiry as reported in the three papers. The objectives of the study were i) to describe arrangements of governance in community-based research collaborations, ii) to describe the experiences of community and university members with respect to community-based research and governance and, iii) to build theory of participation in governance of community-based research collaborations.

Method for a review of the literature

To guide the search for the literature, I developed a framework which provided a map of conceptual domains. This framework is used in this thesis to organize the literature review.

Framework of the literature of governance of community-based research

For the framework of the literature, I used Paquet’s understanding of a conceptual framework as “a preliminary way to organize objects of the inquiry” (Paquet, 1999, p. 24). Paquet’s understanding of a conceptual framework as ‘preliminary’ also permits later revisions, development and theorizing. The framework to structure the literature review is shown below.

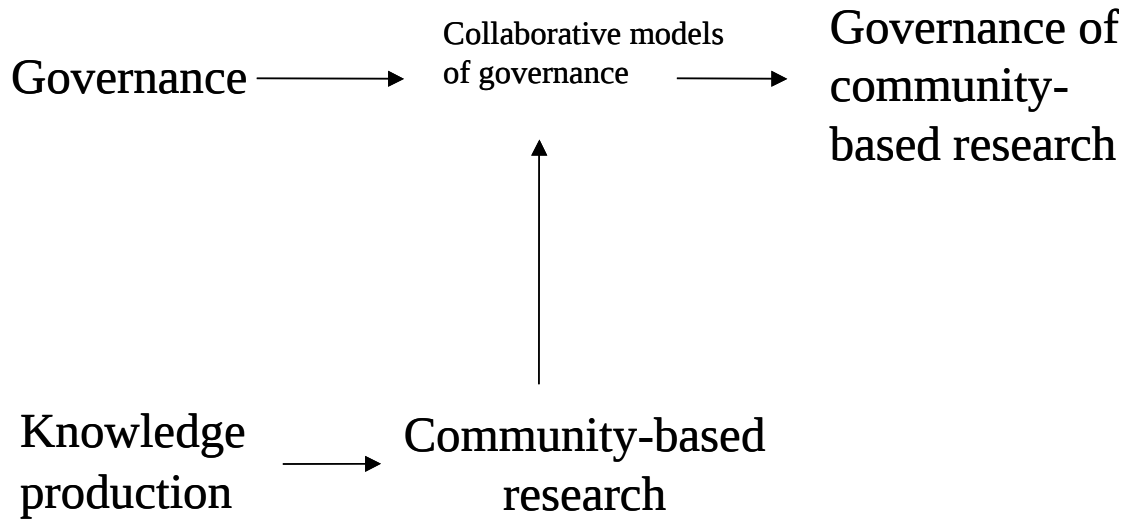


Figure 1: Governance of community-based research: A framework for a review of the literature

The framework shows two pathways to governance of community-based research. The first pathway takes governance and key ideas of democratic societies that contribute to the development of shared or collaborative models of governance. A second pathway shows knowledge production as the domain or context for community-based research. Specifically, community-based research is viewed as a form of knowledge co-production which refers to a distinctive and more recently recognized form of knowledge production which is also referred to broadly as Mode-2 science. In Mode-2, knowledge is produced with contributors other than traditional disciplinary based researchers, and so expands understanding of what counts as research. This stands in contrast to Mode-1 knowledge production in which scientific knowledge is viewed as separately and autonomously produced in contexts which are purposefully designed for the production of knowledge. Mode-2 science recognizes that “science could no longer be regarded as an autonomous space clearly demarcated from the others of society, culture, and (more arguably) economy” (Nowotny, Scott & Gibbons, 2001, p. 1; Gibbons, Limoges, Nowotny, Schwartzman, Scott & Trow, 1994). Mode 2 knowledge production, which is elsewhere referred to as the co-production of knowledge or socially distributed knowledge

production, implicates other non-academic actors (Ferlie & Wood, 2003). Community-based research, in which universities, communities and their citizens “are engaged in the creation, design, implementation and use of research to meet their needs”³ is understood as a form of Mode-2 knowledge production. The decision-making or governance structures of community-based research collaborations are shared or collaborative governance models whose underpinnings are the democratic co-production of knowledge.

To define community-based research, Lantz, Israel, Schulz & Reyes’s definition of community-based participatory research which is “a collaborative approach to research that engages partners from a community - geographic or otherwise defined - in all phases of the research process, with a shared goal of producing knowledge that will be translated into action or positive change for the community” was selected as a guide to the literature search (Lantz, Israel, Schulz & Reyes, 2006, p. 239). In common with other authors, such as Green and Israel, Lantz et al.’s definition holds that the research is collaborative (Green, George, Daniel, Frankish, Herbert, Bowie, & O’Neill, 1995; Israel, Schulz, Parker & Becker, 1998; Lantz et al., 2006). Further, in defining collaborative research as “research that involves the cooperation of researchers, institutions, organizations and/or communities, each bringing distinct expertise to a project, and that is characterized by respectful relationships”, the text and glossary of the recent Tri-Council Policy Statement suggests a broader understanding and acceptance of differently named approaches to research (Canadian Institutes of Health Research, 2010). The Canadian Institutes of Health Research also names integrated knowledge translation, community-based research, Mode 2 knowledge production and participatory research as collaborative approaches to research amongst others.⁴ Community-based research is rarely understood in the literature as a specific research method, but rather as an approach or an orientation to research (Minkler & Wallerstein, 2008). In keeping with this approach to a collaborative form of research, there are suggestions in the literature that in Canada, the

³ Community Based Research Canada (CBRC) Accessed on April 5, 2011 from <http://communityresearchcanada.ca/>

⁴ <http://www.cihir-irsc.gc.ca/e/39537.html>. Accessed April 19, 2011.

term community-based research is utilized as an umbrella term which specifies the collaboration of university (academic) members as well as community members to produce knowledge addressing the needs of communities (Hall, Tremblay & Downing, 2009; Ibáñez-Carrasco & Riaño-Alcalá, 2011; Mykhalovskiy & McCoy, 2002; Williams, Labonte, Randall & Muhajarine, 2005).

Strategies for the search of the literature

I developed a search strategy to acquire English language articles from the academic literature and non-conventional or grey literature (AcademyHealth, 2006; Hopewell, McDonald, Clarke & Egger, 2007). Using the conceptual framework as a content guide, pertinent literature was drawn widely from the disciplines of health and medicine including population health, health promotion and public health, education, the social sciences including political science and organizational management, psychology, sociology, anthropology, urban planning, social work and other disciplines. The development and participatory development literature was included as this has been an important source for discussion and critique of participation in governance, specifically the literature of participatory democracy and participatory research methods such as community-based participatory research, rapid rural appraisal and participatory rural appraisal.

Use of search terms

For the first pathway outlined in the conceptual framework, search terms included governance, governance of research, research governance, governance of non-profit sectors, governance theory. These terms revealed a very broad and extensive literature that is outlined in the literature review. For the second pathway, my previously acquired familiarity with some of the literature of community-based research and knowledge of extensive variations in the use of terminology suggested the use of a broad number of search terms. These terms included community-based research, community-based participatory research, participatory research, participatory action research, action research, appreciative inquiry, community-based research collaborations, community-university research collaborations, academic-community collaboration, partnerships, and alliances, community service-learning, governance of research, research governance,

governance and decision-making. As concepts and theory associated with governance of community-based research became clearer, searches were added to include collaboration, collaboration and related theories, stakeholder theory, critical theory, democratic theory, knowledge and knowledge production and knowledge co-production.

Database searches and use of search engines

Searches were conducted through Web of Science (WoS), and using the internet search engines GoogleScholar⁵ and Google to search the World Wide Web. The WoS is an online resource that combines three databases, the Science Citation Index expanded, the Social Sciences Citation Index, and the Arts & Humanities Citation Index (at the time of searches). The University of Ottawa catalogue was searched using search terms as outlined above. Additional relevant literature was uncovered through citations, internet list-serves such as the Community Campus Partnerships for Health (CCPH), and E-Watch on Innovation in Health Services of the Chair of Knowledge Transfer and Innovation at Laval University.⁶ Journals that contained articles of interest were also subjected to further search. Term lists of PubMed and Reference Manager, a bibliographic management software, were also employed for literature searches. PubMed has a limited scope of medical subject headings (MeSH) applicable to the areas of interest. Reference Manager key words are automatically generated from article titles, keywords and abstracts, and from researcher contributed terms.

Time parameters

Time-parameters for the early literature searches were initially limited from 1980 to 2008 because this time frame incorporated a growth in interest in community-based research in the 'Southern' literature, emanating largely from South American and Africa countries, and India, and in the 'Northern' literature emanating largely from the literature of education and community development. For social determinants of health such as the literature of food insecurity this time frame was also appropriate. For homelessness, the same time frame was utilized initially. These time-parameters were later expanded to

⁵ <http://scholar.google.com/scholar/about.html>

⁶ <http://kuuc.chair.ulaval.ca/english/index.php>

include earlier publications that had bearing on the underpinnings of community-based research, such as those by Freire on popular education, Lewin on action research in psychology, and Dewey's work on democracy and participatory research in education, and others.

Search for social determinants of health literature

Community-based research can encompass a potentially unlimited range of topics in health, including social determinants of health (SDH) research, and draws from, but is not necessarily confined to, the literatures of population health, health promotion, public health, and health interventions research. (At the time of an earlier search, 'population health' for example, did not appear as a MeSH term in PubMed (Tricco, Runnels, Sampson & Bouchard, 2008), so could not be used as a search term in PubMed). The literatures of two determinants of health, food security (including the terms food insecurity and community food security and community food insecurity) and homelessness were searched. These searches allowed me to develop an impression of the extent of SDH as the subject matter of community-based research, and the extent of a focus of governance in SDH research.

Search of the grey literature

The World Wide Web was searched for grey literature regarding community-based research, and social determinants of health including food (in)security and homelessness. The grey literature was included because there was a chance of finding information about governance in community-based research if a report was produced by a community organization and intended for different audiences other than an academic audience.⁷ By grey (GL) or non-conventional (NCL) literature is meant, according to the Luxembourg Convention, "that which is produced on all levels of governmental, academics, business and industry in electronic and print formats, but which is not

⁷ For example, the Ontario Public Health Association's position paper on community food security notes that 53% (n=32) of public health units are involved as a unit or in partnership with the community in food needs assessment, survey or research work (Desjardins et al., 2002) These collaborative efforts produce knowledge of public interest suggesting publication other than in academic journals.

controlled by commercial publishers”(AcademyHealth, 2006; Hopewell et al., 2007). All citations for relevant literature were added to a bibliographic management database.

Box 1: Summary of search strategy and included literature

Language: English language articles and some French language articles from the academic literature and grey literature

Time frame: Unlimited time frame but initial searches of social determinants of health related research were 1980-2008

Summary of Search terms: Governance, governance theory, governance of community-based research and like terms; community-based research and governance and decision-making; population health (and) social determinants of health (food security/insecurity, homelessness/poverty); collaboration; critical theory, and related additions to these themes, and combinations.

Databases: Web of Science

Journals: likely to contain articles of interest

WWW Search engines: GoogleScholar and Google

The literature included any research designs and methods that are community-based research methods, references to CBR studies within articles, articles that had content potentially relevant to governance of community-based research collaborations. Some commentary, opinion pieces and prescriptive, or ‘how to’ literature were included. The citations for the literature that were retrieved, and found relevant were added to a bibliographic management database. Relevance was determined by reading the abstracts or whole articles.

The literature search was continued throughout the thesis project. Articles, books and grey literature items were retrieved and used in the literature review, the research papers, and all other chapters as references or supporting materials. The literature review was focused on English language literature. Some French language literature was also reviewed. Most of the relevant literature was from Canada, the United States of America, Australia, and the United Kingdom. (See Box 1 above for a summary of the search strategy).

Results of the literature search

Searches for the literatures of governance were highly productive, and extended to the literatures of democratic theory and practice. Searches for community-based research, community-based participatory research and other related search terms, uncovered a number of community-based health focused studies, particularly from the United States. The majority of these articles on community-based research focused on health conditions, for example, Type 2 diabetes, HIV/AIDS, respiratory diseases, maternal infant and child health, sexually-transmitted diseases, rather than on social determinants of health, reflecting national policy approaches to health. Such an approach is demonstrated, for example, in Healthy People 2010 which is “a statement of national health objectives designed to identify the most significant preventable threats to health and to establish national goals to reduce these threats where the focus on health improvements is on disease or health conditions”(U.S. Department of Health and Human Services, 2000). In the literature, food insecurity and homelessness were often accompanied by the term ‘poverty’, also a determinant of health.

Search returns through database searches for CBR and SDH were generally disappointing. Articles on CBR that refer to SDH are limited in comparison to community-based research relating to health conditions. For example as shown in Table 1 below, one search conducted in late 2008 through the Web of Science using the search terms community-based participatory research (and) food security, and community-based research (and) food insecurity uncovered 18 articles, one of which was duplicated. Only 3 of these articles had some relevant content for community-based research and governance, one of which was outside a developed country setting. Two of these articles were written by the same authors. Finding research studies on social determinants of health has been reported by Bambra, Gibson, Sowden, Wright, Whitehead and Petticrew (2010), as “difficult and time-consuming” (p. 289), and gaps in this literature are also reflected in systematic reviews on social determinants of health. The limited findings relating to SDH and CBR suggested that the literature review concerning community-based research should not be confined only to social determinants of health related

research, and the search strategy was therefore revised and extended to include studies that related to community-based research for health in general.

Table 1: Search results using Web of Science and terms ‘community-based participatory research and food security’ and ‘community-based research and food insecurity’ (Search conducted on 2008 09 12).

Journal Article Title	Community-based research	Governance-related Content
1 Impact of food and nutrition interventions on poverty in an informal settlement in the Vaal Region of South Africa	No	No
2 Household food insecurity is inversely associated with social capital and health in females from special supplemental nutrition program for women, infants, and children households in Appalachian Ohio	No	No
3 Food supply adequacy in the Lower Mississippi Delta	No	No
4 Food for work program and its implications on food security: A critical review with a practical example from the Amhara region, Ethiopia	No	No
5 Collective kitchens in Canada: A review of the literature	No	No
6 A community-based integrated nutrition research programme to alleviate poverty: baseline survey (x2)	Yes	Yes
7 Mechanisms of power within a community-based food security planning process	Yes	Yes
8 Food insecurity and food supplies in Latino households with young children	No	No
9 Scientific research: Essential, but is it enough to combat world food insecurities?	No	No
10 Measurement of household food security in the USA and other industrialised countries	No	No
11 Measures of food insecurity/security	No	No
12 The process of adapting and validating a perceived household food security scale in a poor community.	No	No
13 Agricultural rehabilitation and food insecurity in post-war Rwanda - Assessing needs designing solutions	No	No
14 Nutrition, disease and death in times of famine	No	No

15 Multi-agent modelling of climate outlooks and food security on a community garden scheme in Limpopo, South Africa	No	No
16 Just small potatoes (and ulluco)? The use of seed-size variation in "native commercialized" agriculture and agrobiodiversity conservation among Peruvian farmers	No	No
17 Use of a participatory planning process as a way to build community food security	Yes	(Yes)

In the health-related research literature, including social determinants of health, few articles dealt specifically with the governance of community-based research. The majority of case or specific studies in the literature were focused on interventions and their health outcomes: few had any content of how decision-making or governance associated with the research was undertaken. In the health literature, governance-related articles dealt with the governance of health care organizations (e.g. Baker, Denis, Pomey & Macintosh-Murray, 2010; Motsi & Plumptre, 2008), including public-private partnerships (e.g. Shortell, Zukoski, Alexander, Bazzolli, Conrad, Hasnain-Wynia, Sofaer, Chan, Casey & Margolin, 2002). Exceptions included one scholarly commentary on governance of community-based participatory research (Israel, 2003), and Cargo and Mercer's review of the literature and development of conceptual framework for the practice of participatory research, focusing on the development and maintenance of partnerships although the review is non-specific with regard to governance (Cargo & Mercer, 2008). Other articles focus on aspects of governing community-based research collaborations such as the distribution and effects of power and control of community-based research in food insecurity in a series of papers by McCullum, Pelletier and collaborators cited in the thesis text. Articles that touched on governance were typically focused on principles of community-based research. Principles are statements of value of community-based research, and partly comparable to mission, values and objectives of community-based organizations (Baker, Homan, Schonhoff & Kreuter, 1999; Centers for Disease Control and Prevention, 1997; Israel et al., 2003; McTaggart, 1991; Strand et al., 2003). Other literature included prescriptive literature on how to carry out and improve CBR. Some of the literature contained single sentences or short sections that had some relevance for governance of community-based research.

With respect to literature focussing on governance of community-based research, the results of searches suggested that ‘governance’ as a term, was rarely used or explained. Other terms that are typically associated with governance, were employed. For example, ‘advisory committees’ or ‘community advisory committee’ were used to express the decision-making governing function vested in a collaboration.

Method for a qualitative study

I conducted personal interviews that focused on experiences of governing community-based research with community and university members. In the following section, I describe and add discussion concerning the empirical study design and its implementation.

Data collection method

Semi-structured in-depth interviews were designed to collect descriptive and experiential data of respondents’ participation in governance of community-based research. The interviews were semi-structured, in so far as there was a list of general thematic questions designed to elicit discussion and information about respondents’ experience in governance of community-based research. ‘Semi-structured’ describes interviews whose questions are “partially prepared” by the researcher/interviewer when “responses can’t be predicted in advance” although they are “fully structured” based on the researcher/interviewer’s concerns, questions, readings of the literature and “initial theoretical framework” (Wengraf, 2001 p.5). “In-depth” refers to the acquisition of specific detail in the knowledge that is sought: where people are the source of data, some of this detail is contained in narrative. Wengraf has referred to semi-structured in-depth interviews as lightly structured depth interviews (Wengraf, 2001, p. 60-61). Semi-structured interviews lend themselves well to both qualitative description and grounded theory. Respondents describe their experiences, but also make observations on their experiences.

Initially I proposed an estimate of the number of interviews required based on guidelines and experience reported in the literature with data saturation (Guest, 2006; Morse, 1995). However, this initial estimate was later felt to be an underestimate of what was required for theory development (Charmaz, 2006). Further, a target of a more or less

equal number of interviews to ensure equal representation of community and university members was set. Additional interviews were therefore added.

Interview Schedule: topic selection and structure

In addition to searching relevant themes for the interview questions suggested by the literature, and to avoid possible duplication, I searched the literature for existing instruments and questionnaires that concerned decision-making or governance of community-based research. Green and colleagues' "Guidelines and categories for classifying participatory research projects in health promotion" is intended for grant application reviewers (external to the partnership) to appraise the extent to which research studies align with principles of participatory research" (Green et al., 1995, p. 43). Weiss, Anderson, and Lasker conducted a U. S. national study on partnership collaboration (defined as "all of the types of collaboration that bring people and organizations together to improve health") and partnership 'synergy' to examine the relationship with six dimensions of partnership functioning: leadership, administration and management, partnership efficiency, nonfinancial resources, partner involvement challenges, and community-related challenges, and used the results to develop a self-assessment (internal) tool for partnerships (Weiss, Anderson & Lasker, 2002)⁸. In essence this partnership tool is based on corporate structures and partnerships, although some of the domains were possibly transferable to a study of governance of community-based research.

Other articles, questionnaires, tools and toolkits were reviewed for possible use and relevant interview questions to answer the questions of interest. These included articles from the organization, health, governance and evaluation literature, and the non-profit and voluntary sector from Agriculture and Agri-Food Canada, (2008); Canadian Policy Research Networks (2005); Graham & Bruhn (2009); Granner & Sharpe (2004); Plumptre (2006); and Mattessich, Murray-Close & Monsey (2004). No toolkit or questionnaire that focussed specifically on this topic or which was wholly suitable for

⁸ Obtainable at <http://cacsh.org/pdf/psatquestionnaire.pdf>

questions for a personal interview was found. I therefore developed an interview schedule for this study.

Topic areas were selected and questions developed to guide the interviewer and the respondent in building answers to the research questions. The final list of topic questions that were used to guide the interview is shown below. The structure of the interview was designed to open with an invitation to “think about” one of the collaborations the participant had been involved with, so a participant could select and narrate his/her own chosen experiences. The list of questions was designed to be used as prompts to the respondents’ narratives, to focus discussion on governance and decision-making, and to act as a checklist for the interviewer to ensure coverage of the topics of interest. The questions used recognizable vocabulary typically associated with governance, particularly for those that are engaged with the community-based or non-profit and voluntary sector either as employees or volunteer board members.

List of questions used to guide the interviews

Thinking about one of the community-based participatory research collaborations that you were involved with

- 1) Describe your part in it - how, why did you become involved and what ensued?
- 2) What were the arrangements that the collaboration made to govern or lead—such as board and committee structures, written documentation?
- 3) What activities or procedures to lead or govern the community-based research did the collaboration perform?
- 4) By whom, when, where and why were decisions made about how the collaboration was going to govern/function?
- 5) How were decisions made as to the development of arrangements of governance that you just described?
- 6) Was there anything in your experience of governance with this collaboration that stood out or was different from other experiences? What were they and why? What would you change and why?
- 7) In your experience, what were the issues that required leadership which you discussed? Were there issues that you thought you should have discussed yet didn't?
- 8) What were the challenges for the governance of the collaboration?
- 9) What arrangements do you think worked well or were helpful and successful for your collaboration's governance?
- 10) What arrangements do you think did not work well or were not helpful or successful?
- 11) Were you satisfied with the arrangements that were made to govern the collaboration? Why or why not?
- 12) What arrangements of governance would you suggest would be most helpful to a new community-based research collaboration?

Sampling and theoretical sampling

Because I sought a specific sample of community and university members who had participated in governing community-based research collaboration, sampling for this study was purposeful. The data that are obtained from small numbers of participants provides rich information “rich, in the sense that a great deal can be learned from a few exemplars of the phenomenon of interest” (Patton, 1997, p. 288; Patton, 1990). The term ‘purposive’ is sometimes used instead of ‘purposeful’. Shadish, Cook and Campbell (2002) employ the term purposive only when referring to two types of sampling (of heterogeneous instances and typical instances). Purposeful sampling is non-probabilistic which means it does not involve random selection, and therefore cannot be treated using the same assumptions for a probabilistic sample working on the basis that the sample is representative of a population.⁹ In addition to the purposeful selection of participants because of their characteristics (Richards & Morse, 2007), a balance in numbers of community and university members was sought to help me avoid the possibility of developing an analysis that focused on one group’s experiences only.

I developed a sampling frame by respondent affiliation and area of research (see below). This frame acted as a fluid guide to ensure interviews were conducted with community and university members of community-based research collaborations in more or less equal numbers. The frame was also subdivided to provide for analysis based on collaborations’ content area of research, although this approach was not used. The total frame size and component units of the frame were flexible keeping in mind ideas of data saturation. Data saturation is a concept developed from researchers’ experiences in qualitative research that suggests that little or no new data will be acquired after a certain number of respondents have been interviewed (Guest, Bunce & Johnson, 2006; Morse, 1995). Qualitative research does not have particular requirements of sample size to demonstrate power in a statistical sense: a small number of in-depth interviews is usually sufficient to reach data saturation. However, theoretical sampling which is a qualitative

⁹ See Trochim, 2006 <http://www.socialresearchmethods.net/kb/sampnon.php>

research concept which means that further sampling or recruitment and data collection can take place in order to help the researcher acquire new data to build theory, may lead to further sampling (Charmaz, 2006). In some cases of sampling for theory development, some respondents may be interviewed more than once.¹⁰ In the current study, theoretical sampling is demonstrated in the study in two ways. First, as the interviews were semi-structured (explanation on the conduct of semi-structured interviews can be found below), as the interviewer, I was in a position on an ongoing basis to explore and get feedback from respondents regarding issues that arose from previous interviews or from data analysis. At a fairly early stage in data collection, that is, after a few interviews had been conducted, an emphasis on questions designed to provide fairly concrete descriptive information gave way to other issue-based questions and probing. Second, towards the end of data collection, as part of the interview I was able to propose certain issues with some of the respondents for their consideration and our joint discussion. The sample size of this study, which may be considered by some as large for a qualitative research study, whilst allowing more or less equal representation from the university and community ‘sides’, was adequate in providing data to answer the research questions descriptively and theoretically.

The final sampling frame of study respondents by affiliation is shown in Table 2. Forty participants were engaged in poverty, homelessness and food insecurity research. The remaining 14 participants were engaged in a variety of community-based health-related research.

¹⁰ Theoretical sampling is not to be confused with “theoretical sensitivity” which was developed by Glaser (1978) Theoretical sensitivity, “refers to a personal quality of the researcher and relates to understanding the meaning and subtlety of data”. Glaser (1978) By gaining theoretical sensitivity the researcher will be able to recognise important data and formulate conceptually dense theory. See for example, Barker, T; Jones, S.; Britton, C. The use of a co-operative student model of learner characteristics to configure a multimedia application. Accessed from http://homepages.feis.herts.ac.uk/~comqtb/Grounded_Theory_intro.htm on April 19, 2011.

Table 2: Numbers and affiliations of study respondents

	Food insecurity	Home lessness	Oth er	Tot al
University respondents	7	11	10	28
Community respondents	17	6	3	26
Total	24	17	13	54

Other=Engaged in community-based research other than food insecurity or homelessness

Recruitment

Potential participants were made aware of the study via announcements of the study through list serves on the Internet that focused on homelessness and food security, through related networks which I had access to, and through personal contacts. No physical locations were used for recruitment. Potential participants were invited to contact the researcher if they were interested in participating in an interview, on the basis of their participation in a community-based research project (referred to in the study documentation as a community-based participatory research project), and as a person who was either a community member or a university member involved in some way with the decision-making or governance of the research project. Potential participants either self-referred, or agreed to participate in reply to an invitation sent by email. Some respondents suggested potential participants and agreed to forward information of the study on the request of the researcher to avoid both third party and direct recruitment by the researcher.

Potential participants were given information about the purpose of the study, the issues that were to be covered in the interview, how they might expect the interview to proceed, any associated risks of participation, and their rights in participating or not participating in the interview.

Participants

All participants (with the exception of one respondent whose data were excluded from the analysis because they were not first-hand) were members of community and university research collaborations focussing on community-based research. Recruits had had one or more experiences of research collaborations focussing on food security/food insecurity research, homelessness-related research, and other areas of community-based research. It should be noted that all these projects are not specifically named to maintain confidentiality and anonymity of respondents. Individuals' personal affiliations or organizational representation had no bearing on the recruitment, nor did they provide reason for exclusion. Recruits came from diverse age-groups, and both men and women were recruited. Some respondents were investigators of publicly-funded studies. Other respondents included academics, project coordinators and community respondents with different affiliations and associations, such as community organization board members, volunteers, workers, users of community services, lay persons and people with lived experience of issues under study.

The small number of participants engaged in community-based research associated with social determinants of health in Canada, and the ethical commitments to anonymity and confidentiality, while limiting the reporting, also has provided conditions in which I could assume "the truthfulness" of respondents. Discussion on the ethical boundaries and implications for reporting of this research is also noted below.

Interview procedure and conduct

Participants took part in one interview. Participants received a copy of the interview questions with consent documents prior to the interview. Interviews and all associated documentation were available in English and French. Informed consent and permission to record the interview was obtained prior to conducting interviews. There were a number of opportunities for a potential participant to ask questions and receive replies about consent and participation, and the study's contents. The participant might consent to participate, but also had the right to withdraw at any time, without consequence. In all cases, the potential participant was offered a brief overview of the consent form at the beginning of the interview. Interviews were recorded using a digital recorder. Some handwritten notes were also made by the researcher during the interview.

Most interviews were completed in approximately one hour or less. Telephone interviews were conducted from my private office. If participants expressed a desire to be interviewed in person, when feasible an in-person interview could be arranged at a time and place that was convenient for the participant and interviewer. If and when these interviews took place was not recorded in the papers, again to preserve confidentiality and anonymity of respondents.

The personal semi-structured interview was conducted using a conversational style designed to encourage the respondents to relate their experiences and tell their stories. I added probes and responded to answers using active or reflective listening which comprise a number of techniques from communication skills training (See, for example, Egan, 2010). The semi-structured interview allowed me to prompt, clarify and pursue themes to enhance my understanding of respondents' knowledge of arrangements and experiences of governance of community-based research. As the interviews were conducted over a period of months, and transcription and analysis were conducted on a concurrent basis, I was able to adjust questioning relating to particular themes, in order to uncover different data and develop interesting leads. For example, learning about the concrete arrangements or structures and understandings of governance as participants understood them, led to a greater emphasis on questions about understanding how these concrete components formed part of the processes and experiences of governance for community-based research participants.

After the interview, I requested permission to contact the respondent again if there was a need to clarify responses. Participants were also asked if they would like to receive a document planned to summarize the study findings. Requests were recorded. Requests by respondents for further information or a copy of the transcription of the interview were also recorded and carried out.

Data coding and data analysis

This section gives an account of data coding and data analysis as I conducted them for this study. To aid coding and analysis of the data, I made use of a commercial

software program (NVivo).¹¹ Coding is defined as “marking the segments of data with symbols, descriptive words, or category names” (Johnson & Christensen, 2008, p. 583). The completed coding framework looks somewhat similar to the contents of a book which has chapters and sub-headings. There is a hierarchy of codes. Higher level codes tend to be broad-ranging and include lower level codes which provide more detail or depth of meaning than the overarching category or heading. It is this ‘richness’ of description that is needed to build theory (Eisenhardt, 1989). Each code (or node) has defined properties developed by the coder/analyst, that is then used to determine if an entry fits or not. The collected properties and the code-names form the equivalent of the contents of a code book.

Whilst a coding framework is being developed, the researcher also makes use of ‘memos’ and ‘annotations’ that accompany the codes. These memos and annotations are intended to keep a record of the researcher’s interpretation of a piece of data and his/her attention to aspects of the data that raise questions of interest, such as confirming or disconfirming examples of an aspect of the phenomenon, and to ultimately help develop theory. Memos are reflections, clarifications, markers and notes that are derived from the data and suggested to the analyst. They are used to develop grounded theory.¹²

Charmaz suggests ‘line-by-line’ coding as one approach to analytic coding (Charmaz, 2006). I coded for this study on the basis of what I determined to be discrete units of meaning to which a code is applied. My approach to coding is similar to Charmaz’s. By dividing data into discrete units which encapsulate single meanings, the analyst can interpret phrases that stand by themselves or full sentences as units for analysis, as well as allowing duplication of these same units for additional or alternative

¹¹ Qualitative data analysis, coding and categorization can be accomplished by using Word tables, however given the amount of material for this study, (well over 55 hours of transcribed material), Word proves to be unwieldy. The commercial software allows the researcher to move and reorganize material readily.

¹² It should be noted that qualitative content analysis, which is sometimes referred to as “strength of coding”, and “data or text mining” is used in qualitative research as a way of referring to the repetition or frequency of codes that either occur across all participants, or in a section of the data. Repetition of themes does not necessarily speak to the importance of the theme for the direction of the analysis, although qualitative content analysis may serve as a starting point for further interpretation of the data (Morgan, 1993). Qualitative content analysis was not employed in this project.

interpretation and coding. An advantage of this approach is that the division of text into units of meaning for analysis, is a way to start the process of thinking about meaning. It therefore provides a thorough and systematic means of becoming familiar with the data. Qualitative data analysis software also allows the analyst to select discrete units of text and code in a single step.

Qualitative description

Qualitative description is described by Sandelowski and other authors as a low-inference approach to qualitative data analysis (Lindlof & Taylor, 2002). It has the specific purpose of description, and is designed to create a robust description of a phenomenon that may be used for theoretical development, such as grounded theory, at a later stage using the same data (Charmaz, 2006; Morse et al., 2009; Sandelowski, 2000). The interviews were initially coded with an eye to qualitative description (Sandelowski, 2000). The first paper in this thesis, which describes the structures of community-based research collaboration governance, is offered as an example of the use of qualitative description.

Qualitative description fulfilled two purposes in this thesis. First, as a method of data analysis in the first paper, it allowed me to describe the observable and describable structures that make up a framework which collaboration members use in pre-determined spaces to guide and determine the nature, content and boundaries of decision-making. These included governance bodies and their membership, and documentation of the collaboration. This filled gaps in the literature with regard to description of structures, tools and associated processes of community-based research collaboration governance. In the second paper, qualitative description was also used as a method to organize descriptive categories. Second, qualitative description provided a foundation for building grounded theory in the third paper.

Grounded theory

The second analytical method utilized in the study was grounded theory. The approach to grounded theory that I adopted emanates from the ‘second generation’ of grounded theory exemplified by Morse, Stern, Corbin, Bowers, Charmaz and Clarke in their (2009) book “Developing grounded theory: The second generation”, and by

Charmaz. in her book, also published in 2009, called “Constructing Grounded Theory”. The interpretive constructivist paradigm of this ‘second generation’ posits that “Knowledge is socially produced, acknowledges multiple standpoints, takes a reflexive stance towards our actions, situation, and participants – and our analytic constructions of them” (Charmaz in Morse et al., 2009, p. 129-130). Constructivism means that “conducting and writing research are not neutral acts...we exist in a world that is acted upon and interpreted by our research participants and by us as well as being affected by other people and circumstances”(Charmaz, 2009, p. 130-131). Grounded theory depends on the researcher’s views, which are, according to Charmaz, “interpretive renderings” not (as) objective reports or the only viewpoint on the topic” (Charmaz, 2009, p. 131).

Grounded theory has the advantage of providing tools for data collection (for example interviews and document analysis), data analysis and synthesis (Morse et al., 2009). It uses the organization of the data themselves, and constant comparison and analysis as methods of creating theory. Constant comparison means comparing incidents to others that are similarly coded, noting differences or similarities, relating them to each other (or not), and to a category and its properties (Dye, Schatz, Rosenberg & Coleman, 2000; Gasson, 2003; Locke & Golden-Biddle, 1997). Greenhalgh describes the constant comparative method as follows: “each new piece of data is compared with the emerging summary of all the previous items, allowing step-by-step refinement of an emerging theory” (Greenhalgh, 2006, p. 174).¹³ As new data (interviews) are added to the data set, there is a continuous process that involves thinking about the data, that is, of “breaking down, examining, comparing, conceptualizing and categorizing data” (Strauss & Corbin, 1990, p. 61), accompanied by the writing of memos.

‘Second generation’ grounded theory has much in common with Glaser and Strauss’s ‘first generation’ grounded theory, including the coding of data, the use of the constant comparative method, and the use of memos throughout analysis and coding. There are flexibilities however that part ways with first generation grounded theory,

¹³ Greenhalgh, T. (2006) 3rd ed. “How to read a paper” p 174 citing (Glaser & Strauss, 1967)

particularly with the approach of Glaser who, for example, required researchers to conduct their reviews of the literature after data had been collected and analyzed in order to reduce the likelihood of bias. Comparisons with existing theories, and taking different theoretical starting points are not excluded from the second generation approach.

In this study, I reviewed the literature before, during and after the conduct of the study. I used nodes, free nodes (or codes), descriptions of codes (or axial coding which specifies the properties and dimensions of a category according to Strauss & Corbin), to help code and categorize data and to develop theory using the software. I also handwrote memos that were in the form of comments, diagrams, maps and questions in notebooks, whose contents contributed to changes in the interview, the coding framework and later analysis. I also used existing theory (Arnstein's (1969) ladder of participation in governance) in the third paper for comparison with my findings or grounded theory.

Qualitative description was a first step and an appropriate analysis for providing me with description and features of the phenomenon of interest. However, steps towards developing grounded theory were undertaken through iterative readings of the data, the making of connections and relationships of meaning between codes, and comparing incidents (in this case participants' experiences) to find differences and similarities, and to develop abstractions (Charmaz, 2009, in Morse et al., p. 138). These analyses ran in parallel but not separately from the descriptive analytic process. Therefore my approaches to grounded theory could be characterized as incremental, building from previous knowledge. Although the review of the literature, knowledge of extant theories of shared or collaborative governance models, and the research orientation of the researcher (Caelli, Ray & Mill, 2003) all influence the approach and understanding of the research, the analysis and theory is grounded in the data: that is to say, grounded theory was developed as a result of the respondents' reported experiences.¹⁴ The two methods

¹⁴ To give one example of the development of theory through an iterative process, an earlier interpretation suggested that participation in governance of community-based research for community participants fell along a continuum of active and passive types of participation. Active participation depended on the existence of collaboration discourse around governance, which was initially uncovered through the descriptions of accounts of failures of governance. Later I came to link the accounts of failures of

of analysis, qualitative description and grounded theory thus formed steps of the analysis, yet offered an integrated approach to the analysis.

Ethics

All procedures were approved by the University of Ottawa Research Ethics Board. The certificate of approval and study documentation that was reviewed by the institutional research ethics board at the University of Ottawa can be found in the Appendix.

Consent procedures

Signed consent was furnished by participants. Some individuals gave verbal consent which was digitally recorded at the beginning of an interview and provided signed consent at a later date. At the beginning of each interview, the researcher briefly reiterated the conditions of participation and the choices of the respondent to withdraw at any time.

Anonymity was assured to research participants. The identity of participants was not revealed to others. The recordings of the interviews for transcription and the transcribed text were erased by the transcribers. The transcripts of the interviews were only available to the researcher and her supervisor, except in the case where a respondent requested a copy of the interview for his/her personal use. In the reporting of the study, anonymity was ensured by the removal of any personal and geographical identifiers and references to the studies in which participants were involved. Quotations which were used in the text, were assessed carefully for personal identification. Other identifiers such as references to studies or notable idiosyncratic speech patterns, were removed.

governance with the lack of space or opportunity for participation. The concept of a continuum or range of types of participation which was originally conceived, gave way to a further conceptualization of participation in governance developed in the third research paper.

Confidentiality

The identity of research participants in interviews was only known to the researcher, and accessible to the supervisor. Neither the researcher nor her supervisor (who had access to the raw data) disclosed any identifying information at any time to others about the participants. Interviews were conducted by the researcher from her private home office where it was not possible for others to overhear the interview and identify participants. Confidentiality is maintained in perpetuity by the researcher and her supervisor. Because the findings are reported anonymously, no breach of confidentiality is anticipated.

Assuring confidentiality and anonymity to respondents, necessary for the small number of participants engaged in community-based research associated with social determinants of health in Canada, has had the effect of limiting the description of the respondents, the studies they were involved in and the location of their research in the research papers. However, the ethical commitments to anonymity and confidentiality, also has provided conditions in which I could assume “the truthfulness” of respondents.

Compensation

No participant was offered or received compensation for his/her participation in the study.

Data storage

Copies of electronic text and sound files were stored on a DVD which is held by the supervisor, Dr. Caroline Andrew, at the University of Ottawa. Copies of the sound and text files were located on the researcher’s personal computer. Only the researcher Vivien Runnels and her supervisor, Dr. Andrew, have access to these data. Completed consent forms were collected by the researcher, and later transferred to the Centre of Governance at the University of Ottawa where they are held in a locked filing cabinet for later disposal. Data will be conserved for approximately five years after the posting of the thesis (2016), at which time the necessity of continuing to store data will be reviewed. Any remaining hard copies will be shredded and digital files erased. At the present, no

benefit to retaining the consent forms and original data is envisaged beyond the five-year mark.

Research paradigms and the conduct of research

In this last section of the chapter on methods, I briefly revisit the interpretive/constructivist research paradigm written about at the beginning of the chapter and finish by reflecting on the subjectivities or personal biases which are an integral part of the conduct and method of the research conducted for this thesis. The basis for offering these subjectivities is based on a theory of knowledge or epistemology in an interpretive-constructivist research paradigm which means the researcher cannot separate his or her interpretation of the phenomenon as a separate or universal ‘truth’, and acknowledges social reality as one in which he or she is naturally a participant (Robson, 1993). Sandelowski and Barroso remind researchers that in their view all research is interpretive. They explain that “what is deemed to be evidence is always theoretically informed, historically situated, socially constructed and even politically motivated” (Sandelowski & Barroso, 2007 p. 6).

The collection and interpretation of qualitative data in this thesis lie in the interpretive paradigm, although this does not necessarily mean that qualitative data and their analyses are always neatly confined to one paradigm. Charmaz, for example, conceives of grounded theory as a continuum of interpretation and writes of ‘objectivist’ grounded theory at one end of the continuum (Charmaz, 2009). Qualitative description may be thought to be closer to an objectivist interpretation of grounded theory, or fitting into a post-positivist paradigm that espouses critical realism. Others make use of qualitative data in their research, and interpret them from a critical theoretical perspective. Much community-based research itself spans both interpretive and critical paradigms, involving an examination of qualitative data specifically for relationships of power, with an intentional outcome of altering relationships of domination and oppression (See for example, de Koning & Martin, 1996).

There is an extensive literature, discourse and debate that discuss research paradigms and disciplinary expressions of paradigmatic allegiances, which include

concepts of other ‘emerging’ paradigms such as critical realism, interdisciplinary and transdisciplinary research and mixed methods research. All these ‘trouble’ traditional understandings of the organization of knowledge. A full investigation and discussion of these paradigms is beyond the remit of this chapter: however, the interpretive constructivist paradigm and its perspectives, and the selection of qualitative approaches, all underpin the implementation of this thesis research, its analyses and interpretation of the data.

Reflexivity and subjectivities

In the paragraphs above on qualitative description and grounded theory, I explained qualitative description as a low inference approach which requires a low degree of ‘subjectivity’ on the part of the researcher (Lindlof & Taylor, 2002, p. 215). Grounded theory is interpretive and it incorporates multiple subjective understandings, and is high inference (Lindlof & Taylor, 2002; Higginbotham, Albrecht & Connor, 2001). High inference “requires judgment, insider knowledge or researcher needs to integrate a number of pieces of evidence, & a high degree of subjectivity on the part of the researcher” (Lindlof & Taylor, 2002, p. 215). Interpretive theory such as grounded theory, acknowledges “subjectivity in theorizing and hence the role of negotiation, dialogue, understanding” (Charmaz, 2009, p. 127).

As the sole researcher, research designer, data collector and data interpreter on this project, not introducing some sort of personal bias is unlikely. Although in some quarters this might be seen as a fault of the research, some authors have made a case against worrying about personal subjectivity. For example, Brannick and Coghlan refer to insider research and self-ethnography. In this approach insider-researchers take advantage of their lived experience and see this as a benefit. Practising methodological and epistemic reflexivity is the means whereby researchers explore the relationship between themselves and the object of their research. “Epistemic reflexivity focuses on researchers’ belief systems and is a process for analyzing and challenging meta-theoretical assumptions. Methodological reflexivity is concerned with the monitoring of the behavioural impact on the research setting as a result of carrying out the research” (Brannick & Coghlan, 2007, p. 60). Rosemary Reilly has explained that researcher ‘bias’ is a huge topic which is not fully resolved but “that it is more important to identify and

name one's standpoint and biases than to try to remove them". As Kelly notes "all writing and all science are socially constructed and therefore subject to bias...the solution is to acknowledge this fact and to seek to make the biases explicit" (Kelly, Morgan, Bonnefoy, Butt, Bergman et al., 2007). Kelly et al.'s solutions to bias are "to describe any political bias that is inherent in the argument, and the second is to seek to determine whether the political biases have influenced the selection and interpretation of the evidence" (Kelly et al, 2007, p.19).

Tom Wengraf notes that, "any particular method of data-collection requires the elaboration of informal procedures and perspectives...which increases the chances of the researcher's subjectivity being a crucial source of understanding and which lower the chance of the researcher's (uninspected, unexplored, unilluminated) subjectivity, being a predominant source of misunderstanding and misrecognition."¹⁵ Rosemary Reilly points out that the subjective experiences of the researcher contribute to the understandings of the researcher. "The researcher is an instrument for collecting and understanding social experiences. I would not want to eliminate *my subjectivity-- my subjective experiences*—while being a researcher since I believe that they contribute to my understanding. My positions, or standpoints, or "biases" if you will, become problematic when they *undermine my ability* to co-create a shared understanding with participants about their constructions of their social world and experiences. But they can also be a source of questioning the status quo and power hierarchies."¹⁶

Subjectivity and subjectivities refer to the whole influence or personal bias, including disciplinary influences, that a researcher brings to the research context in its entirety. These subjectivities are not measurable nor simply determined, but uncovered and reported through a careful and ongoing reflection and critical thinking or 'reflexivity' throughout the research endeavour. This following section is a brief account of my

¹⁵ Tom Wengraf To: QUALRS-L@LISTSERV.UGA.EDU Sun, January 30, 2011 2:39:47 PM Re: Subjectivity.

¹⁶ Rosemary Reilly, Centre for Human Relations and Community Studies, Concordia University. Sunday, January 30, 2011.

subjectivities and a summary assessment of their possible influences on the research process and products.

During the conduct of fieldwork over a period of a year in a multiethnic high school, Peshkin identified a number of personal qualities that “have the capacity to filter, skew, shape, block, transform, construe, and misconstrue what transpires from the outset of a research project to its culmination in a written statement” (Peshkin, 1988, p. 17). An examination of self revealed what Peshkin realized were important different aspects of his self, such as the self that was concerned with seeking justice. He realized these different ‘selves’ came into play at different times during the project. They influenced his interactions with the researched populations and his interpretations of what he was observing and writing about. I too have reflected on and recognized a number of ‘I’s or subjectivities. These have changed over the period of the research. At the beginning of the research, I identified the “community-located I”. This meant that my voluntary sector experience as an adult over many years, and strong identification as a member of the community in which I lived and volunteered, were contributors to the self that I defined. Questions about how the governance of community-based research was formed and practiced had arisen from my experience of governance in the non-profit and voluntary sector. My affiliations and associations, as well as my research interests were implicated in the shaping of the research that was to be undertaken. My “community-located I” suggests a sympathy with community views, and a research perspective which sought to produce practical research which could assist community members in their participation in the governance of community-based research.

Becoming a graduate student meant taking some decisions to allow me to devote as much time as possible to my studies. A decision to give up community volunteer positions was a difficult although pragmatic one. However the decision to maintain one of the positions was based on a personal need to continue an important aspect of my pre-graduate student life. I recall explaining this to a colleague, maintaining this volunteer work would help to keep me ‘grounded’ in the community in contrast to what I thought was the somewhat esoteric atmosphere of a university. But reflecting on this statement, made me realize that my subjectivities had changed vis à vis the research. Approximately half-way through the program trajectory, I saw myself as having feet planted in both

camps. I was situated in the intersections of community and university, seeing myself as members of both, and feeling I had a grasp of the perspectives of community members and university members, and part insider and part outsider in both environments. On reflection, I described this as the “community and university I”. This, I thought placed me in a good position to collect data through interviews using the communication skills I have developed over many years as a community volunteer, and engage with respondents without seeming to favour one ‘side’ over the other. I thought that being in this position would eventually allow me to interpret fairly and evenly the experiences of community and university members in governing community-university research collaborations without much of what might be described as bias or favouritism.

Towards the end of the research, whilst analyzing the data and writing up the results, I realized that the academic environment, the knowledge that I have been exposed to, the language I used in writing and in day-to-day speech, and my personal development and ‘professionalization’ as an academic, had all affected me sufficiently that I can no longer claim outsider or part outsider or neutral status. My reflections on my identity as “university I” acknowledges that my subjectivities have changed. My interests in completing the research and the thesis had also become a priority.

Although specific personal bias is difficult to discern, I believe these subjectivities can be traced to a certain extent in the content of the research papers, starting with a concrete and descriptive approach in the first (with a view to transferring this concrete knowledge to serve the community), the second introducing theory (which underpins the reasons for paying attention to governance when doing community-based research for both academics and community members), and the third fully engaging with theory (which to a certain extent returns to the origins but in a theoretical way). My subjectivities I believe have not led me to alter or change things in ways that I felt might have been ‘better’ for the research outcomes. I was not conducting field research so ‘involvement’ or ‘going native’ beyond the interview either with university or community respondents although a possibility was unlikely. As the interviewer, or co-producer of knowledge, I did not offer advice to participants, or consciously try to lead questions in the interview situation. I had no desire nor a need to agree with or seek agreement from respondents with my ideas. Some ideas that I had which arose through

interviews and their analyses were floated in some subsequent interviews to test their sense, workability or viability, which I thought of as theoretical sampling.

My subjectivities also include the ‘I’ that possesses good social skills, a non-threatening manner, an open and honest empathic approach, and respect for others. I also reflected on whether these introduced researcher bias in some way. Do these personal characteristics allow access to respondents where none might otherwise be granted, or vice versa? All of these are considerations for researcher bias in the interaction that takes place in the interview and in the interpretation of the evidence. My subjectivities thus are an integral part of the research, not readily discernible but clearly existing and dependent on my life-history. Some of these are more proximally influential, but also too have the effect of limiting or bounding in some way my interpretation of the research.

Generalizability and “fittingness”

To complete this methods chapter, I pose a question that is continually raised with respect to qualitative research, are the findings that are generated through this qualitative study generalizable? Research approaches that are based in the interpretive constructivist paradigm do not make any claims to generalizability. Concepts of external validity that are appropriate for quantitative research are not applicable to qualitative research because “it emphasizes the study of phenomena in their natural settings and with few controlling conditions” (Sandelowski, 1986, p. 31). Sandelowski further explains, “From the qualitative perspective, generalizability is based on the reification of a context-free structure that does not exist and the assumption that the multiple realities in any given situation can be controlled to illuminate the effects of a few variables” (Sandelowski, 1986, p. 31).

Research paradigms have different ways of justifying and assessing their approaches. In the interpretive paradigm, and depending on the author, criteria for assessing interpretive research include trustworthiness, credibility, dependability and confirmability. For Gephart, the key categories or tools of assessment are listed as trustworthiness and authenticity (Gephart, 1999). Trustworthiness is a general category that incorporates credibility, transferability, dependability and confirmability (Graneheim & Lundman, 2004). Credibility refers to ‘truth value’ (Miles & Huberman, 1994), or it is equally understood as the confidence in how well data and analytical processes address

the intended focus (Graneheim & Lundman, 2004, p. 109). Transferability refers to “whether the conclusions of a study have any larger import”, that is, whether the conclusions of a study have any import elsewhere or in other contexts (Miles & Huberman, 1994, p. 279). This decision rests not on the judgment of the researcher but on the judgment of readers who “transfer this understanding to other contexts and assess the similarity” (Miles & Huberman, 1994, p. 279). Dependability refers to the stability of the study process across time and across researchers and methods (Miles & Huberman, 1994, p. 278). Confirmability is described as “a degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest” (Lincoln & Guba, 1985).¹⁷

What is produced in qualitative research and grounded theory is typically low level, local or micro-scale theory which aims to understand and reconstruct the symbolic world that people create in a particular context (Higginbotham et al., 2001; Guba, 1994). But the different approaches to assessment of qualitative research are often compared and even likened to positivist paradigms of research inquiry. Guba and Lincoln therefore have suggested “fittingness” as the criterion which appears to come closest to the concept of generalizability for the purposes of qualitative research, but using the language of qualitative research. “Fittingness” is present when a study’s findings “can fit into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences” (Sandelowski, 1986, p. 32). In the conclusions to the third research paper, readers are invited to consider and assess the findings in light of their own experiences. Returning the findings to the co-creators of knowledge or to others who are similarly placed to assess their ‘fittingness’ is a method that is allocated to the future for this research.

¹⁷ Accessed from Robert Wood Johnson Qualitative Research Guidelines Project at <http://www.qualres.org/HomeLinc-3684.html>

Summary and conclusion

In summary, the study which I designed and developed using the methods described in this chapter was an inquiry into the governance experience and practices of community and university members working in collaboration in community-based health-related research in Canada. Methods were deployed to build responses to two general research questions, “What are the arrangements of governance of community-based research collaborations?”, and “What are the experiences of community-based research collaboration members with respect to governing community-based research collaborations?” These general questions were refined at a later date to adjust the focus of the three research papers that were produced for this thesis. The objectives of the study were therefore: i) to describe arrangements of governance in community-based research collaborations; ii) to describe the experiences of community and university members with respect to community-based research and governance and, iii) to build theory of participation in governance of community-based research collaborations. The study was not funded. The author was a recipient of scholarships from three bodies: the Social Sciences and Humanities Research Council, the University of Ottawa, and the Province of Ontario (Ontario Graduate Scholarship). The author declares no financial conflicts of interest in producing this work.

CHAPTER 3

GOVERNANCE OF COMMUNITY-BASED RESEARCH: A REVIEW OF THE LITERATURE

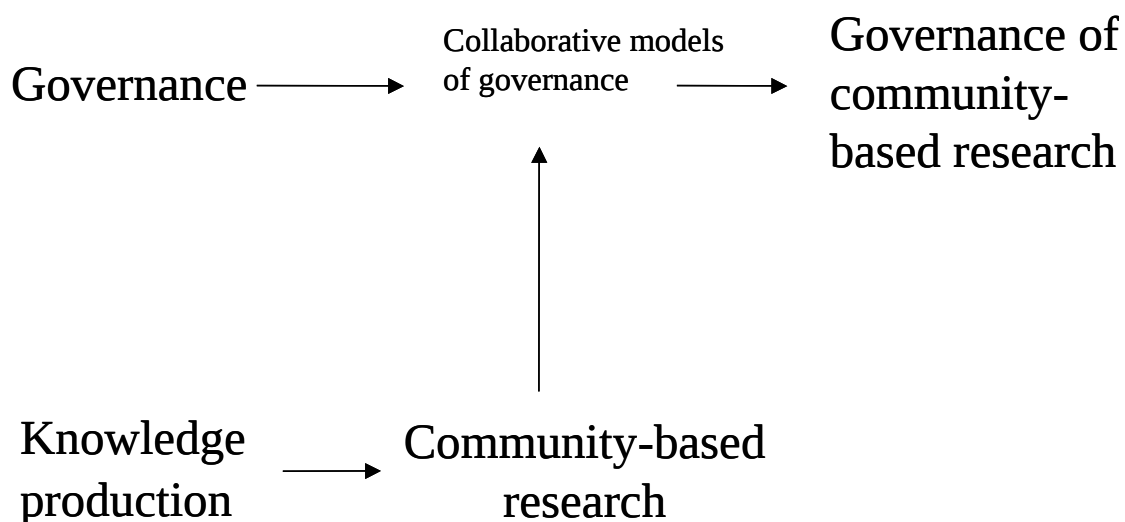
Introduction

Governance is increasingly becoming a topic of interest, so much so that the public administration scholar Rhodes has referred to governance as “the currently fashionable notion” (Rhodes, 2000, p. 54). Kooiman has noted its success as a concept because “it reflects the societal need for new initiatives based upon the realization of growing societal interdependencies” (Kooiman, 1999, p. 67). As Kooiman’s statement infers, governance has become widespread for the purpose of coordinating interests across societies. This is reflected in the literature of governance which is dispersed across a number of disciplines. Although many disciplines have touched on governance, a review of the literature relating to governance in the context of community-based research is lacking. The intent of this literature review is to inform and assist the thesis inquiry by giving account of the published knowledge of governance drawing from different disciplines, and to relate what is known about governance in the context of community-based research. The search for literature was continued throughout the thesis project. At the beginning of the project, the search was concerted and structured, with the researcher using key words and phrases to search academic databases and library collections. Searches of the Internet for academic literature and grey literature were facilitated using the web browsers, GoogleScholar and Google. Grey literature was not excluded because information intended for non-academic audiences about governance in community-based research collaborations is likely to be published in the grey literature (AcademyHealth, 2006; Hopewell et al., 2007). Literature was also acquired from authors’ cited references. Further searches to find literature-based answers to questions raised during the research process were conducted as required.

An organizing framework for a review of the literature

I used Paquet's understanding of a conceptual framework, "...a preliminary way to organize objects of the inquiry", as a means to structure the review (Paquet, 1999, p. 24). The conceptual framework suggests two main pathways connecting different concepts derived from different disciplinary literatures, leading to a literature of governance of community-based research. The framework is shown figuratively in Figure 1 below, and an explanation of the framework follows.

Figure 1: Governance of community-based research: A framework for a review of the literature



The first pathway in Figure 1 starts with governance. Governance is closely related to the ways that democratic states are organized and administered. Democratic principles are expressed through structures of governance, and contribute to ideas of shared or collaborative models of governance in which citizens participate alongside state actors. This pathway is the focus of the literature in Part I of the review. Part II of the review traces the second pathway in the framework. The second pathway starts with an account of the knowledge system in society, its organization and administration, and specifically knowledge production. This pathway leads to a discussion of community-

based research as an intentional approach to co-producing knowledge. The decision-making or governance structures of community-based research (which is by common definition a collaborative process), are conceived as being shaped by democratic origins of governance. Governance joins with knowledge production (community-based research) to form shared or collaborative governance models of community-based research. Part III of the review, governance of community-based research, looks more closely at governance and associated issues of governance which have received some specific attention in the literature of community-based research. There are other potential routes of enquiry with regard to the workings of governance of community-based research collaborations that are not specified in this basic framework, such as, for example, discussions of interpersonal factors and behaviours within collaborations (See for example, Logsdon, 1991). Alliances, subgroups or factions that form within a collaboration provide one additional area of study, and analysis of them may also have relevance to understanding interpersonal power dynamics and effects on decision-making within a governing body. I do not ignore suggestions that these and some other possible influences affect decision-making. However, these issues add to the complexity of the framework, lie outside the scope and focus of the study, and require additional research questions and methods.

Part I Governance

Describing and defining governance

In the 20th and early 21st century, the word ‘governance’ has been used to describe “a wide variety of phenomena in state, business and society” (Pierre & Peters, 2000, p. 9). Exploration of the concept of governance and its definitions emerged largely from political science and associated disciplines and literatures such as public administration, to describe a variety of forms of organization and their interactive processes and structures found at different levels and scales (Flinders, 2002; Kaufmann, Kraay & Zoido-Lobaton, 2000; Sloat, 2003). These forms are expressions of arrangements determined by governments, organizations and collaborations through which decisions regarding sharing, allocating and coordinating responsibilities, resources and knowledge are made (Stoker, 1998).

Governance differs from government. ‘Government’ refers to institutions, and personnel who occupy institutional roles and positions. Government has a monopoly of power through formal and legislated capacity to make decisions that concern the maintenance of public order and the facilitation of collective actions, and to enforce them (Stoker, 1998; Caporaso, 1996). Governance broadly refers to activities that are backed by shared goals (Rosenau, 1992), and to an idea largely agreed to in the literature, that the mechanisms of governance “do not rest on recourse to the authority and sanctions of government” (Stoker, 1998, p. 17).

To add a further challenge to defining governance, and extending the governance and government literature is Foucault’s concept of ‘governmentality’ (Mitchell, 1994). Briefly, this concept expands the conception of the state and government to new forms of organization within nation states, where the tasks of government are reallocated and where the locus of power is located away from the centre (Appadurai, 2001; Ilcan & Basok, 2004). Laborier’s and Papadopoulos’s interpretation of Foucault’s understanding of governmentality incorporates the use of ‘new’ tactics or technologies to ensure that ends will be met, rather than using and implementing laws (Laborier & Papadopoulos, 2004). There is some conflation of the terms in dictionary definitions and the literature, with ‘governance’ being used “as a kind of catch-all to refer to any strategy, tactic, process, procedure, or programme for controlling, regulating, shaping, mastering or exercising authority over others in a nation, organization or locality” which have rendered some difficulties in differentiating government, governmentality and governance” (Rose, 1999, p 15). The variety of definitions and descriptions of governance, government and governmentality, seem to provide a justification for the description of the literature of governance as “eclectic” and “relatively disjointed” (Jessop, 1995 cited in Stoker, 1998, p. 18).

Definitions of governance

Definitions of governance referring to specific organizational forms and their processes and structures are often matched to different levels of government. These include the global, federal, state, provincial and municipal levels. Definitions of governance also refer to other types of non-governmental societal organization including the governance of corporations and civil society organizations. For the purpose of

illustrating the varied presentations of governance, Table 3 presents some definitions, their levels of application, and the disciplinary associations of their authors. A review of these definitions shows the definitions are useful for differentiating governance from government. However, the definitions can be challenging in their application. Definitions of governance which are intended to have universal meaning and application are challenging to develop without risking loss of focus. Most definitions consequently lack parsimony: sometimes in attempting universal definition and application they are compilations of statements, as demonstrated in Imperial's definition. Paquet's succinct definition which has been translated as "governance is best defined as effective coordination when power, resources and information are widely distributed" (Hubbard & Paquet, 2007), is transferable to many forms of state-related governance, but does not necessarily rule out other forms that take on the rubric of governance. As a stand-alone definition though, it is necessary that the reader has some preliminary ideas of governance to make sense of it. In its original French, Paquet's definition is more specific by including an idea of a "problématique". This noun does not exist comfortably in English, but it encompasses more than the idea of a problem and adds the possibility of theorizing a problem. In the final phrase in the original French, the definition incorporates the notion of collectivity required to conduct the work of governance, as follows: "La problématique de la gouvernance ... propose la recherche des moyens d'assurer une coordination efficace quand ressources, pouvoir et information sont vastement distribués et que personne ne peut prétendre avoir la possibilité de faire le travail seul" (Paquet, 2005, p. 11). Rather than providing a definition, Stoker takes a different approach to defining governance. Stoker's propositions of governance can be seen to provide a means of summarizing and theorizing the key components of governance (Stoker, 1998). Stoker's propositions are outlined in Table 3.

Table 3: Definitions of governance

Author	A. Level and B. Discipline	Full Definition
Gustafsson (2005)	A.Governance B.Social Science	“the organizational forms and practices through which collective action occurs” (Gustafsson & Driver, 2005, p. 531).
Kaufmann, Kray and Lobitano (2000)	A. ‘Good’ governance B.Economics	The traditions and institutions that determine how authority is exercised in a particular country. This includes (1) the process by which governments are selected, held accountable, monitored, and replaced; (2) the capacity of governments to manage resources efficiently and formulate, implement, and enforce sound policies and regulations; and (3) the respect of citizens and the state for the institutions that govern economic and social interactions among them.(Kaufmann et al., 2000)
Edgar, Marshall & Bassett (2006)	A. ‘Good’ governance and civil society B. Economics/Business Administration	The process whereby societies or organizations make their important decisions, determine who has voice, who is engaged in the process and how account is rendered (Edgar et al., 2006).
Chhotray and Stoker (2009)	A. Multi-level B. Multi-disciplinary (Political science/development studies)	Governance is about the rules of collective decision-making in settings where there are a plurality of actors or organizations and where no formal control system can dictate the terms of the relationship between these actors and organizations (Chhotray & Stoker, 2009)
Andrew, Cardinal, Gattinger, Juillet, Lane and Paquet (2009)	A. Multi-level, B. Political science/public administration	Governance is the process of effective coordination whereby an organization or a system guides itself when resources, power, and information are widely distributed. (Introduction to the Governance Series in (Andrew et al., 2009)
Stoker (Stoker, 1998)	A.Institutional, national and sub/national or urban governments B. Political science/Public administration	Five propositions 1. Governance refers to a set of institutions and actors that are drawn from but also beyond government 2. Governance identifies the blurring of boundaries and responsibilities for tackling social and economic issues

		3. Governance identifies the power dependence involved in the relationships between institutions involved in collective action. 4. Governance is about autonomous self-governing networks of actors 5. Governance recognizes the capacity to get things done which does not rest on the power of government to command or use its authority. It sees government as able to use new tools and techniques to steer and guide. (Stoker, 1998) p18.
Rhodes (1996)	A. Central government B. Political science	'governance' refers to 'self-organizing, interorganizational networks' (Rhodes, 1996)
Potapchuk (1999)	A. Community collaboration governance B. Political science	"Governance encompasses three interlocking elements: the institutions and mechanisms through which communities make decisions, the formal and informal processes used to this end, and the stakeholders who are included in the deliberations" (Potapchuk et al., 1999, p. 218)
Auditor General of Canada	A. Corporate governance	Corporate governance refers to the process and structure for overseeing the direction and management of a corporation so that it carries out its mandate and objectives effectively. http://www.oag-bvg.gc.ca/internet/English/aud_ch_oag_200403_1_e_14893.html
Bovaird and Löffler (2002)	A. Local governance B. Economics/Public Management/Political science	Local governance - the set of formal and informal rules, structures and processes which determine the ways in which individuals and organizations can exercise power over the decisions (by other stakeholders) which affect their welfare at local levels. (Bovaird & Löffler, 2002)
Imperial (2005)	A. Network governance B. Public management/public affairs	Governance refers to the means for achieving direction, control, and coordination of individuals and organizations with varying degrees of autonomy to advance joint objectives p 282 (Frederickson, 1996; Lynn, Heinrich, & Hill, 2000). ... Governance includes their (NGOs') enabling statutes, organizational and financial resources, programmatic structures, and administrative rules and routines. It also includes the formal and informal rules, social norms, and structures that govern relationships among organizations (Frederickson, 1996; Lynn et al., 2000; Milward & Provan, 2000). Thus, it is inherently political and involves bargaining, negotiation, and compromise" (Imperial, 2005, p. 282).
Jones, Hesterly and Borgatti	Network governance B. Business administration/Business	Network governance involves a select, persistent, and structures set of autonomous firms (as well as non-profit agencies) engaged in creating products or services based on implicit and open-ended contracts to adapt to environmental

(1997)	management/Mathematical social science (Borgatti)	contingencies and to coordinate and safeguard exchanges. These contracts are socially-not legally-binding (Jones et al., 1997, p. 914).
Hubbard and Paquet (2007)	A.Solidarity organizations B. Economics/Public administration	Governance is best defined as effective coordination when power, resources and information are widely distributed. (Hubbard & Paquet, 2007)
Hirst (2000)	A.State B.Sociology	Governance can be generally defined as the means by which an activity or ensemble of activities is controlled or directed, such that it delivers an acceptable range of outcomes according to some established social standard. Also governance is a continuous process and all of its decisions cannot be subject to majority approval (Hirst, 2000).
Kooiman (in Rhodes, 1996)	A.State B.Public administration	Governance, can be seen as the pattern of structure that emerges in a socio-political system as ‘common ‘ result or outcome of the interacting intervention efforts of all involved actors. This pattern cannot be reduced to one actor or group of actors in particular cited in (Rhodes, 1996).
Pierre (2000)	A.State B.Political science	Governance refers to the empirical manifestations of state adaptation to its external environment. Governance also denotes a conceptual or theoretical representation of co-ordination of social systems, and for the most part, the role of the state in that process. Governance refers to sustaining coordination and coherence among a wide variety of actors with different purposes and objectives (Pierre, 2000)

Governance and democratic theory

In order to maintain focus on defining “governance”, I made no reference in the previous paragraphs specifically to the relationship of “governance” with democratic contexts. Yet in most forms, governance is implicitly and closely tied to democracy. It is a principal subject for philosophy and political science discussions that concern the relationships of citizens and the state, and citizens’ associated participation and engagement with the state. In this section, I touch on democratic theory and participation to draw its links with governance. Robert Dahl suggests that “at a minimum...democratic theory is concerned with processes by which ordinary citizens exert a relatively high degree of control over leaders” (Dahl, 1956, p. 3). For Chekki, these processes are also “all acts of citizens that are intended to influence the behaviour of those empowered to make the decisions”, and are defining acts of participatory democracy (Chekki, 1979, p. xiii). Button and Ryfe’s definition of democracy suggest that citizens who are ‘free and equal’ have equal opportunities to participate in public acts of citizens so that they can shape decisions that affect them (Button & Ryfe, 2005). Fung specifies democracy as “any ideal or conception of democracy is composed of both an account of important values, such as self-rule, accountability, political equality, and liberty, and a prescription about governance institutions such as elections, deliberation, or direct participation” (Fung, 2007, p. 444).

In order for citizens to exert control and influence over leaders, democracy requires participation. “Participation serves three particularly important democratic values, legitimacy, justice, and the effectiveness of public action”, although “no single participatory design is suited to serving all three values simultaneously: particular designs are suited to specific objectives” (Fung, 2006, p. 74). “Legitimacy is a quality that is attributed to a regime by a population”, meaning that it is seen as proper, ‘right’ or acceptable to that population (Merelman, 1966, p. 548). Legitimacy is related to the inclusion, participation and representation of particular stakeholders in collaborations. In some accounts legitimacy relates to procedures. For example, a deliberative democratic process or procedure which is “inclusive, voluntary, reasoned, and equal” is the source of legitimacy itself because it “takes seriously the idea that the exercise of collective political authority must be capable of being justified to all those who will be bound by it”

(Gastil & Levine, 2005, p. 27). In other accounts, legitimacy is related more closely to those who take part in collaborations and deliberation. As Button suggests, democratic theory also has a practical side in that it provides a guide to the selection of institutions that offer legitimacy, or which have legitimate governing authority as well as better outcomes that are in keeping with values and principles of democracy (Button & Ryfe, 2005, p. 28; Gastil & Levine, 2005). There are several forms of legitimacy, a criterion of input-legitimacy is “the availability of opportunities for citizen participation” (Bekkers & Edwards, 2007, p. 35).

Justice, the second democratic value as Fung conceives it, refers broadly to political justice intertwined with social justice. Those who are excluded from democratic processes are unlikely to be served well because policies and laws cannot be assured to reflect their interests. For example, racialized and gendered exclusion, can lead to social injustices or political inequalities in a democratic system. The third value, effectiveness of public action, refers to the ability of authorities to implement decisions that are legitimate and justly derived. As “public hierarchies”, as Fung refers to authorities, may lack “the information, ingenuity, know-how, or resources necessary to address social problems effectively”, enhancing effectiveness of public action may mean shifting authority to participating citizens (Fung, 2006, p. 73). Fung’s democracy “cube” or model can be used to describe different forms of participation and inclusion and ways of enhancing justice (Fung, 2006).

Participatory democracy, and deliberative democratic participation

Manifestations of participatory democracy in Western democracies include choice-making by citizens such as electing citizen representatives to political office, and voting in referenda to determine societal direction where popular input is seen as required. Deliberative democratic processes are processes of democracy in which discussion is central. Deliberation “describes the process used by juries, councils, legislatures, and other bodies that make decisions after a period of reasoned discussion” (Gastil & Levine, 2005, p. 6). Better outcomes may mean that “no force except that of the better argument” is utilized (Habermas, 1975, p. 108, cited in Cohen & Fung, 2004).

Habermas’ theory of communicative action has provided theoretical guidelines for participation and deliberation, and for determining the nature of discourse. In order to

obtain ‘better’ outcomes, ideally, “no force except that of the better argument” is sought in the deliberative process. How this better argument is determined according to Habermas’ theory of society, is through “fair and competent discourse” (Habermas 1984, 1987; Armour, 1995; Dietz, 1995, p. xvii; Bowen, 2008). ‘Fair’ refers to access to decision-making (Tickner, 2001, p. 98). ‘Competent’ means “access (to) tools and information to participate on an equal basis”. “Fair and competent discourse” means participants have equitable access and ability to participate (in discourse) and thus to defend their claims. The process is transparent. Language is the critical means whereby participants exchange ideas and concepts (Fairclough, 2001). The ability to participate democratically is therefore dependent on the expression of ‘voice’ and “honest co-ordination of the purposes of multiple actors” (Vandenburg, 2004, p. 475). The form and function of the deliberative space is critical for allowing the generation of the ‘best’ decision on the merits of the best argument presented at the time. This does not preclude the occurrence of conflict. In decision-making, preference is often expressed for consensus, as if decision by consensus is somehow more democratic and bearable than decision-making that arises out of conflict (Andersen & Jaeger, 1999; Sidaway, 2005). Some cultures use silence to indicate approval or disapproval, so clarifying what is meant by ‘voice’ requires a deeper and more careful analysis than ‘being heard’.

Some of Chekki’s acts of citizens referred to above include participatory acts such as voting, participating in interest groups, advocacy and lobbying, and demonstrating. Other acts are more deliberative such as consensus conferences and scenario workshops (Andersen & Jaeger, 1999), citizens’ juries, and town halls which “involves decentralised or dispersed forms of decision-making and the direct involvement of amateurs in the making of decisions” (Cook & Morgan, 1971 cited in James & Blamey, 1999, p. 2). Other methods that lay claim to being participatory, emancipatory and of a democratic nature include search conferences used in systems planning (Emery, 1993 cited in Jackson, 2000). Cardenas (2000) says “the single major emphasis of Search Conferences lies in promoting and providing the means for actualizing a democratic ideal through participative group processes” (cited in Jackson, 2000, p. 310). Van den Hove also has built an extensive list of means of deliberative and participatory democratic methods and processes that include amongst many others: focus groups, citizens’ juries, consensus

conferences, co-operative discourse, dialogue groups, stakeholder workshops, participatory expert workshops, policy simulation exercises, regulatory negotiation, consultative forums, deliberative conflict resolution processes, and environmental negotiations (van den Hove, 2003).

Much of the literature on decision-making pays attention to a variety of forms of deliberation or deliberative processes, and compares them with more narrow 'expert' approaches, such as those used in regulatory bodies. Deliberation describes the process of 'reasoned discussion' which is used by juries, councils, legislatures, and other bodies to make decisions (Gastil & Levine, 2005). Also associated with deliberative forms are the 'rules of engagement' or procedures such as those associated with consensus conferences, scenario workshops, and formal processes of governance. Depending on the context, or the part or problem that is being dealt with, processes for making decisions are sometimes generated at some point in time, not through any codification. For example, Andersen and Jaeger write of consensus conferences (where) there have been moments of conflict and sometimes negotiations until late in the night (Andersen & Jaeger, 1999, p. 335). Agreements obtained through an ideal, codified process are not always possible, portraying human proclivities to creatively operate outside the law when solving problems. A conundrum of democracy as citizens understand it, is having the democratic choice to participate and deliberate, or neither to participate nor to deliberate, although it has been argued that opportunities for participation as active citizen may be insufficient, exclusionary or poorly located, leading to choices not to participate or deliberate.

Modern democracies have developed deliberative and participatory methods such as those named above for the purpose of encouraging citizenship and developing citizens. But notions of citizenship and participation and their implementation, are intertwined and complicated. In a discussion of governance and the notion of citizenship, Cornwall writes that it is necessary for us to understand more about the cultural, political and historical contexts that set the conditions for participation, if we want to make sure that people have opportunities to realise citizenship that is both inclusive and active (Cornwall, 2002). Lister provides a nuanced insight into citizenship and participation: "to be a citizen in the legal and sociological sense means to enjoy the rights of citizenship

necessary for agency and social and political participation. To *act* as a citizen involves fulfilling the potential of that status” (Lister, 1997, p. 41). However, following Foucault Cruikshank (1999, p.1) argues that “democratic citizenship is less a solution to political problems than a strategy of government”. In other words, there is little that should be taken for granted or assumed to work regarding democratic participation (or non-participation). Governance is also concerned with the engagement of citizens in ways that are both participatory and deliberative for the purposes of policy making (Baccaro & Papadakis, 2009; Dietz & Stern, 2008; Fischer, 1993; Fischer, 2003; Gastil, 1993; Gastil, 2007; Smith, 2003). Dahl’s quote that “democratic theory is concerned with processes by which ordinary citizens exert a relatively high degree of control over leaders” (Dahl, 1956, p. 3) is inclusive of processes of governance which provides forms or spaces where citizens participate and make decisions in place or on behalf of the state.

Measuring governance

Democratic theory is closely tied to governance through notions of ‘good’ governance. Much of the literature on governance is suggestive, and even prescriptive, for what is required in order for governance to be ‘good’ in a democratically virtuous sense. Some sources suggest principles for governance which are value or moral statements setting standards of ‘good’ necessary for success of an organization’s endeavours. The Institute on Governance, for example, proposes (1) legitimacy and voice; (2) direction/strategic vision; (3) performance; (4) accountability; and (5) fairness (Edgar, Marshall & Bassett, 2006). For the United Nations, ‘good’ governance is gauged by governments’ following prescribed principles (United Nations Economic and Social Commission for Asia and the Pacific, 2007). Good governance is accountable, transparent, responsive, equitable and inclusive, effective and efficient, follows the rule of law, is participatory and consensus oriented and therefore aligned in principle with democratic theory. These values or moral statements are also used as the basis to measure success (United Nations Economic and Social Commission for Asia and the Pacific, 2007). Taking a global perspective of governance, Kaufmann, Kray and Lobitano (2000) propose “a systematic approach for measuring governance, its determinants, and its consequences” for countries, because “good governance provides significant benefits”. For these authors measures of good governance include

assessments of voice and accountability, political stability and violence, government effectiveness, regulatory burden, rule of law and control of corruption (Kaufmann, Kray & Lobitano, 2000). Transferring similar principles of ‘good’ governance to other forms of governance, suggests one approach for measuring success in achieving ‘good’. However, there is not full agreement with the idea of ‘good governance’. Governance is viewed by some authors as “a value neutral concept” (Lee, 2003). According to Rhodes, “none of these (governance) structures for authoritatively allocating resources and exercising control and coordination are intrinsically good or bad... the choice is of ‘practicality’ – under what conditions does each governing structure work effectively?” (Rhodes, 1996, p. 653). Paquet’s reading of governance is also more closely aligned with a ‘value-neutral’ conception of governance. He defines ‘good governance’ as the ability of governance to withstand shocks, “to ensure resilience, i.e. the capacity for the system to spring back on its feet undamaged” (Paquet, 2003, p. 9).

Collaboration and collaboration governance

Wood and Gray have defined “collaboration” as occurring “when a group of autonomous stakeholders of a problem domain engage in an interactive process, using shared rules, norms, and structures, to act or decide on issues related to the domain” (Wood & Gray, 1991, p. 146). It is “an inter-organizational phenomenon designed to achieve desired ends that no single organization can achieve acting unilaterally” (Wood & Gray, 1991, p. 140). Working interdependently, collaboration members achieve objectives better than they could alone through the generation of collaborative advantage (Huxham, 1996; Huxham, 1993; John-Steiner, 2000). Huxham’s understanding of collaborative advantage is also supported by other authors who agree that it contributes to collaboration creativity and innovation (Granovetter, 1973; John-Steiner, 2000). Dowsett proposes that collaborative advantage stimulates research on important health issues (Dowsett 1999). Collaboration also provides opportunities to change traditional or disciplinary-bound ways of undertaking research (Koelen, Vaandrager & Colomer, 2001; Labonté & Robertson, 1996; Leung, Yen & Minkler, 2004), for producing new and different types of knowledge (Gibbons et al., 1994; Israel et al., 1998; John-Steiner, 2000); and for supporting community development and empowerment through research (Florin & Wandersman, 1990; McMillan, Florin, Stevenson, Kerman & Mitchell, 1995).

Collaboration theory appears to be a central contributor to notions of collaborative governance, but weaknesses have also been identified. Collaboration theory and associated theories such as collaborative planning theory, all work on the assumption that stakeholders or collaborators are motivated to work with each other. However, collective action theory criticizes the assumption that there is always “an unproblematic congruence between individual interests and group interests”, and suggests that rational actors in fact, only serve their self-interests (Oliver, 1993; Olson, 1965). This theory also suggests that without coordination and discussion of values, incentives and benefits, and contributions, the added value that collaboration creates according to collaboration theory, could be absent. Gunton and Day note that collaborative planning groups that represent special interests and which are not “democratically accountable, (they) can be inimical to the public interest (Gunton & Day, 2003, p. 8). They also note that decision-making through consensus is time-consuming and resource-heavy; may lead to ‘second-best solutions’; and may not be appropriate (in some planning contexts) where problems are ‘intractable’ or unsuitable for the consensual decision-making that is preferred in collaboration theory (Gunton & Day, 2003).

Despite these problems with collaboration theory, a comparatively recent literature brings concepts of collaboration and governance together. Collaborative governance is defined as “A governing arrangement where one or more public agencies directly engage non-state stakeholders in a collective decision-making process that is formal, consensus-oriented, and deliberative and that aims to make or implement public policy or manage public programs or assets (Ansell & Gash, 2008, p. 544). In this definition, collaborative governance is clearly set in the public arena, and democratic theory which is behind most forms of governance, is evident. Ansell and Gash write that there are two types of collaborative governance which they classify as ‘species’ and ‘genus’. Their view is that the most influential theoretical accounts of this phenomenon are focused on specific types or ‘species’ of collaborative governance in contrast to the more general accounts offered by Gray (Gray, 1989), Susskind and Cruikshank (Susskind & Cruikshank, 1987), and Fung and Wright (Fung & Wright, 2001). Mykhalovskiy and McCoy write that with few exceptions, “little has yet been written about what those partnerships (collaborations) might look like, how to form them, and the issues that arise

in them” (Mykhalovskiy & McCoy, 2002, p. 33). Some of the literature published in the near-decade after Mykhalovskiy and McCoy made this statement addresses some of these issues (and noted in subsequent sections of the review). However, although a likely candidate, the governance of community-based research collaborations consisting of university and community organization members, has yet to be described or identified as a ‘species’ of collaborative governance.

In the modelling of collaborative governance, adversarialism and managerialism that characterize other decision-making processes which occur in the organizational contexts that Ansell and Gash describe, are in theory put aside in favour of cooperative relationships and deliberative processes. Chrislip and Larson’s work supports this approach to decision-making. They see a need for collaboration to solve complex problems, and provide evidence of accompanying changes in decision-making processes. Collaboration reflects “a deeper, more intimate, and more inclusive kind of democracy – one that is more direct than representative, and more consensual than majoritarian. It is a shift in the practice of democracy from hostility to civility, from advocacy to engagement, from confrontation to conversation, from debate to dialogue, and from separation to community” (Chrislip & Larson, 1994, p. 4). A recurring notion of governance and collaboration governance is that of ‘stakeholder’. In a collaboration, stakeholders are “those people who are responsible for problems or issues, those who are affected by them, those whose perspectives or knowledge are needed to develop good solutions or strategies, and those who have the power and resources to block or implement solutions and strategies” (Chrislip & Larson, 1994, p. 65). Although such definitions may lead to thinking that it is difficult to exclude anyone from being a stakeholder in governance, stakeholder theory is designed to help identify who is appropriately represented (Mitchell, Agle & Wood, 1997).

Forms of collaborative governance

A number of forms or models of collaborative governance have been proposed in the literature. ‘Negotiated governance’ is developed from a theory of negotiated order,

which broadly “depict(s) social organization occurring in and through people negotiating with each other.”¹⁸ Pierre notes that ‘negotiated forms of governance’ found at the micro- and mid-levels of society, is “growing in salience...and (is) encouraging from a democratic perspective”. Negotiated forms of governance contrast with hierarchical corporatist models, admitting “a diverse range of actors: including firms, trade associations and labour unions, non-governmental organizations and others”. But Pierre also sees them as problematic because they are “local and evanescent...making social learning difficult...” and leading to exclusive forms of network governance (Pierre, 2000, p. 19).

The governance of multiple organizational networks, or networked and network governance, has also added to the literature of forms of governance. These similar sounding forms of governance differ in the centre of governance: one form has a strong centre, the other is decentralized. However, authors do not use the terms consistently. Provan and Kenis (2008) characterize networks as ‘goal-directed’ rather than ‘serendipitous’ or opportunistic: in other words their establishment is deliberate. Networks deal with complex problems and coordination issues requiring shared or centralized governance by network members or network administrative organizations created specifically for the purpose, rather than counting on the achievements of individual organizations operating unilaterally. Building on a basis of social network analysis, network and partnership theory, “networked governance encompasses networked and partnership processes that are supplementing and perhaps supplanting the decision making that occurs through traditional, administrative hierarchies” (Creech, Vetter, Matus & Seymour, 2008, p. 1). Network governance for Powell, constitutes a “distinct form of coordinating economic activity” which contrasts (and competes) with markets and hierarchies (Powell, 1990, p. 301). Joerges’s view is that “most versions of network governance describe a configuration of voluntary interdependent public and private actors involved in partnerships and joint ventures. Coordination takes place

¹⁸ Marshall, G. (1998) A dictionary of sociology. Accessed September 9, 2010 from <http://www.encyclopedia.com/doc/1O88-negotiatedorder.html>

without a dominant center imposing a structure of hierarchical authority in the service of a predetermined objective” (Joerges 2002, p. 3 cited in Olsen, 2004, p. 70). Jansen defines a network as “a type of governance structure between markets and organizations” (Jansen, 2004, p. 12). Although the use of terms (network, networked, and networking) is not always precise, network formation is seen as a valued objective in itself because “networks provide a mechanism for preventing social exclusion” (Leydesdorff & Ward, 2005, p. 366).

In another approach to modelling collaboration governance, Potapchuk (1999) has compared ‘traditional’ versus new or organic models of governance. In organic governance, governance moves away from ‘stovepipe’ thinking based on traditional models of organization at the community/municipal level where relationships are codified, structures are unchanging and centralized, and decision-making is characterized by votes counted (‘majority rules’) (Potapchuk, Crocker & Schechter, 1999). Organic governance consists of formal and informal connections, using ‘bridging’ social capital to connect communities and linking ‘clusters’ of stakeholders in horizontal relationships (Potapchuk et al., 1999).

Failures of governance

The literature of governance has provided ample discussion of failures of governance. Much of this literature relates to the different ways that corporations, markets and states fail, and the various responses that are employed to deal with them. According to Jessop, the literature on failures of governance is important for considering “what affects its likelihood and the capacities for recuperating or responding to such failure”, if not to simply balance tendencies in the literature to emphasize successful governance (Jessop, 2002, p. 8). However, although failure is something collaborations might try to avoid in their governance, “failure is a central feature of all social relations...governance is necessarily incomplete and as a necessary consequence must always fail” (Malpas and Wickham 1995, p. 40 cited in Jessop, 2002). What failure actually means for collaborations is not really clear. Some authors associate failures of collaboration governance with its effects on individual participation and collaboration performance. For example, failures of governance according to Gaventa are marked by

lack of commitment, apathy, alienation (Gaventa, 2003); Provan & Kenis (2008) refer to lack of meaningful participation, member burnout and turnover; for Huxham (2003), governance failure risks “alliance instability and failure” and “collaborative inertia”, and others find governance failure has negative consequences for collaboration performance, outputs and outcomes (James & Blamey, 1999; Kishchuk, 2003).

Part II Knowledge production and community-based research

In this part of the literature review I first provide some clarification with respect to different forms and definitions of knowledge organization. The organization of formally produced knowledge, which is centred on the university as a dominant institution of societally sanctioned knowledge production, is briefly explored. The university and its members, are the base from which much community-based research is conducted. The social organization of knowledge, the intellectual organization of knowledge (Whitley, 2000), and knowledge organization all have distinctive definitions. The social organization of knowledge is used to refer to relatively stable forms, structures or relations of groups “which provide a basis for order and patterns for new members”.¹⁹ The disciplines, for example, provide one manifestation of the social organization of knowledge. Knowledge organization is used to refer to the science, methods and systematic organization of “knowledge units (concepts) such as the use of databases, bibliographic and other records, and disciplinary organization and preferences for ordering knowledge” (Dahlberg, 2006 cited in Hjørland, 2006). These forms of organizing knowledge, the development of the ‘knowledge society’, changes in higher education, and other factors that include globalization, have all played a part in the shaping of the knowledge system and knowledge production as we currently perceive and understand it (Gibbons et al., 1994; Moravec, 2008). In recent years, knowledge and its production and delivery has increasingly been recognized as an economic commodity

¹⁹ <http://www.thefreedictionary.com/social+organization>

(Geuna & Muscio, 2009; Whitley, 2000), standing in contrast to an idea of knowledge as a ‘commons’, a ‘public good’ or a ‘global public good’ (Stiglitz, 1999; Hess & Ostrom, 2007), and complicating views of the purposes and uses of knowledge production. Formal institutions of knowledge production, the universities, are not unaffected by these changes, however, the focus in this literature review is not on the changes per se, but rather on the examination of the structures and arrangements which govern knowledge production.

The organization of formally produced knowledge

The organization of formally produced knowledge is supported by social, economic and political systems and their institutions such as governments, ministries and universities. These institutions provide financial and other forms of support to the disciplines. As Blau notes, it is “Universities (that) create the institutional conditions that foster creative research and help advance knowledge” (Blau, 1994, p. 214). Formal knowledge is predominantly organized through the disciplines within the universities. Marked by “a significant consensus about what counts as a discipline and what does not” (Becher, 1994, p. 152), the disciplines are distinct in culture, yet together they share a common culture that determines the social organization of (higher education) (Becher, 1994). Kolb writes of the different cultures and learning demands of the disciplines and departments which serve to produce homogeneity in individual disciplines: “education in an academic field is a continuing process of selection and socialization to the pivotal norms of the field governing criteria for truth and how it is to be achieved, communicated, and used... (to) produce an increasingly homogeneous disciplinary culture (Biglan, 1973; Kolb, 1981, p. 233-234). Disciplines or groupings of disciplines are therefore aligned with particular paradigms or ways of looking at the world.

Knowledge production and knowledge co-production

In an important and influential contribution to the literature, Gibbons, Limoges, Nowotny, Schwartzman, Scott and Trow have proposed that the production of knowledge can be allocated to particular types or ‘Modes’ (Gibbons et al., 1994; Nowotny, Scott & Gibbons, 2001). Mode-1 knowledge production refers to the ‘traditional’ production of knowledge, its description encapsulating “...the cognitive and social norms which must

be followed in the production, legitimation and diffusion of knowledge” (Gibbons et al., 1994, p. 2). The ideal-type for Mode 1 is Newtonian empirical and mathematical physics. Mode 2 knowledge production however, is created in different social and economic contexts (Gibbons et al., 1994). Mode 2 knowledge production is claimed as a relatively recent theoretical development, and enabled by global change, that sees knowledge production as an interdisciplinary venture, driven by context-based problems, and carried out in an applied or practice context (Gibbons et al., 1994). In this conception, collaboration is essential for knowledge co-production, but equally important at a later stage in the knowledge system, for the validation and implementation of knowledge (Jansen, 2004).

In a different approach to modelling knowledge production, Callon has proposed three models which look closely at a range of participation by non-specialists in research (Callon, 1999). The first model, called public education, effectively excludes the public from knowledge production but the model’s effectiveness depends on how well the public or citizenry trusts the scientists who produce the knowledge. The antidote to mistrust which occurs because of the “illiteracy and ignorance of the public ... is to intensify educational and informative actions” (Callon, 1999, p. 83). The second model is called the public debate model in which scientific and popular knowledge are at odds, but the development of “richer relations between lay people and scientists” is sought (Callon, 1999). Callon’s third model, the co-production of knowledge model, or Model 3, overcomes the limitations of Model 1 and Model 2 knowledge production “by actively involving lay people in the creation of knowledge concerning them” (Callon, 1999, p. 89). Research participation is collaborative and interactive, and members participate on an equal footing. The knowledge that is produced is also mutually enriching, and learning occurs throughout the co-production process. As well as offering an explanation as to how producers of knowledge effectively manage the public’s responses to knowledge in Models 1 and 2, Model 3 offers the possibility for a collaborative approach to knowledge production. Although there are some similarities in Callon’s account of models of knowledge production with Gibbons et al., it is less well-known, and provides some fodder for continuing study of models of the co-production of knowledge (Callon, 1999).

An additional perspective on knowledge co-production in a community context, is research which has been referred to as ‘civic science’ (Bäckstrand, 2003; Clark & Illman, 2001, p. 63). However, civic science has a number of different and identifiable usages. The term ‘civic science’, “has many meanings and aspirations”, and is used as an umbrella term to increase public participation in knowledge production and utilization. It is also used interchangeably with civil, participatory, citizen, stakeholder, and democratic, to refer to any relationship of science with lay knowledge and participation (Bäckstrand, 2003). One example of its many meanings, is a description of a civic scientist who is a scientist who “communicates with general audiences and brings knowledge and expertise into the public arena to increase awareness about science and/or facilitate discussion and decision making on issues of importance to society” suggesting scientists have a specific knowledge transfer role in increasing scientific literacy of the public rather than directly engaging with them (Clark & Illman, 2001). This has some similarities with Callon’s Model 1. The definition distinguishes civic scientists from ‘citizen scientists’ and citizen volunteers and activists all of whom are understood to be members of the lay public participating in projects (Clark & Illman, 2001). However, citizen scientists and volunteers’ participation in science-related monitoring or data collection such as bird and fish counts is limited. They do not participate in the design of research and the creation of new knowledge. From their review of the literature, Clark and Illman note that the goals of civic science appear “to lie on a continuum ranging from passive appreciation of science to an increase in the ability of citizens to analyze a situation and take action” (Clark & Illman, 2001, p. 22).

Despite the array of terms and forms of research, what is clear from the literature is a growth in discussion of participation tied to the democratic deliberation of scientific research and related policies. The literature of civic science is probably most useful in our discussion in highlighting common problems in the relations of science, the academic world, and citizens, in democratic societies. Specifically, these problems include elitism, lack of knowledge transfer and the concomitant retention of knowledge in the hands of academics, and a related public scepticism of the ability of science to resolve problems (Bäckstrand, 2003; Clark & Illman, 2001). Reed and McIlveen note an apparently unresolved issue which Bäckstrand has also identified. This issue concerns the

identification of actors, qualifications and methods used to oversee knowledge production. The introduction of participatory approaches suggests, according to these authors, that the stewards of scientific knowledge production could be, scientists and engineers, or societal stakeholders (Bäckstrand, 2003; Reed & McIlveen, 2006). Further, Reed and McIlveen's focus on three key elements drawn from feminist scholarship and civic science, which are "challenging the production of knowledge; querying effective participation; and encouraging critical reflection", also suggest the importance of critical theoretical analytical approaches in knowledge production and co-production (Reed & McIlveen, 2006, p. 593). The effects of "multiple axes of power and politics", they claim, are significant for determining "the boundaries of scientific knowledge and in the processes used to put knowledge into action" (Reed & McIlveen, 2006, p. 593). Other authors have referred to the way that different modes of producing knowledge is changing the face of research and knowledge production, whilst reinforcing the Mode 1/Mode 2 knowledge production thesis (Chopyak & Levesque, 2002). Critical theoretical analyses such as feminist theory have had a particularly important contribution to make to the study of the production of knowledge by pointing to inherent biases that decontextualize and depoliticize issues (such as women's health risks). These analyses have also offered encouragement to affected communities (such as women) to participate and address biases. Inhorn and Whittle have also noted that questions about power relations in the production of knowledge, and resultant claims made for the knowledge that is produced, are not likely to be asked in 'traditional' disciplines (Inhorn & Whittle, 2001).

Power and knowledge production

The relationship of knowledge production to power is one that has been described as "neither straightforward nor commonly understood" (Gaventa & Cornwall, 2001, p. 71). Directly linking the production of knowledge with power opens up possibilities for the use of power, as well as possibilities for the abuse of power (Quigley, 1998). By virtue of their societally-sanctioned positions in the knowledge system, researchers have significant influence over decisions concerning knowledge production and knowledge transfer. Community-based research and associated approaches to research are intended to close the gap of power inequities created in part by the organization of knowledge, by

strengthening “voice, organization and action” (Gaventa & Cornwall, 2001). Discussion of power and knowledge production is closely linked to active participation and action of lay people. In an integrated analysis of dimensions of power after Lukes (1974), and Gaventa’s critically important work on power in an Appalachian valley (Gaventa, 1980), Gaventa and Cornwall argue that “control of societal or knowledge mechanisms ... is critical to the exercise of power” (Lukes, 2005; Gaventa & Cornwall, 2001, p. 72).²⁰ Countering power “involves using and producing knowledge in a way that affects popular awareness and consciousness of the issues which affect their lives” (Gaventa & Cornwall, 2001, p. 72). Who should create and own knowledge (and therefore power) are critical questions. The answers to these not only reveal bias in knowledge production, but also the biases of knowledge producers and those who have control over the knowledge production process (Gaventa & Cornwall, 2001). Social movements offer evidence of the conscious awareness of citizens facing power located elsewhere. Social movements also demonstrate that members of the public are not as inactive in political matters as is commonly painted but can be active in the process of even “creating the significance of their own protest” (Farge & Revel, p. 57, cited in Traugott, 1995).

A well-developed theory of knowledge as power has been advanced and elaborated by Foucault, and also linked to governmentality. Foucault has directed attention to the organization of power as it is represented in the professions (referred to as the ‘disciplines’), and administrative forms of the organization of knowledge (Foucault, 1980). In the formal knowledge system, society gives university members a position of power and authority and independence in terms of making research decisions, sometimes to the exclusion of other members and those who are being researched. From this perspective of knowledge as power, knowledge that is produced outside of the formal knowledge system also is subjected to the conditions for assessment of knowledge within the formal knowledge system. The status and power of such knowledge, and the legitimacy of its contributions are thus relegated to the margins.

²⁰ These mechanisms include “socialization, education, media, secrecy, information control, and the shaping of political beliefs and ideologies (Gaventa, 2001).

Community-based research

Emerging as an approach to research in the second half of the 20th century, community-based research has been defined as “a collaborative approach to research that engages partners from a community - geographic or otherwise defined - in all phases of the research process, with a shared goal of producing knowledge that will be translated into action or positive change for the community” (Lantz, Israel, Schulz & Reyes, 2006, p. 239). Israel, Schulz, Parker & Becker (1998) also define community-based participatory research to include the notion of collaboration. Their definition is “a collaborative approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process...(in which) partners contribute unique strengths and shared responsibilities” (Israel et al., 1998, p. 177). Green et al.’s definition also highlights “extensive collaboration between traditionally defined researchers and the community” (Green, George, Daniel, Frankish, Herbert, Bowie, O’Neill & Richard, 1995, p. 3).

Also referred to as participatory research, community-based research has been defined specifically by Gall, Millot and Neubauer, as “research conducted in partnership between civil society groups and academics. It seeks to democratize knowledge creation by validating multiple sources of knowledge and promoting the use of multiple methods of discovery and dissemination. The goal of participatory research is social innovation and action” (Gall, Millot & Neubauer, 2009, p. 23). It is in such definitions as Gall’s that the pathways between knowledge production and governance proposed in the conceptual framework at the beginning of this review are more specifically drawn. The democratic roots of governance, the demand for and pragmatic responses to acquiring knowledge from other than academic or technical sources leading to integrated efforts in new knowledge production, is clearly more than a response to assure ‘popular’ participation. Israel et al. have emphasized the participation of non-academic researchers in community-based research, but from a perspective of emphasizing critical theory and the social construction of knowledge, rather than linking this to democratic roots (Israel et al., 1998). Recognizing these links of critical theory, democratic theory and knowledge production, Muller and Cloete have proposed that rather than encouraging the participation of members of communities in the production of knowledge just to

legitimize the status quo, an aim of democratization should be “to empower a community to start contesting knowledge, to enter the arena of the politics of knowledge” (Muller & Cloete, 1986, p. 11). Regardless of whether members of communities conform, participate or even contest knowledge production, community-based research has had the effect of expanding and ‘turn(ing) on its head’ established ways of thinking about and doing research (Minkler & Wallerstein, 2003, p. 4).

Community-based research as an approach, has provided an alternative to research conducted by single-discipline researchers using traditional research methods (Fischer, 2000; Nyden, 2003). It has also provided opportunities to link the scientific knowledge held by academics with the technical knowledge of practitioners, and the lay or local knowledge of communities, to produce new knowledge. A specific value of knowledge co-production is in part, as some have argued, to prevent the monopolization of knowledge and science by elites (Bagby & Kusel, 2003). Community-based research is also intentionally implemented to build community capacity, whilst academic research teams working alongside communities can also benefit from co-learning and sharing of knowledge (Labonté, 2005; Ortiz, 2003; Wallerstein & Duran, 2006; Walter, Nutley & Davies, 2003b). The literature that looks at the practice of theory and action research suggests that new knowledge is generated as a result of reflective practice. However, although in the literature reflexivity often relates to an individual’s knowing and thinking, in a collaboration reflexivity can be applied to group processes and practices of learning, knowing and critical thinking.

Now widely utilized, and referred to by many different names, community-based research appears in a variety of community-based settings to answer a variety of research topics, and is increasingly discussed, debated and documented (Green et al., 1995). In the health domain, community-based research is largely taken as an intentional approach with an end goal of addressing health inequalities and improving health of communities (Lantz et al., 2006; Wallerstein & Duran, 2006). Health inequalities do not solely refer to distributions of health. Health inequalities are also viewed from a social justice standpoint, as unfair and unjust, or inequitable, and avoidable (Evans, Whitehead, Diderichsen, Bhuiya & Wirth, 2001). Thus, marginalized or vulnerable communities are often seen as ideal partners for community-based research because of the theory-based

belief that by participating in research, community members have opportunities for emancipation and empowerment, and social justice (Boog, 2003; Kemmis, 2001). However, the adoption of community based research as an approach has been reluctant in some arenas. Past research that has done significant harm to communities has served to sustain the mistrust of the public in participating in research (Centers for Disease Control and Prevention, 2008). Even the definition of ‘community’ itself has raised a number of questions. Its definition is often contested, not only in the literature but also by individuals who are purported to make up a community but choose not to identify with one (MacQueen, McLellan, Metzger, Kegeles, Strauss, Scotti, et al., 2001; Perez, Lefevre, Romero, Sanchez, De Vos & Van der Stuyft, 2009; Israel et al., 2003; Labonté, 2005).

Collaboration theory and community-based research

The literature on health and health research governance acknowledges the complexity of what Kooiman refers to as (inter)dependencies where “no single actor, public or private, has all knowledge and information required to solve complex, dynamic and diversified problems: ...no single actor has sufficient action potential to dominate unilaterally in a particular governing model” (Kooiman, 1993, p. 4). Collaborators believe that they can accomplish something together that they cannot accomplish by themselves. This added value that has been gained through collaboration has been referred to as ‘collaborative advantage’ by Huxham (1993 and 2003), and as ‘collaborative synergy’ by Lasker (Lasker, Weiss & Miller, 2001). Each party expects to gain some benefit from collaboration. However whatever reasons or benefits for collaboration are put forward, putting collaboration into practice is not an easy undertaking nor readily assessed, although collaboration theory offers an approach for assessing collaboration (Gajda, 2004). In community-based research, although it may be assumed that the research problem provides a reason for the formation of a research collaboration, what individual members bring to the collaboration or want from the collaboration may differ. Sofaer and Myrtle’s review of interorganizational theory suggests reasons for collaboration include, exchange of “scarce and valued resources” which include economic (e.g. funds, clients and raw materials) and non-economic resources (e.g. information, political support and legitimacy) (Sofaer & Myrtle, 1991, p.

389). Caldwell, Zimmerman and Isichei caution that agreement to work together is not a reason to assume that members hold all things in common (Caldwell, Zimmerman & Isichei, 2001).

Part III Governance of community-based research

In this final part of the literature review, I look at the literature of community-based research and determine issues of governance of community-based research which have received attention and those that have not. This part also completes the framework for the review of the literature. First, I review some concepts associated with governance of community-based research. Distribution of power is linked with empowerment and views of lay knowledge. Principles of community-based research are intended in part to help address imbalances of power. The literature concerning participation and representation in governance of community-based research opens with Arnstein's contributions to studies of participation in governance. I extend the discussion of associated concepts of governance to include ethics and ethical issues of community-based research, and trust. Forms or models of community-based governance are presented, followed by a discussion on external influences on governance of community-based research. How success and failures of governance of community-based research are presented in the literature is reviewed. After summarizing the literature of governance of community-based research, in closing I suggest some steps for future work.

Knowledge, empowerment, and lay knowledge

“Participatory researchers maintain that knowledge has become the single most important basis of power and control... and that the oppressors’ power is, in part, derived from control of both the process and the products of knowledge generation” (Selener, 1997, p. 24). In this statement, Selener presents the owners or holders of knowledge as elites who control knowledge, determine which knowledge is important to produce and which has value, and who has access to this knowledge. The elite view of knowledge production and control, locates knowledge in the hands of the ‘oppressors’, to use Selener’s terms, typically represented as the state or institutions and individuals that represent the state. In other words knowledge is produced and used by elite or dominant groups for their purposes with the result that other groups are disadvantaged (Reason, 1998). In order to address the oppression experienced by vulnerable, marginalized groups, and to allow the use of their knowledge and experience of their lives to solve their problems, a redistribution of power is needed. As a facility provided by democracy

(Sen, 2011), governance offers one possible means for redistributing power. For example, a principle of community-based research is that membership of governing bodies in community-based research consist of a mix of power holders and other stakeholders who seek benefit from the generation of new knowledge. Recognition of different forms of knowledge such as lay knowledge in the context of governance, also holds potential for shifting power into the hands of non-researchers.

Empowerment

Concepts of empowerment are integral for explaining the distribution and redistribution of power, knowledge and resources in governance of community-based research. Empowerment means “enhancing an individual’s or group’s capacity to make choices and transform those choices into desired actions and outcomes” (Alsop & Heinsohn, 2005, p. 5). Alsop sees empowerment as both a process and an outcome. In a narrative review of empowering approaches to health, Wallerstein (2006) sees empowerment as closely linked to participation at the individual and community level, and resulting from “participatory empowering strategies and interventions” (p. 8). Strategies that favour participation encourage empowerment. Participation however can be constrained by a number of factors which include a lack of willingness to challenge powerful institutions or to seek redress in power imbalances (p. 15), lack of knowledge about empowerment, or unwillingness to extend beyond the engagement of key informants in order to genuinely facilitate community-decision making (p. 9). Wallerstein indicates the most effective community empowerment strategies related to forms of decision-making, include “promoting community action through collective involvement in decision-making” and “transfer of power and decision-making authority to participants of interventions,” and strategies “that build on and reinforce authentic participation ensuring autonomy in decision-making, sense of community and local bonding, and psychological empowerment of the community members themselves” (Wallerstein, 2006, p. 5-9).

Drawing mainly from Freire and the feminist and development literature, Luttrell, Quiroz and Scrutton expand on single interpretations of power and what this means for empowerment. Using Rowlands' (1997) work as a basis for their analysis²¹, Luttrell and colleagues write that the operationalization of empowerment depends on an understanding of power, whether it is interpreted as 'power over' (referring to coercion or influence), 'power to' (referring to organization and changing existing hierarchies), 'power with' (that results from collective action) and 'power within' (that is generated from individual consciousness) (Luttrell, Quiroz & Scrutton, 2007).

Cruikshank raises some challenging questions in her critique of democratic theory, putting forward the proposition that citizens' empowerment, which suggests an independence or autonomy to think and act apart from the state, is in fact determined by methods of the state designed to shape citizens. These methods are referred to by Cruikshank as 'technologies of citizenship'. These technologies include participatory methods that are designed to enable citizens to govern themselves, such as, for example, user participation in health and social services which are designed to enhance the welfare of all citizens. Although empowerment to all intents and purposes is concerned with shifting, balancing or transferring power to those who are dominated or subject to oppression, the state's "will to empower contains the twin possibilities of domination and freedom" which are conflicting objectives (Cruikshank, 1999, p. 2).

Different understandings of power thus lead to different interventions for operationalizing empowerment. Mendell's paper explains that "empowerment refers both to mobilized opposition that contests the system from the outside as well as to groups, associations, movements that are inventing and constructing participatory alternatives from the *inside*, often in partnership or by forming alliances with various social actors, including the state". Additionally Mendell recognizes that "empowerment in any sense that really matters must result in a substantive transfer of resources" (Mendell, 2005, p. 2). In addition to individual empowerment, Laverack & Labonté see

²¹ Rowlands, J.(1997) Questioning empowerment: Working with women in Honduras. Oxford, U.K: Oxfam Publications.

community empowerment as “shifts towards greater equality in the social relations of power (who has resources, authority, legitimacy or influence)” (Laverack & Labonté, 2000, p. 255). In health promotion practice, “(community empowerment) arises as an effect of which health issues are ‘targeted’ for action, how resources are allocated, what strategies are selected and, most importantly, which stakeholders retain or share authority over these decisions” (Laverack & Labonté, 2000, p. 255). Laverack and Labonté suggest however, despite the prominent discourse of “bottom-up” power and control, that health promotion uses “top-down” structures in its programs (Laverack & Labonté, 2000). Claims for power redistribution and empowerment that are made for community-based research, can also be likened to those for health promotion. In other words, the discourse of empowerment does not always match the practice.

Lay knowledge

Lay or local knowledge, is promoted as an essential component of community-based research for its pragmatic value in filling in knowledge gaps, and providing access to populations or contextual features that academic researchers lack and require (Fischer, 2000). However, in some contexts which includes governance of research, lay knowledge may find itself either neglected or in direct competition with scientific and professional or technical knowledge.

Lay knowledge, sometimes referred to as local or cultural knowledge, is knowledge that some researchers seek through collaboration with community members and organizations. As a contributor to understanding health and determinants of health, lay or local knowledge incorporates individuals’ understanding of their own lives, personal or collective theories of causality, and predictions that arise from these theories. Lay knowledge adds to the scientific meanings of health, illness, disability and risk, all of which are necessary for explaining social patterning of health and illness in contemporary society (Popay & Williams, 1996).

Lay knowledge, defined as “the meanings people attach to their experience of places and how this shapes social action” (Popay, Williams, Thomas & Gatrell, 1998, p. 636), is considered by Popay and Williams (1996) to be a legitimate form of knowledge. Lay people constantly and systematically check their experiences against life events so

that lay people “acquire an ‘expert’ body of knowledge” (Popay & Williams, 1996, p. 760). Neglecting lay knowledge therefore comes with a risk of neglecting emerging critical issues and future health problems (Nyden, 2005; Popay & Williams, 1996). The Leeds Declaration’s third principle also acknowledged and asserted the legitimacy and centrality of lay knowledge for public health research: “lay people are experts and experts are lay people” (Nuffield Institute for Health, 1993). Reasons for devaluing lay or local knowledge in decision-making contexts, (and therefore the holders of lay knowledge), are based on holders’ lack of scientific or technical expertise. Objections to lay knowledge also lie within the very ways that knowledge is conceived. Positivism and positivist research, for example, have been unable to integrate lay knowledge because positivism is based on a conception of knowledge as a truth that lies outside the knower (members of society).

To theoretically satisfy and ensure the integration of different types of knowledge to solve social and health problems, in the face of conflicting positions and research traditions, is a challenge for community-based research. McCullum, Pelletier and colleagues’ collected works on food security have looked at aspects of power, knowledge and resources of participants and their distribution in the context of a community-based research project (McCullum, Pelletier, Barr & Wilkins, 2003; McCullum, Pelletier, Barr, Wilkins & Habicht, 2004; Pelletier, McCullum, Kraak & Asher, 2003; Pelletier, Kraak, McCullum, Uusitalo & Rich, 1999; Pelletier, Kraak, McCullum & Uusitalo, 2000). In a paper published in 2004, the authors deconstructed the mechanisms of power that affected food-insecure participants (McCullum et al., 2004). This study was informed by the findings of two Canadian studies, Tarasuk and Reynolds (1999), and Travers (1996).²² Both of these papers showed that despite having taken significant steps to address food insecurity, structural limitations (such as chronic poverty and corporate advertising) prevented food insecure women from becoming self-reliant. McCullum and

²² Tarasuk, V. & Reynolds, R. (1999). A qualitative study of community kitchens as a response to income-related food insecurity. *Canadian Journal of Dietetic Practice and Research*, 60, 11-16. Travers, K. D. (1997). Reducing inequities through participatory research and community empowerment. *Health Education & Behavior*, 24, 344-356.

colleagues determined the management of problem framing, trust, knowledge and consent, as mechanisms of power. These influenced the participation of disenfranchised people in decision-making, agenda-setting and in the shaping of their perceived needs so that ultimately, their views, interests and needs were not served (McCullum et al., 2004). The mechanisms of power were subtle and difficult to discern, yet had important implications for the nature of participation of community members and for the praxis of others such as community developers.

Raising and explaining abstract issues of power and its potential and subtle effects for harm or disempowerment is challenging at the best of times. However, steps to ensure the conditions for equitable distribution or redistribution of power, knowledge and resources, can be taken. These may include the adoption of formalized sets of values statements or principles that are accessible by all participants.

Principles of community-based research

Principles of community-based research are statements of values, defined as “relatively stable cultural propositions about what is deemed to be good or bad by a society” (Values Working Group, 1997), and the assumptions underlying this approach to research. Principles act as guidelines for stakeholders. Several contributors have put forward principles of collaboration in community-based research. The Centers for Disease Control (CDC), referring to any engagement with communities including research, have developed a list of principles of community engagement (Centers for Disease Control and Prevention, 1997). Drawing from an extensive review of the literature, Israel et al. (2003), have identified a list of nine principles or characteristics of community-based participatory research (CBPR) which are summarized below in Box 2 (Israel, Schulz, Parker, Becker, Allen III & Guzman, 2003). Arguing that individual collaborations need to determine their own values, Green and colleagues note that the principles listed by Israel et al. are an ideal set (Green et al. 2003). The Seattle Partners for Healthy Communities, a community collaboration associated with the CDC-funded Urban Research Centers, discussed and adopted community collaboration principles reported in (Eisinger & Senturia, 2001; Sullivan, Chao, Allen, Kone, Pierre-Louis & Krieger, 2002). Translating principles into plain language has been addressed by Browne (Browne, 1995). The majority of these principles of community-based research were

developed in the North American context. Other sets of principles have been developed elsewhere. For example, the U.K.'s National Health Service (NHS) utilizes a set of principles for consumer involvement in NHS research adapted from Boote, Barber and Cooper (2006) (Staley, 2009).

The adoption of participatory principles is important for addressing equity: indeed Rifkin, Muller and Bichmann (1988) argue that “participation cannot be divorced from equity” (p. 931). As a concept or equity principle for tackling social inequalities in health, “seeking the views of marginalized groups and increasing their genuine participation” to increase voice, suggests an important contributor (Whitehead & Dahlgren, 2006, p. 20). Adger claims that “Equity within decision-making processes is as important as equity in outcome in reducing vulnerability”: the influence that vulnerable or marginalized people bring to the deliberation is essential because outcomes match the fairness of the opportunity to participate meaningfully” (Adger, 2006, p. 277).

Baker's discussion of the operationalization of participatory principles in the context of a family violence prevention program suggests that the selection and adoption of a limited number of principles is somewhat problematic. By this, I understand her to mean that principles of community-based research are interconnected, and therefore cannot be operationalized separately. Baker also suggests that some principles come into play at different stages of collaboration, and others are more responsive to specific contexts. Including contexts in considering principles is of importance not only for equity reasons, but to avoid a common tendency to approach all situations in a similar manner as if all problems and their solutions are constructed in the same way (Baker, Homan, Schonhoff & Kreuter, 1999). Cornwall also suggests consideration of local cultural, political and historical contexts and “moving away from the one-size-fits-all best practices paradigm” (Cornwall, 2002, p. 28).

Box 2: A summary of Israel's and colleagues' key principles of community-based participatory research

Community-based participatory research:

Recognizes community as a unit of identify. p. 55

Builds on strengths and resources within the community. p. 55-56

Facilitates a collaborative, equitable partnership in all phases of the research involving an empowering and power-sharing process that attends to social inequalities. p. 56

Promotes co-learning and capacity-building among all partners. p. 56

Integrates and achieves a balance between research and action for the mutual benefit of all partners. p. 56-57

Emphasizes local relevance of public health problems and ecological perspectives that recognize and attend to the multiple determinants of health and disease. p. 57

Involves systems development through a cyclical and iterative process. p. 57

Disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process. p. 57

Involves a long-term process and commitment p 58.

Source: Israel, B. A., Schulz, A. J., Parker, E. A., Becker, A. B., Allen III, A. J., & Guzman, J. R. (2003). Critical Issues in developing and following community-based participatory research principles. In M. Minkler & N. Wallerstein (Eds.), *Community-Based Participatory Research for Health* (pp. 53-76). San Francisco: Jossey-Bass.

Participation and representation in governance of community-based research

Arnstein's seminal work and typology of participation is an important contribution to the literature which continues to offer a basis for analyses of the nature or depth of public participation in decision-making, and the decision-making power that accompanies it (Arnstein, 1969).²³ Arnstein summarizes the central issue of participation and power as follows: although "it is the redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be deliberately included in the future... there is a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process" (Arnstein, 1969, p. 216). Gustafsson and Driver, for example, examined parent participation in Sure Start partnerships (a British program that was aimed at giving support to families with young children living in deprived areas, at the same time as promoting the concept of active citizen). They specifically focused on an analysis of forms or modes of public participation in governance to determine any changes to the distribution of power within a system of multi-level governance. Their adaptation of Arnstein's ladder of participation, determined different modes of participation (co-option, compliance, consultation, cooperation, co-learning and collective action) and described the nature of the relationship of local people (community members) with research and action. For example, collective action meant that local people set the agenda and implemented it without outside involvement such that research and action were carried out *by* local people. Co-option in research and action, at the other end of the continuum, meant that local people were researched and acted on (Gustafsson & Driver, 2005).

Arnstein and others who have used her work as a springboard towards their own studies of participation have made important contributions towards understanding participation in governance. However, the examples that Arnstein uses for her ladder of

²³ Fung (2006) has noted that the Social Science Citation Index listed 491 works which cited Arnstein's piece.

participation have yet to be fully adapted to more contemporary arrangements of citizen participation that include internet based methods, such as social networking and polling. Fung is simultaneously complimentary and critical of Arnstein's work, referring to its obsolescence and advances in theory since her essay was first published. Fung also offers an alternative design to public participation in decision-making, using a formula of dimensions of participation: "who participates (referring to representation), how do they communicate and make decisions (processes), and what is the connection between their conclusions and opinions on one hand and (public policy and) action on the other i.e. what authority a group has to make and carry out decisions" (Fung, 2006, p. 66). Together these dimensions constitute a design space for addressing the three important problems of democratic governance: legitimacy, justice and effective action.

There are diverse opinions on who participates in community-based research. Some participatory processes are open to all who wish to engage, whereas others invite only elite stakeholders (Fung, 2006, p. 66). In a community context, "Who best represents a community (is) a complex problem that defies easy answers" (Koné, Sullivan, Senturia, Chrisman, Ciske & Krieger, 2000, p. 245). Members of communities interviewed for a collaborative research project, the Seattle Partners for Healthy Communities, thought that representatives of formal community-based organizations were more likely to focus on their own agendas rather than representing communities as a whole in community issues. Grassroots activists without institutional membership were also viewed as likely to miss the bigger picture of a community issue (Koné et al., 2000). Brown and colleagues' article on the development of the California Health Interview Survey also reported that representation is an important issue for decision-making (Brown, Holtby, Zahnd & Abbott, 2005). In their study, population groups that were not well-represented on the Technical Advisory Committee on Multicultural issues, had no real opportunity to express their views on sampling of different ethnic groups which led to oversampling in some groups and no sampling in others. Also citing Wallerstein, Brown and colleagues attributed inadequate sampling to lack of representation of different ethnic groups in research design (Brown et al., 2005; Wallerstein & Duran, 2003).

In effect, participatory approaches are designed to move the focus of a change agenda from individual behavioural change to political change. The selection of stakeholders and their power to select issues, frame and evaluate them as they understand them are also an important part of advancing change (Bäckstrand, 2003; Bryson, 1995; Bryson, Cunningham & Lokkesmoe, 2002; Cousins & Whitmore, 1998; Minkler & Hancock, 2003; Springett, 2002). However, if participation is limited and no change results, the experience of community members can be disempowering, or prevent their future participation (Titterton & Smart, 2008). Travers also warns that imposing solutions from an expert or elite perspective amounts to “cultural invasion”. This is in contrast to participatory processes where researchers or health educators might adopt facilitating or advocacy roles rather than controlling a process, and helping to create a space where community members can generate knowledge collectively and collaboratively to effect social change (Titterton & Smart, 2008; Travers, 1997). As certain authors in the participatory development literature have pointed out, in spite of the desirability of participatory approaches and enabling structures, meaningful processes and democratic results are not always features of participation in governance. The participation and representation of vulnerable populations is particularly problematic. In an article that looked at system theories of vulnerability, Adger noted that “vulnerable people and places are often excluded from decision-making and from access to power and resources... Vulnerability ... challenges the design of good governance to promote resilience, to minimize exclusion” (Adger, 2006, p. 276).

Ethics and ethical issues of governance and community-based research

“Ethics is a social product that establishes standards for human actions, power relationships, and certain degrees of freedom for individuals” (Gutierrez 2004 cited in Perez et al., 2009, p. 338). At the basis of all ethical research is an overarching and guiding principle which is fundamental regard for the uniqueness of every human being. Because of this uniqueness each human being deserves or is owed dignity and respect (Canadian Institutes of Health Research et al., 1998; De Koninck, 1995). In the undertaking of human research the cardinal principle is human dignity (Canadian Institutes of Health Research et al., 1998). Koski links governance, defined as the ways that people organize activities “using structures, policies and procedures to obtain desired

results” is based on and builds from ethical principles (Koski, 2009). In a definition of ethics that also appears to transfer readily to governance, Castellano describes ethics as “the rules governing relationships” (Castellano, 2004, p. 100).

In Canada, research governance is undertaken by university research ethics boards (REBs) which use the Tri-Council Policy Statement to guide decisions to ensure ethical principles are pursued, and that human beings are protected from harm that may result from participation in research (Canadian Institutes of Health Research et al., 1998; Canadian Institutes of Health Research et al., 2010). However, research designs that include community-based research, present challenges to internal REBs. Issues of research ethics have traditionally been confined to effects of research on individual research subjects. Community-based research and its underpinning values “challenge(s) us to expand the traditional framework of ethical analysis to include community-level and partnership-oriented considerations” (Shore et al., 2008, p. 1).

Consideration of ethical issues in community-based research, such as protection of research participants, is made on the basis of documentation which researchers are required to complete and submit to REBs. Flicker, Guta and colleagues have shown that institutional REBs do not typically include any ‘room’ in the documentation for consideration of principles which underlie community-based research (Flicker, Travers, Guta, McDonald & Meagher, 2007; Guta, Flicker, Travers, Mason, Wenyeve & O'Campo, 2010). In these respects, the governance of research ethics, its structures, policies and procedures, has direct influence on, and potentially impedes the shape, implementation and eventual outcomes of governance and community-engaged research. REB members’ decisions regarding community-based research may be limited by institution-specific policies and guidelines and other legally-binding agreements with funding agencies; members’ knowledge may be grounded in dominant models of scientific and biomedical research which focus on protection and prevention of harm; they may be unfamiliar with partnership or collaborative community-based or community-engaged research. This may have the effect of REBs’ requiring research design and implementation to fit academic and institutionally based conceptions of research, all of which may serve to undermine principles of equity, power-sharing and acknowledgment and use of different types of knowledge that underlie models of

partnered or collaboratively governed research such as community-based research (Weijer, Goldsand & Emanuel, 1999). Referring to the ethical goals that community consultation is designed to achieve, Dickert and Sugarman propose 4 universal ethical principles (Dickert & Sugarman, 2005). These are: (1) enhanced protection, (2) enhanced benefits (consistent with the duty of beneficence), (3) ethical legitimacy (that refers to opportunities for voice of stakeholders in the face of risks which differs from political legitimacy) and (4) shared responsibility. By shared responsibility Dickert and Sugarman refer to communities themselves taking responsibility for the research, although they add that this also places additional responsibility on investigators, and means that individual consent is still required. However as the authors point out, it remains to be determined what types of studies require community consultation and what types of consultation are needed for particular research projects. The ethics of confidentiality may also limit the “wishes of some participants to have their voices heard” in community-based research (Downie & Cottrell, 2001, p. 11). A recent example of shared responsibility is the community-based recruitment of populations to cancer clinical trials (Education Network to Advance Cancer Clinical Trials (ENACCT) and Community-Campus Partnerships for Health, 2008). These studies are still in their early stages and the impacts of communities participating other than only as research participants in clinical trials, have yet to be evaluated.

Trust

The generation of the ENACCT partnership arose out of a complex environment which was characterized by a lack of trust in medical research (Education Network to Advance Cancer Clinical Trials (ENACCT) and Community-Campus Partnerships for Health, 2008). Trust between collaborators and the communities that they represent, is presented as a critical and necessary quality for the successful development of community-based research collaborations, countering reluctance to participate, scepticism of research, and leading directly to better quality, more relevant research (Mattessich et al., 2004; O'Fallon & Dearry, 2002). Paying attention to trust in community-based research may mean setting the conditions for equal participation. For example, Elias et al. reported that bringing symbols of oppression to the attention of community stakeholders helped to create trust in research collaboration (Elias et al.,

2004). Definitions of trust however are largely taken for granted, and a number of assumptions around the concept of trust are made in the literature. Provan and Kenis noted that trust is not inevitable or immediate. In their case study Provan and colleagues found evidence that trust may actually decline when collaborators become more familiar with each other (Provan et al., 2003), which also suggests that relationships are fluid, not always stable, and trust cannot be viewed as a constant factor (Provan & Kenis, 2008). The governance of community-based research can provide the conditions and processes necessary for the study of controversial issues so that, “Through dialogue and critical reflection, hard issues can receive the benefit of open and frank scrutiny and debate” (Minkler, 2004, p. 688). On the other hand, because community-based research is committed to strengthening community capacity and trust, choosing an issue that already divides community members and which may further divide them, may hold considerable risk (Minkler, 2004).

Models of community-based governance

The literature of the non-profit and voluntary sector offers typologies or models of governance based on different characteristics that are determined or classified by presenting authors. These characteristics may include: the level of participation of board members; the nature of the relationships with the executive director of the organization – as advisors, as quasi-staff members and in other capacities. An example of a typology can be found in Gill (2002). Models of governance in the non-profit sector provide some insights into governance and how collaborations might define success. The Policy Governance model of John Carver, for example, provides for formal codification of a board’s processes, roles, and responsibilities in relation to the work of the organization (Carver, 1990). With regard to effectiveness of governance, the locus is with the Board and how effectively it does the job of governing itself, meaning how it carries out its own work in order to carry out the mission of the organization (Carver, 1990). However, most models of governance in the non-profit sector are non-specific with regard to effectiveness, and measure governance performance on the basis of the organization’s outputs, as appears to be the case for community-based research collaborations. A second problem in general is a lack of codification on governance of community-based research collaborations, although the literature on board governance, for example,

suggests that certain arrangements assist governing bodies (Gill, Flynn & Reissing, 2005).

Examples of models based on levels of participation have been suggested by Gustafsson, and Hatch and colleagues (Gustafsson & Driver, 2005; Hatch, Moss, Saran, Presley-Cantrell & Mallory, 1993). Hatch and colleagues, who are also cited by Richards et al. (2002) have suggested the degree of participation in community-based research as the basis for categorizing four approaches to community-based research, with the fourth (most inclusive) model as featuring the most involvement of community members in design and implementation of research (Richards, Kennedy, Krulewitch, Wingrove, Katz, Wesley, Feinson & Herman, 2002). Chrislip and Larson (1994) emphasise the participation of stakeholders for successful collaboration: "...it must be broadly inclusive of all stakeholders who are affected by or care about the issue" (Chrislip & Larson, 1994 cited in Ansell & Gash, 2008). But even in collaborations where inclusion, particularly of the vulnerable or marginalized is assured, representation and participation are not. The selection of any one of inclusion, participation and representation as a focus is problematic though, as to operate effectively, each must operate in relation with the others. But according to Gray, a solution lies in "including a broad enough spectrum of stakeholders to mirror the problem" (Gray 1989, p. 155 cited in Ansell & Gash, 2008). Suarez-Balcazar, Harper and Lewis (2005) developed a model of community-university collaborations focusing on research, and providing a model designed for practitioners and researchers to work together. In this model, teams were formed for feedback, input and celebration, but the community's participation appeared to be dependent on the researchers' invitation and control. How the partnership teams discussed issues of resources, power, and knowledge were dependent on the researchers' decisions to initiate the discussion (Suarez-Balcazar, Harper & Lewis, 2005).

Potapchuk focuses on collaboration governance at the level of what Canadians refer to as local or municipal government (Potapchuk, 1999). In this context, he sees governance as encompassing three elements. The institutions and mechanisms through which communities make decisions, formal and informal processes used to this end, and the stakeholders who are included in the deliberations. These elements are sometimes covered in discussions of participation, representation and definitions of 'stakeholders' in

community-based research. In the next paragraphs, I look at literature where reference is made to these elements or arrangements of governance of community-based research.

A number of articles emanating from a major project funded by the U.S. Centers for Disease Control, the Seattle, Harlem and Detroit Urban Research Centers (URC), make specific reference to structures and tools of governance of community-based research (Israel et al., 2001; Israel et al., 2006; Lantz et al., 2001; Schulz et al., 2002b; Schulz et al., 2002a). Each research centre had specific missions built around community-based research. The Harlem Community and Academic Partnership's mission, for example, was focused on examining social determinants of health through a community-based participatory research approach (Boutin-Foster et al., 2008), and implementing community-based interventions to improve the health and well-being of urban residents.

For over nine years (1995-2004) the Seattle Partners' Board dealt with governance issues related to decision-making, selection of projects and board composition. The Seattle partnership had several structures other than the Partners' Board including a community advisory board whose members consisted of community residents, activists and health professionals (Eisinger & Senturia, 2001). The authors reported that the process of the community advisory board was not always smooth. However, difficult issues were reported as being openly discussed and usually resolved in a collaborative manner, despite some members' having reported negative experiences with other research projects (Koné, Sullivan, Senturia, Chrisman, Ciske & Krieger, 2000, p. 248). The Detroit Community-Academic URC, worked under the guidance of the URC Board which consisted of representatives from a number of partner organizations and faculty representatives. To conduct its work, the URC board adopted community-based research principles. Its job was "to identify priorities, overseeing the development of new CBR projects". This Board had other structures supporting the projects. Steering committees, for example, developed proposals for new CBPR projects.²⁴ Brown and colleagues reported in detail the participatory planning that led to the design and

²⁴ http://www.detroiturc.org/index.php?option=com_content&view=article&id=5&Itemid=5

development of the ongoing California Health Interview Survey (CHIS) (Brown et al., 2005). As a result of the preparatory work, governance, described as “structure and process”, was developed to include a number of feeder committees and an advisory board which reported to a governing board which was described as the ‘ultimate’ decision-making body. A major public funder took part in the participatory process, which the authors reported “provides latitude for the CHIS (research) team to be responsive to other funders and the broader constituency” (p. 5). Also noted was the differentiation of advisory roles from the work of the CHIS research team which was responsible for obtaining funding and managing the technical task of developing questionnaires, and collecting data (Brown et al., 2005).

Tools or instruments of governance may refer to documentation of the governance of a collaboration. Some articles make reference to collaboration documentation in governance of community-based research. For example, the Harlem Community and Academic Partnership, had a mission statement and Principles of Involvement in Research, Program and Project Activities”; and Operating procedures and by-laws.²⁵ Some tools of governance describe procedures of governance such as Roberts Rules of Order (Robert III & et al., 2000).

The governance of the First Nations Kahnawake Schools Diabetes Prevention Project (KSDPP) in Canada is held up as an exemplar of successful governance in research and intervention management because the arrangements that were developed met the cultural needs and requirements of the community with regard to research. Arrangements of governance were built from community norms and values and included participatory structures, a community advisory board, a supervisory committee to oversee fiscal and administrative accountability, and advisory committees. The project’s main decision-making body was composed of research and investigation staff and investigators. Tools of governance included a Code of Research Ethics (later revised) which outlined the roles, responsibilities and obligations of both the researchers and the community. This prevented conflict and academic-community dissonance and reflected

²⁵ http://depts.washington.edu/ccph/pdf_files/Plen3%20Hands.pdf

community ownership of the research (Cargo, Levesque, Macaulay, McComber, Desrosiers, Delormier, Potvin, 2003; Kahnawake Schools Diabetes Prevention Project, 2007; Macaulay, Commanda, Freeman, Gibson, McCabe, Robbins & Twohig, 1999; Potvin, Cargo, McComber, Delormier & Macaulay, 2003).

External influences on governance of community-based research

Organizations either select models of governance that seem to suit their situations, or models of governance are determined for them. However, governance rarely stands alone, meaning that models of governance are often affected by other levels of governance. Jansen refers to this as the ‘embeddedness’ of governance. Her suggestion is that research governance is subject to decisions made by related governance bodies that are located elsewhere, “governance on one level needs complementary governance on upper and lower levels” (Jansen, 2004, p. 4). These related governance bodies include university governance and research governance bodies.

University governance is underwritten by values attached to the roles or missions of universities. These values which include freedom of inquiry, freedom of speech and criticism, are all needed to ensure academic competence (Husen, 1992). The production of new knowledge, as Husen argues, should proceed unfettered and “neither the state nor the governing board at the university intervenes into affairs regarded as the proper territory for the academics themselves” (Husen, 1992, p. 13). The pursuit and production of knowledge itself is largely regulated, not so much by institutional governance, but by self-regulating or heterarchical disciplines, and the production of knowledge by academics is protected and upheld by their institution’s governance. University (institutional) governance, although concerned with preserving academic freedoms, juggles with a number of interests that have potential to undermine academic freedom. It is therefore likely to be careful, even conservative, with regard to changes in the research system, or to any suggestion of reform of research governance that emanates from outside universities or academic institutions.

Shaw and colleagues define research governance as “the system of administration and supervision through which research is managed, participants and staff are protected, and accountability is assured” (Shaw, Boynton & Greenhalgh, 2005, p. 497). This

definition was developed in the context of the regulation of health and social care research, but despite the definition and other explanation, there still remains some lack of clarity as to how research governance interacts with university governance and academic freedom, and how accountability is transferred to other levels. For example, research governance and research ethics boards, are not part of community-based research collaborations but the guidelines that they are obliged to observe can affect collaborations' choices of arrangements and decisions, and influence the operationalization of research (Downie & Cottrell, 2001). Research governance also ensures that academics are traditional primary decision-makers with regard to community-based research (Caldwell et al., 2001; Jansen, 2007; Shaw et al., 2005; Viswanathan et al., 2004). There is little evidence to suggest that there is any encouragement from research governance and research ethics boards for downstream recipients of funding, such as community-based research collaborations, to pay attention to their own governance.

Other external influences on the governance of community-based research include the governance and management of community organizations which may influence and affect the amount and quality of participation of community members and practitioners in governance of community-based research. Such influences may impact the progress of research collaborations. For example, McDermott, Moote and Danks (2005), found a number of external structures likely to impede the progress of individual collaborations working towards environmental goals. One obstacle was the lack of authority and legitimacy that was accorded to collaborations. Contandriopoulos has also recognized the role of institutions at different levels and the impact of their regulations on participation: "Any form of participation will be mediated through institutions and institutional regulations. It is thus obvious that policy-making regarding public participation should be concerned with institutional arrangements" (Contandriopoulos, 2004, p. 329).

Success and failures of governance of community-based research

What is meant by success in governance of community-based research collaboration? Carver separates the work and performance of the organization and the work and performance of the governing Board, encouraging governing bodies to pay

closer attention to their internal workings, rather than to firm or organization performance, thereby suggesting that governance should be separately assessed from operations. In contrast, Drucker suggests that the dividing lines between governance and operations of a non-profit (voluntary sector) organization are not so clear, and boards should ‘meddle’ in the work of the organization (Drucker, 1990). Drucker does not define success, but links success to an organization’s mission which clearly defines the results that the organization seeks (Drucker, 1990).

Through their synthesis of the literature, Mattessich, Monsey and Murray-Close have identified 20 factors which influence the success of collaboration (Mattessich, Murray-Close & Monsey, 2004). These factors are classified within six groups which are relationship to the environment; membership characteristics, process and structure; communication, purpose, and resources. The six groups of factors can also be applied to research collaborations. Success, which was not defined by the authors, rests on the collaboration accomplishing various tasks towards a number of different goals, such as improving community conditions (Mattessich et al., 2004).

Reardon lists five elements that contribute to success in partnerships. These are: a) both community and campus (university) partners are clear about their self-interests, and benefits gained must be comparable; b) partnerships require significant executive leadership; c) partnerships benefit from skilled “boundary-crossing” staff; and d) successful partnerships need time to develop relationships, referred to by Mattessich and Murray-Close as “appropriate pace of development” (Mattessich et al., 2004). The fifth element is e) a central requirement for campus and community leaders to be reflective, and willingly learn and adjust to challenges and mistakes with which they are presented (Reardon, 2005, p. 10). Gunton and Day reviewed a number of studies in collective planning and drew key performance measures of governance from them. They found that evaluators have identified four key evaluative criteria of performance in collaborative planning processes. These included: 1. success in reaching an agreement; 2. efficiency of the collaborative process relative to alternative processes; 3. satisfaction of stakeholders with the process and the outcome and; 4. achievement of other “social capital” benefits such as improved relationships among stakeholders and enhanced stakeholder skills and knowledge (Gunton & Day, 2003, p. 10).

In a systematic review of the literature with regard to watershed partnerships, and an analysis of factors that accounted for partnership success, Leach, Pelkey and Sabatier noted that because of the importance (and variation) of local circumstances, the success of partnerships could not be determined by “hard formulas”, although directions for success were suggested using clear decision rules (Leach, Pelkey & Sabatier, 2001, p. 383). This approach supports the recommendations of others such as Green et al. (1995) who proposed guidelines in the form of a list of questions to be answered for appraising participatory research proposals using criteria for participatory research. However, Green and colleagues avoided “attaching a single summative scoring procedure ...(leaving) open the choice of classification procedures and weights to the funding agency or project collaborators according to the relative importance they would attach to the various dimensions and to the categories within each criterion or guidelines” (Green et al., 1995, p. 41-42). The approach of leaving decisions with regard to evaluating collaborations to collaborators themselves, is also consistent with thinking that collaborations should also select their own principles of community-based research.

Understanding that successful governance should bear a direct relationship with the implementation or operationalization of research as planned, and measured through summative evaluations, seems like a rational approach. But as Carver argues for non-profit and voluntary sector governance, governance can be separately considered from the work of the collaboration and its work-related outcomes. Assessing governance by itself, has an advantage in that it can potentially allow community-based research collaborations to understand causes of failures, by specifying potential contributors to failure. Types of failures include failures of interventions, failure of the implementation or operationalization of the research, failure of program theory, or the failure of governance itself. In some accounts there is little or no distinction made between project management or implementation or conduct of the research, and distinctive acts of decision-making or governance. For example, Fielden and colleagues’ work on the development of a program management logic model for community-academic partnership research refers to ‘decision-making’ in general. Although decision-making bodies such as a Steering Council were part of the organizational structure, the logic model itself was focussed on program management, and did not include evaluation of

decision-making itself. Non-specified, decision-making that would come under the rubric of governance, is not a separate component of the logic model, therefore does not undergo its own scrutiny (Fielden, Rusch, Masinda, Sands, Frankish & Evoy, 2007). However, addressing this need for separation likely requires a change in culture. There has been little evaluation of the governance of programs such as the Community-University Research Alliances (CURAs) of the Social Sciences and Humanities Research Council of Canada which “supports the creation of community university alliances which, through a process of ongoing collaboration and mutual learning, foster innovative research, training and the creation of new knowledge in areas of importance for the social, cultural or economic development of Canadian communities” or of the governance of the research projects that are CURAs themselves (Barrington Research Group, 2004, p. iii).

Funding agencies and programs in the German research system broadly attributed their failures of quality and productivity in research outputs to the lack of collaboration between disciplines, research organizations and basic and applied research. How an increase in collaboration (networking) should increase quality and productivity, however, was not made clear (Jansen, 2004, p. 7).

During approximately the same period as research was taking place with the Kahnawake Schools Diabetes Prevention Project, which was an example of successful governance in community-based research as noted above, the Canadian Institutes of Health Research Ethics Office in conjunction with its Institute of Aboriginal Peoples’ Health developed guidelines for aboriginal research (Schnarch, 2004). These guidelines for aboriginal peoples’ research were developed in part in response to colonialism, unethical practices in some aboriginal and indigenous peoples’ research, and to ‘helicopter’ research, referring to a process where researchers would fly into communities, conduct research, and leave without providing knowledge of the research to communities (Ethics Office of the Canadian Institutes of Health Research, 2007; Kahnawake Schools Diabetes Prevention Project, 2007; Macaulay et al., 1999; Potvin et al., 2003). The descriptions of governance of the First Nations Kahnawake Schools Diabetes Prevention Project not only demonstrated a recognition of governance as a separate domain from the research work itself, but also the importance of a space for

decision-making in which local contexts and knowledge are incorporated into the conduct of community-based research.

A summation of the literature of governance of community-based research

In a systematic review of community-based participatory research (CBPR) Viswanathan et al. acknowledged supporting factors of their definition of CBPR to be “(1) co-learning and reciprocal transfer of expertise, 2) shared decision-making power and 3) mutual ownership of the processes and products of the research enterprise” (Viswanathan et al., 2004, p. 3). These additions are transferable as principles of CBPR (Israel, Eng, Schulz & Parker, 2005). However, they may also be usefully understood as principles for arranging community-based research governance. Viswanathan et al.’s systematic review is a good example of how governance and arrangements of governance are indirectly referred to but clearly implicated in the collaborative processes of community-based research (Viswanathan et al., 2004). In the community-based research literature for health, with the exceptions of the Kahnawake Schools Diabetes Prevention Project and a handful of other research collaborations such as the Urban Research Centers and the California Health Interview Survey collaboration, ‘governance’ is rarely described or specified. Cargo & Mercer’s review of the literature and development of a conceptual framework for the practice of participatory research focuses on the development and maintenance of partnerships although the review is non-specific with regard to governance (Cargo & Mercer, 2008). Governance of community-based research collaborations remains poorly understood, understudied and underdeveloped (Barrington Research Group, 2004). Evidence, or perhaps more accurately, lack of focused evidence in the published literature, suggests that the arrangements of governance in much health-focused community-based research, form a ‘behind-the-scenes’ set of activities.

Attention to central conceptual issues of concern to governance is evident in the literature. Such issues include power and empowerment, participation and representation, collaboration, ethics and ethical issues. Many of these concepts are implicated in the governance of community-based research, but governance is rarely referred to specifically. Why this is the case is unclear, nor are the reasons why it is the case approached in the literature. From our review there are a number of suggestions that

might be put forward for the paucity of studies and understatement of governance in community-based research. Defining governance, its arrangements and implications in the context of community-based research, has not been required by funding agencies, or required to any great extent in formal research proposals. The short term nature and other limitations of research projects also encourage collaborations to focus on doing research, not on how they are going to approach decision-making.

Other explanations for a lack of attention to governance of community-based research in the research have been offered. In the real world context, some research collaborations' governance may be built on collaborators' understanding and or experiences of governance, and the use of familiar models. Collaborations might appear to make progress in their research work on the basis of trust and common disciplinary backgrounds such as might be found in some basic science collaborations, operating with a minimal or implicit governance that pays little overt attention to explicit governance processes, structures and instruments. Explicit attention to governance for some research groups may be seen as an unnecessary, and a burdensome condition of participation that reduces individual agency and creativity, or that takes up unnecessary time that could be devoted to doing the work of the research collaboration.

There is little evidence to suggest that thinking about governance takes place to any great extent in community-based research. Descriptions of the arrangements of governance, structures and processes of community-based research collaborations are not the focus of articles, or, articles are generally spare in content with regard to governance. However, neglected or overlooked governance may result in the curtailment of purported benefits of community-based research, which include positive development of community capacity, community and individual empowerment and increased civic engagement (Flicker et al., 2007; Green et al., 1995; Viswanathan et al., 2004).

Conclusion

With few exceptions, the spaces where decisions are deliberated and their associated structures, tools and processes are not reported making it difficult to describe and analyze governance of community-based research by way of the literature. However, the literature of community-based research is relatively recent, and supporting theories of

community-based research, such as collaboration theory and governance theory, are also recent and considered to be ‘works in progress’, suggesting that the literature of governance of community-based research has yet to be developed (Smith, Baugh Littlejohns & Roy, 2003). Governance is one of a number of contributors that shape the production of knowledge: improved knowledge and implementation of governance in the context of community-based research may help to produce new knowledge that is relevant for improving population health. Research, description and theorizing of governance in community-based research are required.

[Link to the first research paper](#)

The first paper focuses on uncovering and describing the observable arrangements or rules that community-based research collaborations make and use to govern. What are the arrangements of governance of community-based research collaborations, and how are they used in governing community-based research? Through findings from a set of interviews with community and university members of community-based research collaborations in Canada, the paper describes observable structures of governance of community-based research, and suggests further inquiry and theoretical approaches.

CHAPTER 4. ARRANGEMENTS OF GOVERNANCE OF COMMUNITY-BASED RESEARCH COLLABORATIONS: IDENTIFICATION AND EXPERIENCES

Abstract

A central component of governance is the “formal arrangements (rules) that exist to structure decision-making” (Chhotray & Stoker, 2009). Community-based research is becoming an important means of conducting social and health-related research, and often governed collaboratively by community and university members. However, descriptions of arrangements for decision-making are scant. What arrangements are used for governing community-based research collaborations, and what are collaborators’ experiences of them? To answer these questions, qualitative description was used to draw evidence from 54 interviews conducted with members of community-based research collaborations in Canada. Three forms of arrangements were determined. These were organizing structures such as committees and membership; documentation which included required documentation for research applications and documents that collaborations generated for their own use; and meetings which were locations and spaces for decision-making. Respondents’ assessments of success and failures of collaborations pointed to important roles for governance. When arrangements of governance were clear, collaboration members had useful structures, tools and processes for decision-making, helping them to realize the value of collaboration. Where discussions and utilization of governance arrangements in community-based research collaborations were perfunctory or absent, collaborations were built on soft ground and experienced collaboration failure. Suggestions for future directions of inquiry and theoretical development of collaboration governance in community-based research on the basis of the findings are proposed. Attention to governance in the context of community-based research can help to turn the benefits of research into benefits for the community.

Introduction

Governance has been defined as “the rules of collective decision-making in settings where there are a plurality of actors or organizations and where no formal control system can dictate the terms of the relationship between these actors and organizations” (Chhotray & Stoker, 2009, p. 3). In the broader context, governance is a response to a recognition that traditional forms of decision-making had become inadequate to address complex problems presented by significant social and global changes (Chhotray & Stoker, 2009).

Community-based research (CBR) emerged in the second half of the 20th century as “a collaborative approach to research that engages partners from a community - geographic or otherwise defined - in all phases of the research process, with a shared goal of producing knowledge that will be translated into action or positive change for the community” (Lantz, Israel, Schulz & Reyes, 2006, p. 239). Community-based research is undertaken through collaboration of community members and academic researchers who each bring different skills, knowledge and resources to governance and research. Offering an alternative approach to traditional researcher-controlled research, this approach to research means that community members can share control and represent their own interests.

The study of governance and descriptions of arrangements for making decisions in the context of community-based research, despite critiques related to distribution of control and power in governance and community-based research, are scant in the literature (Cornwall & Jewkes, 1995; Strand, Marullo, Cutforth, Stoecker & Donohue, 2003). Arrangements of governance have implications for facilitating the missions of community-based research collaborations, but are somewhat of an unknown.

In order to gain some understanding of these arrangements of governance and their uses in the specific context of governance of community-based research, a research study was designed to provide answers to the questions: What arrangements are used for governing community-based research collaborations, and what are collaborators’ experiences of them? The article describing this study and its findings is organized as follows. First, the article looks at the literature of governance, collaboration, and

community-based research. The study's methods are described. After setting a typical context for collaborators commencing a publicly funded research project in Canada, the paper continues with a description and the qualitative findings of semi-structured interviews conducted with community and university members of community-based research collaborations looking into community health and social problems in Canada. The paper continues with a discussion of findings and recommendations for further research, and in conclusion, revisits the role of governance.

Some terms that are used in this paper require clarification. Although in the literature, the terms collaboration and partnership are often used interchangeably, the term 'collaboration' is used here to refer to a group of people organized to form the research collective, and the collective process that forms the basis of community-based research in keeping with dictionary definitions. 'Partnership' often has contractual or commercial connotations (Ansell & Gash, 2008). 'Decision-making' is used in day-to-day language and interchangeably with governance in the literature. However, the term 'governance' is preferred in this paper because it focuses attention on those arrangements specifically associated with governance, which are different from decisions made in carrying out the day-to-day operations of community-based research, referred to in some settings as research coordination or project management activities.

On a final note of clarification, research governance, which refers to macro-level upstream regulatory structures that govern research and research ethics, such as the Canadian Institutes for Health Research and the Canadian Tri-Council Policy Statement, is not a focus of this study (Canadian Institutes of Health Research et al., 1998; Canadian Institutes of Health Research et al., 2010; Dixon-Woods & Ashcroft, 2008; Jansen, 2004; Jansen, 2007; Shaw, Boynton & Greenhalgh, 2005). This is not to say that research governance does not influence or impact what takes place downstream at the community project level, but rather that this is outside the scope of this paper.

Governance, collaboration, and community-based research

In addition to the definition offered at the beginning of the paper, 'governance', has been defined as "a process whereby societies or organizations make their important decisions, determine whom they involve in the process and how they render account" (Graham et al., 2003, p.1). Governance can have the effect of dispersing power so that

leaders do not have sole control or direction of the organization (Paquet, 1999).

Although the literature of governance predominantly refers to the governance of states and other levels of government, markets and corporate governance, networks, and notions of ‘good’ governance in assessing performance (Bovaird & Löffler, 2002; Dodgson, Lee & Drager, 2002; Edgar, Marshall & Bassett, 2006; Folke, Hahn, Olsson, & Norberg, 2005; Hubbard & Paquet, 2007; Kaufmann & Kraay, 2006; Moro, 2001; Pierre, 2000; Rhodes, 1996; Stoker, 1998), ‘governance’ is also understood as a versatile concept and not solely confined to these contexts (Bardach, 2001; Imperial, 2005; Ostrom, 1990).

Gray and Wood describe ‘collaboration’ as “a process through which parties who see different aspects of a problem can constructively explore their differences and search for solutions that go beyond their own limited vision of what is possible” (Gray, 1989, p. 11). In a revised definition, the same authors define collaboration as a phenomenon that takes place “when a group of autonomous stakeholders of a problem domain engage in an interactive process, using shared rules, norms, and structures, to act or decide on issues related to the domain” (Wood & Gray, 1991, p. 146). The emphasis around ‘problem domain’, and related ‘action’ and ‘decision’, according to Labonté, differentiates collaboration from consultation in which organizations have already defined both the issue and often what the desired outcome would be (Labonté, 2005). By working together, collaboration members share responsibilities and rewards, as well as risks (Himmelman, 2009), and achieve results that individual organizations could not achieve by themselves (Friend, 1993). Understanding and problem-solving is enhanced through “complementarity” (Schrage, 1990), and “collaborative advantage” (Huxham, 1993; Vangen & Huxham, 2003). However, the literature of collaboration is by no means integrated. It has been characterized as “untidy” and reflecting “the way it has bubbled up from many local experiments” (Ansell & Gash, 2008, p. 544).

The literature of community-based research could also be characterized as ‘untidy’, in a similar manner to the literature of collaboration. This untidiness manifests itself in a number of ways. Community-based research is rarely understood as a specific research method, but rather as an approach or an orientation to research (Minkler & Wallerstein, 2008). The term ‘community-based research’ also acts as an umbrella to incorporate a range of research methods that include, for example, community-based

participatory research, action research, appreciative inquiry and experiential research, amongst others (Minkler & Wallerstein, 2008). Community-based research is conducted with a community “geographic or otherwise defined”, according to Lantz’s definition (Lantz et al., 2006, p. 239). The definition of ‘community’, however, is often subject to debate and contestation, needing clarification not just in the academic literature but also by collaboration members and individual projects (Labonté, 2005; Minkler & Wallerstein, 2003; North American Primary Care Research Group, 2007; Viswanathan, Ammerman, Eng, Gartlehner, Lohr, Griffith et al., 2004; Gaventa, 2004 ; Chanan, 2003; Eisinger, 2001). Definitions and research approaches of community-based research however, do have in common a focus on collaboration, collaborative processes and collaborative approaches. In the context of community-based research, collaboration means that research is conducted with academic researchers, community members and other stakeholders (Green et al., 1995b; Israel et al., 1998; Lantz et al., 2006; Viswanathan et al., 2004). Regardless of the different definitions, disputes and discussions, the claimed advantages of community-based research as a collaborative form and approach to research, include many which are not typically associated with traditional research methods. Israel et al. have recorded a number of advantages amongst which is listed, “Enhanc(ing) the relevance, usefulness, and use of the research data by all partners involved” (Israel et al., 1998, p.180).

Issues of governance of community-based research have been identified in the literature of international participatory development research, sometimes referred to as the ‘Southern’ tradition of community-based research (Hall, 1992; Tandon, 1989; Vernooy, 1997). This literature suggests that arrangements made for governance will have positive or negative effects on access to governance space and structures, and the degree of participation of members, as well as the authenticity of the research and its utilization (Cooke & Kothari, 2001). Other authors coming out of the ‘Northern’ or developed world tradition in community-based research, have investigated some aspects of governance. These include community ownership and decision-making (Cargo et al., 2003), participatory principles and participatory mechanisms (Krieger et al., 2002), partnership development (Metzler et al., 2003; Eisinger & Senturia, 2001), power (Barnett, 1993; Boser, 2006; Hall, 1981; Mason & Boutilier, 1996; McCullum, Pelletier,

Barr & Wilkins, 2003; McCullum, Pelletier, Barr, Wilkins & Habicht, 2004), participation (Chung & Lounsbury, 2006; Cornwall, 2002; Gastil, 1993; Lasker & Weiss, 2003; Macaulay, Commanda, Freeman, Gibson, McCabe, Robbins & Twohig, 1999; Reutter, Stewart, Raine, Williamson, Letourneau & McFall, 2005; Wallerstein & Duran, 2006), and empowerment (Fawcett, Paine-Andrews, Francisco, Schultz, Richter, Lewis, et al., 1995; Fetterman & Wandersman, 2004; Fetterman, 1996; Florin & Wandersman, 1990; Labonté, 1990; Luttrell, Quiroz & Scrutton, 2007; Ristock & Pennell, 1996; Titterton & Smart, 2008). There are principles, frameworks and guidelines for doing ‘ethical’ community-based research: all of these are useful for preparing the ground for sharing values, perspectives, knowledge and understandings (Baker, Homan, Schonhoff & Kreuter, 1999; Connors & Seifer, 2000; Eisinger & Senturia, 2001; Israel, Schulz, Parker, Becker, Allen III & Guzman, 2003; Ruttan, 2004). They may be implicitly or explicitly included in arrangements of governance of community-based research.

Method

In order to describe people’s knowledge of arrangements of governance of community-based research and their experiences of these arrangements, I designed a qualitative study in which data were collected directly from participants through interviews (Miles & Huberman, 1994). Specifically, I used qualitative description which is a low-inference approach to qualitative research and data analysis that allows data to be presented descriptively, while providing a basis for subsequent theoretical development (Sandelowski, 2000).

Sampling and recruitment

Participants were members of community-based research collaborations that included both community and university members. All participants self-identified as being involved in community-based research. Research topics in collaborations were varied, but most were related to social determinants of health research including food insecurity, housing and homelessness and other studies whose focus was on the health and social problems of particular communities including youth, women and aboriginal peoples (Marmot, 2007; World Health Organization, 2004).

Potential participants were recruited through announcements of the study via list serves on the Internet, networks which the author had access to, and personal contacts. Potential participants were invited to contact the researcher if they were interested in participating in an interview. Potential participants either self-referred in response to the general announcement, or agreed to participate in reply to an invitation sent by email. Some authors with publications on community-based research in the peer-reviewed literature were contacted by email. No physical locations were used for recruitment.

The number of participants to be recruited for interviews was initially guided by the literature on data saturation (Charmaz, 2006; Guest, Bunce & Johnson, 2006; Morse, 1995). Data saturation is a concept that suggests that little or no new data will be acquired after a number of respondents have been interviewed (Guest et al., 2006; Morse, 1995). One indication of this is that coding no longer creates new categories. The decision to discontinue recruitment in this study was also based on the attainment of a sample which ensured approximate equal representation of community and academic collaboration members, helping to avoid weighting data in favour of one group over another.

Implementation

I conducted 55 semi-structured interviews. The majority of the interviews were conducted over the telephone. Some interviews took place in person. The word ‘governance’ was used in the recruitment email and in the interview to orient potential participants to the topic of the interview. The introduction to the interview was designed to elicit recollection of a participant’s experience of a community-based research collaboration (“thinking about one of the community-based research collaborations that you were involved with...”), and to encourage discussion. Questions (which can be found in the Appendix) were designed to provide descriptions of arrangements, rules or ‘forms’, such as board and committee structures and documentation, and experiences of collaboration including challenges and facilitators of governance (what was helpful and what was not, and what would you do differently?). Interviews were conducted using a conversational style. Probes were used to clarify respondents’ answers or to pursue lines of questioning when new issues were raised.

Analysis

Completed interviews were transcribed from digital recordings. As the transcriptions were received, they were reviewed for accuracy, and interviews were coded and analyzed. The analysis for this article used the data to develop “descriptive summaries of interview (or observation) data” to build a qualitative description of the arrangements of governance and respondents’ experiences of them (Sandelowski, 2000, p. 336).

Ethics

Research design and methods were reviewed and approved by the University of Ottawa Research Ethics Board. Potential participants were given information in writing about the purpose of the study, the issues that were to be covered in the interview, how they might expect the interview to proceed, any associated risks of participation, and their rights in participating or not participating in the interview. A summary of potential participants’ rights was reiterated prior to the interview at which point informed consent and permission to digitally record the interview was obtained or confirmed.

As the interviews were conducted in confidence, description of the sample of respondents is limited. Quotes have also been edited in order to remove any identifiers of respondents, research collaborations and their locations to maintain anonymity and for ease of reading.

Results

Fifty-five interviews were conducted. One interview was excluded from analysis because the participant did not have personal direct experience of community-based research collaboration. Twenty-six participants were community members located in Canada and 28 were faculty members of Canadian universities, for a total of 54 interviews. All respondents self-identified as members of community-based research collaborations. Almost all interviews were conducted over a period of several months from October 2008 to May 2009. Two interviews were conducted after this date.

Setting the context for the findings

In Canada, researchers may apply for funds to conduct research through competitive, peer-reviewed processes set up by the major public research funding

agencies (Social Sciences and Humanities Research Council (of Canada) or SSHRC, Canadian Institutes of Health Research (CIHR) and the Natural Sciences and Engineering Research Council of Canada (NSERC), provincial and federal government ministries, and private foundations or charitable or non-profit organizations (for example, Canadian Heart and Stroke Foundation, Canadian Diabetes Association, McConnell Family Foundation). Other funding sources which are available to academic researchers and new investigators include internal university sources. Additionally, individuals and community-based organizations may self-fund research, or be awarded funds to conduct research and evaluation by institutions such as local governments.

Although some public research competitions are regularly offered such as CIHR's open operating grants, some other procedures for public research competitions may start with a notification and a request or call for proposals from the funding body, which are oftentimes transmitted to researchers through university channels. Interested parties make a decision to apply for funds. Some research funding agencies' competitions use a letter of registration or a letter of intent (LOI) as a first step in a process to inform the agency of a researcher's and/or collaboration's intention to develop a full research proposal and apply for a grant. An LOI includes some content of the proposed research, and may require some information on governance structure and procedures: for example in SSHRC's Community University Research Alliances (CURAs), governance is a criterion for evaluation of the LOI.²⁶ Approval of an LOI by a funding agency results in an award of funding for researchers to develop a full proposal.

Full proposals require details of the research problem and associated literatures, methods, budgets, and participants' qualifications and contributions. Applicants may be required to demonstrate the expected contributions and roles of collaborators. In the case of health research involving aboriginal people, detailed reflection and documentation on governance is required (Ethics Office of the Canadian Institutes of Health Research, 2007). The SSHRC CURAs, which are designed to enable collaboration and non-

²⁶ http://www.sshrc.ca/site/apply-demande/program_descriptions-descriptions_de_programmes/cura-aruc-eng.aspx

academic involvement in research, also require that participants define “the participatory arrangements under which individual researchers and research teams will carry out those (research) activities”²⁷. However, the level of detail or thinking about governance arrangements, and the level of accountability invested in such arrangements is not specified further.

Putting together a research proposal for funding may be a complex and long process requiring coordination. Coordination may or may not be funded depending on the availability of funding after the completion of a Letter of Intent. The decision to apply for research funds, in many cases, formally marks the beginning of a community-university research collaboration.

Findings

Respondents described three types of arrangements. These were 1) structures such as committees and membership, 2) documentation which included formal requirements for research proposals such as letters of intent, and documentation that was internal to the collaboration such as memoranda of agreement or understanding, and 3) meetings which were formally arranged for the purpose of decision-making and knowledge transfer. Respondents also reported on how the different arrangements of governance contributed to success or failure of the community-based research collaboration.

1. Structures of governance

Governance bodies

When research proposals were funded, the convening members typically formed the main governing body of the collaboration, whose function was broadly to steer the project. These bodies were called by different names such as committees, working committees, project steering committees, steering groups, teams and task groups. They were responsible for giving research advice and making decisions. A respondent in one

²⁷ <http://www.sshrc-crsh.gc.ca/funding-financement/programs-programmes/cura-aruc-eng.aspx>

collaboration, described the main body and its associated decisions: “the steering group (which) dealt with most of the executive decisions, most of the implementation related decisions and sometimes even some of the more philosophical decisions as well”.

Some research collaborations had more than one level of governance. In one multi-site study, principal investigators and other collaborators formed a primary or core group, which gave overall direction to local groups. These local groups would autonomously take care of local arrangements. Other formats of governance included university researchers collaborating with existing bodies or coalitions of organizations, or sub-groups of coalitions. Working with existing bodies was an advantageous arrangement for establishing a research collaboration, and transferring and utilizing new knowledge as this university member pointed out: “we link to existing groups to take advantage (of the coalition’s) history, some maturity in the community and familiarity and credibility. Some of the (member) organizations would have been users of research information as well”. Other groups had advisory committees or reference groups that provided advice or local content on request by the ‘main’ steering committee. In one research collaboration a research team was responsible for determining the structures and procedures of governance but “the project also had a reference group that had multiple different stakeholders, including other academics and community and people with lived experience and family members as well”.

Other than to ensure that the research was carried out, few respondents remarked on the purposes of governance of the community-university research collaboration. One community member linked the purpose of governance with underlying values of democracy: “the structures that exist are not there simply to create irritation, and bureaucratize what you do... they maintain and preserve a continuous form of democracy ... or checks and balances and validating the work ...if anything goes wrong we’re all aware and it’s a collective responsibility”.

Membership

Membership of the governance bodies described above included academics, community members or members of the public, workers and professionals, people who were members of populations being researched who were also referred to as people with

lived experience, and project coordination team members. Community collaboration members included members of local geographic communities such as residents. Other collaborations included youth and members with lived experience including people who were homeless, poor or food insecure. Members of collaborations were referred to as representing either the community ‘side’ or the university ‘side’. This division had the result that everyone who was not from the university, including those from the public sector, was referred to as a ‘community’ member. Community members who participated in governance were typically invited on the basis of their putative roles as representatives of a constituency of stakeholders or because they represented a researched group. They were also seen to act as a ‘voice’ for a community, because of their contextual knowledge gained through lived experience. However, even though representation was seen as important, being a representative did not ensure participation. In one collaboration, lack of communication from academic partners suggested to community members that their inclusion was tokenistic, such that this community respondent said, “(the university members) should... maintain communications with their key community informants so that they don’t start to feel that they’re just sitting on the sidelines waiting to be pulled in for a dog and pony show”. In addition to examples of tokenism, some community members were reported to have had difficulties in participation. Formal bodies, as this respondent said, “frighten people and they cause people not to quit always, but to sit on their hands a lot and wait for the ones they figure are a little more outspoken or a little more knowledgeable”.

Community members indicated that despite their willingness to participate in governance of community-based research, they were often compromised in their ability to participate fully. A major factor which impacted participation adversely was the “busy-ness (sic)” of community members and their commitments to paid work. This community respondent, for example, recognized his participation in research collaboration governance as superficial and constrained by other responsibilities: “I may sign on as a co-participant...but ...whatever I’m going to do is going to be on the run”. “Busy-ness” was used globally as an excuse for community members’ absence from meetings, and as a reason for limiting the number of meetings that community members

would have to attend. Community member “busy-ness” and responses to “busy-ness” appeared to diminish representation and therefore participation in some collaborations.

2. Documentation of governance

Documentation for the collaborations’ governance included letters of intent, research proposals, letters of agreement and memorandums (memoranda) of understanding (MOU). Documentation was used to keep records, provide information, provide clarity, and serve as a historical account of the collaboration. Documentation was also recognized for its importance and usefulness for evaluation purposes.

Letter of intent

Experiences of developing an LOI, which is a necessary process for academics for some competitions, were rarely reported by community respondents. However, those that referred to letters of intent, spoke positively of them. Preparing for an LOI marked the initial formal activity of the collaboration, with the LOI as the first formal document. The two stage structure of the LOI and the development of a full proposal helped to solidify relationships and provided “a great structure especially for large projects” as one respondent described it, with the ability to move a relationship based on a probability, to one that was based on firm grounds. An LOI gave some researchers reason to spend time up front with potential collaborators, developing and explaining the research projects and sometimes formalizing governance agreements.

Research Proposal

Collaboration members had different experiences and perspectives on the process of developing a research proposal. For university members, proposal development was a very important process for those who were principal investigators, because research proposals that result in external funding are used as an institutional means of assessing and recognizing individuals’ work performance. For some academic respondents, status as a co-investigator did not guarantee participation in proposal development. Some community participants reported that they were “consulted” on the proposal, and were able to make “some suggestions”, and to make the proposal “a little bit more palatable to people at a community level”, suggesting challenges in writing proposals for different

audiences. One community participant reported relinquishing any participation in proposal writing. A member of a community organization reported providing a letter in support of the research proposal for a study in which members “were to be collaborative partners”, yet never saw the content of the proposal. For most community respondents, research proposal development was not a significant process, nor the proposal a significant document for them. Any participation in its development or the support they gave to it was often a recollection in passing.

In the case of some collaborations whose members had sustained long-term relationships, members spent months and sometimes years discussing projects and associated issues before writing a proposal. This preparatory time allowed discussion, including ways to resolve potential problematic issues. Structures and processes for governing were therefore established well before collaborations received approval and funding for the research project. As one respondent explained: “The advantage of going slow was actually enormous because it allowed us to develop relationships and think about what we wanted to do... we said ‘what do we think is important to do and how can we work together to do it?’ After they do get the money to do the research they’re no longer issues ‘cause they’ve already hammered them out at the table – a lot you can’t anticipate. But you can outline a process”.

For a number of community participants, the lengthy time from a submission of an LOI, preparation and full proposal submission to the final receipt of a funder’s decision, resulted in a loss of interest, and sometimes a withdrawal from a community-based research project.

Memorandum of understanding and letter of agreement

A memorandum of understanding (MOU), or letter of agreement, was the most important collaboration document of governance. Generated by collaboration members for internal collaboration use, they were used as a type of contract to describe the parameters of roles, involvements, and responsibilities of parties and organizations with regard to the collaboration’s governance and work plans. Some of these documents included clauses outlining financial arrangements and transfer of resources, ownership of intellectual property and data, and expectations of collaborators.

Much of the value of a letter of agreement or MOU lay in the collaborators' discussion and clarification of values, roles and responsibilities. For example, this respondent thought "A letter of agreement at least sets out expectations. Often people run into trouble because expectations are unclear and people expect different things and that needs to be sorted out". Another respondent identified that "(we) agreed on principles and a contract that we all signed. We had found that those kinds of structures, the contracts and principles are really helpful, especially when things don't go according to what was planned".

3. Meetings of community-based research collaborations

Meetings were arranged for the purpose of decision-making and knowledge transfer. They denoted the location or space for governance activities of research collaborations. The content of meetings related directly to governance matters including decision-making in general, values clarification, visioning and planning; communicating, learning and exchanging information with regard to the planned research. This respondent described the content of one of these meetings as a space for the expression of members' values, principles and goals in relation to the research study: "we actually spent most of the meeting talking about what we wanted, what our vision was for, what we wanted to accomplish and then we spent a lot of time discussing what kind of research we thought was needed".

Some collaborations met by teleconference when in-person meetings were not possible. Where in-person meetings were possible, the location of the meeting was felt to be critical in sending a message to community members that the academics were not 'all-powerful' as this university respondent identified: "having meetings at the community agency, you don't always have them at the university. . . Those little things are symbolic". Meetings also provided opportunities for the development of interpersonal and inter-organizational relationships as this respondent noted: "we took time to develop relationships and find common understandings and to set goals that we thought were shared".

When meetings were not arranged and information about the study was not transferred, some community members lost interest. An example was given by a

community respondent: “we haven’t had any calls or meetings for quite some time. Somebody I recruited said that nobody called her and it had been months and months. So she decided that she had other things to commit herself to”. In another collaboration, the respondent thought that regular meetings might have been a solution to a collaboration problem but also pondered whether “people would have had the time for meetings”. In some collaborations, meetings were rarely called, if at all.

Identification and experiences of collaboration success and failure

Respondents identified and assessed collaboration success in different ways. Some assessments were related to the use of arrangements of governance, and others were dependent on the particular perspectives and values of community or university members. Others used the combined outputs and outcomes of community-based research projects as a way of assessing success.

Clarity in process, integrity of roles, and satisfaction with the final product were important to this community respondent: “people having a fair understanding about what the roles are and that those roles are honoured and that people feel good walking away from the end product”. Definitions of success were also based on understanding differences in values. One community respondent thought the marker of success was directly connected to research goals, but suggested that both university and community collaboration members needed to be satisfied “...creating new knowledge and understanding that was acknowledged on both sides”. Another participant made distinctions between research success and success for the community, implying differences in success for academics and community members. Research success meant: “meeting the expectations of your funder (for university members)...But is this the checklist of where community is going to be satisfied?” Another community respondent thought that success was related to the different reward systems of community and university members at the individual level and at the organizational level: “I wasn’t looking for tenure...I was looking for social action. There’s a totally different structure of what research success means and you have to be willing to say these are the points at which we consider this a community success and these are the points at which it’s a research success and these are the points at which the whole project has elements of success”. A third means of assessing success, was related to the outputs and outcomes of

community-based research. However, these types of assessment evaluated community-based research rather than assessing governance of the collaboration.

Failures, in the sense of collaboration collapse, were reported by some respondents. Community and university members did not anticipate, plan for or expect failures of research collaboration. Community respondents thought in retrospect that clarity around structures of governance might have prevented or mitigated them. For example, this respondent said, “some of it just unfolded as we moved along and I think it would have been really useful at the beginning to have all of that (clarity)”. In the absence of clear guidelines with regard to roles and responsibilities, one community participant felt that a structure would have helped, “my instinct was to create an advisory committee”.

In one collaboration, a community respondent reported there was a provision in the research proposal for the creation of a community advisory committee that would be consulted on a regular basis but “that never happened”. In one instance, disagreement “divided the community markedly and those wounds and scars are still in our community so it’s not a pleasant thing. There were lots of efforts to mend the fences, to try and make things work all to no avail”. Other respondents who registered concerns or worries about their research collaboration felt that some sort of formal venue or agreement was needed to address them: “it wasn’t totally clear from the beginning, there wasn’t a lot shared and that should have been a bit of a red flag. But it seemed to be a great thing and we sort of went along with it...once we got to that point (of concern) we realized that really we needed to have something more formal and have some kind of agreement”.

Other examples of failure related to breaches of agreement. A community member was concerned about an agreement that had been made with regard to publications: “it was the student’s work and my own. (Our authorship) was an agreement that was made at the beginning in terms of the publishing of findings. (The academic supervisor) was using a position of power to publish the findings, but was that agreement written down? No”. The effects of such breaches of agreement on individual community members were upsetting and disappointing. In some instances, breaches of agreement led members to either refuse to consider any future collaboration, or at least to consider their involvement gingerly. One respondent’s response was to anticipate failure

and develop organizational back-up plans to address its possibility. Others felt that developing written agreements with academic partners could mitigate risk.

University members also identified related concerns. Some thought that “...some of the problems encountered in this research would have been (better) if the outcomes of the project and what everyone's expectations of the project were had been spelled out more carefully”. From university members’ perspectives, failures associated with collaboration governance were mostly confined to complaints about community members’ absence from meetings, and their limited participation in governance. Lack of participation was often explained away by “busy-ness” as noted earlier, or simply as a lack of interest in the research project. The absence of some community members did not appear to negatively affect university members from continuing with research. How to address the experience of collaboration failure or potential for failure, was sometimes discussed between members. One community respondent and community colleagues wondered if the funding body was an avenue for bringing up complaints or concerns: “We had discussed whether we should take it to that level and in the end we decided against that”. Another community participant thought that funding bodies naturally favoured universities which therefore did not place them (universities or funders) in a position to act as neutral arbiters in disagreements: “who is the advocate on the community side? ...all the biases are working for the academic...so academics have a whole green light on a whole series of accountabilities”.

Universities have structures and procedures in place which human research participants can access to raise research concerns and problems. However research offices and institutional ethics boards and committees that address ethical concerns for research participants, were not seen as serving a similar purpose for community research collaborators: “there was no support from the administration at the university (to address the problem)”. Community participants thought that universities could go further to develop relationships with communities “If they really cared about community relationships they would set up something to support those activities”.

University members proposed structures and procedures of governance to prevent possible failures and improve coordination: “Dispute is normal. There are going to be tensions. There are going to be problems. So let’s build in a number of procedures and

understandings from the beginning... permanent coordination structures within universities to interface between community and university and solve problems”. However, some university members were reluctant to consider formal structures within universities which could aid collaboration, fearing their potential to interfere or restrict academic autonomy and research creativity. Formal structures themselves were also negatively viewed as barriers which restricted participation and representation particularly of members of marginalized and vulnerable populations. Making reference to a standard ‘formal’ governance tool, this participant said, “We don’t do Roberts’ Rules of Order. We don’t motion and second and that kind of thing. It just doesn’t fit with the relationship or with our partnership”.

Discussion

For community-based research collaborations, observable arrangements of governance provided the bricks and mortar for a governance framework and forms for organizing collaboration members whilst providing for different configurations. For some research collaborations, small committees, however named, made the majority of decisions. In others, layers of structures or single larger bodies, which were set up specifically for the purpose or already existing, were composed to ensure stakeholder involvement at the appropriate level and location. Membership of these structures was designed to ensure that stakeholders important for the purposes of the research were represented, giving legitimacy to the research collaboration. Externally required formal documents associated with the research application marked the initiation of formal research collaboration activities. Collaboration-specific documentation, such as memoranda of understanding, served to record members’ agreements about assorted issues such as the distribution of responsibilities and resource allocation. Meetings provided the space for the work of governance which included discussions of values, knowledge exchange, and decision-making with regard to research direction.

Arrangements of governance were implicated directly or indirectly as contributors to governance success and failures, regardless of how respondents assessed success. Active use of governance structures, documents and meetings enabled members to come to agreement. Where failures were experienced, governance structures were viewed as

neither accessible nor functioning for collaboration members, including keeping stakeholders from access to any governance, or by failing to use governance arrangements for responding to collaboration problems. Neither were there structures external to the collaboration that respondents felt they could approach to help resolve the collaboration's governance problems. Collaboration failures did not affect all parties equally. Community members reported that governance failures did not appear to prevent academics from fulfilling their academic responsibilities such as reporting and publishing research findings. So although collaborations may have failed, from some perspectives research outputs could still be assessed as successful.

Evidence of success and failures in respondents' collaborations, have pointed to important roles for structures, tools and meetings determined as arrangements of governance in this study. However, it is not the structures, tools and meetings per se that are important, but what was accomplished through, by and with them. In whatever way community and university members assessed success, when arrangements of governance were palpable, collaboration members had useful structures, tools and processes for decision-making, helping them to realize the value of collaboration in the context of community-based research. Where discussions and utilization of governance arrangements in community-based research collaborations were perfunctory or even absent, collaborations lacked foundations, and experienced collaboration failure. Omission of governance and the opportunities it provided for discussion and deliberation also were demonstrations of lost opportunities for developing understanding and commitments to the approach and values orientation which is exemplified in community-based research. Collaboration failures were also governance failures. Failures generated by omitted governance of community-based research, might now be added to the failures of commissioned governance reported in the broader literature of governance.

Further research

Bringing together community members and researchers who are drawn from different disciplinary, professional, technical and experiential backgrounds, and who have different values, goals, and reward systems, raises a range of challenges for governance of community-based research, and poses both practical and theoretical questions for

further research. Further study of the value which is theoretically added through collaboration in the context of community-based research, would be helpful for governance studies in general, and an addition to collaboration theory. How community and university members of research collaborations gain awareness of the salience of internal arrangements and how these impact knowledge production requires critical capacity and further research and development. Understanding how collaboration governance in community-based research itself may be shaped or influenced by external structures such as institutional research ethics boards, charitable foundations, funding agencies, and government policies, also needs further study.

Conclusion

The arrangements of governance described in this paper provided community-based research collaborations with organized approaches, documentation and venues for governing, setting the conditions for directing and authoritatively overseeing research projects. These arrangements were structural means to develop and maintain collaboration functioning. In some collaborations, little or no participation in governance, led to the experience of failure. The increased acceptance and growing use of community-based research reveal a widespread desire to improve social and community health through collective forms of knowledge production. When governance is made clear and utilized, it is a means of providing collaborations with useful structures, tools and procedures. Promoting clarity around governance is justifiable for its potential impacts because in the context of community-based research, as one respondent stated, “the benefits of research can turn around and help benefit the community”.

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Appendix

Selected questions from the interview. Thinking about one of the community-based participatory research collaborations that you were involved with

Describe your part in it - how, why did you become involved and what ensued?

What were the arrangements that the collaboration made to govern or lead (such as board and committee structures, written documentation?).

By whom, when, where and why were decisions made about how the collaboration was going to govern/ function?

What activities or procedures to lead or govern the community-based research did the collaboration perform?

What arrangements do you think worked well or were helpful and successful for your collaboration's governance?

Were you satisfied with the arrangements that were made to govern the collaboration? Why or why not?

Link to the second research paper

From the description of arrangements that are used in governance of community-based research collaborations presented in the previous paper, I turn next to the nature of problems that respondents experienced in governing community-based research collaborations. What are these problems? Through a qualitative descriptive analysis of a set of in-depth interviews conducted with academic and non-academic community-based research collaborators from across Canada, some common problems were uncovered. Suggestions were offered by respondents for solving problems. However, analysis of these problems, some of which have been reported in the literature, suggests that a return to the theoretical and critical underpinnings of governance in community-based research is required.

CHAPTER 5

PROBLEMS OF COLLABORATIVE GOVERNANCE OF COMMUNITY-BASED RESEARCH COLLABORATIONS

Abstract

Advantages and benefits of collaboration have been well documented in the literature. However, problems of collaborative governance in the context of community-based research defined as “an organized process whereby members of defined communities in collaboration with academic researchers, democratically participate in making decisions towards producing new knowledge from the context and experience of their lives”, although reported, are less well documented. A study which sampled university and community members who governed community-based research (CBR) collaborations in Canada, was conducted to determine members’ experiences of governing. Respondents who took part in semi-structured interviews identified and described common problems in governing CBR. These included disincentives to collaborate; insufficient resources; unequal decision-making; divergent thinking about knowledge; and difficulties in organizing the production and translation of new knowledge. Problems caused conflict, tension and upset for some collaborations, with some problems being severe enough to bring down collaborations. The brunt of these problems was felt by community collaborators and thus raised questions about the authenticity or meaningfulness of the research for the community context. Some suggestions for new collaborations in community-based research were offered by respondents. Collaboration theory can be enhanced by critical approaches opening up reflection on problems, and orienting action towards problem resolution and social change. Further investigation of a definition and theory of collaborative governance in the context of community-based research is necessary.

Introduction

Tackling complex community health and social problems requires the resources, knowledge and participation of multiple organizations and disciplines (Israel, Schulz, Parker & Becker, 1998; Wood & Gray, 1991). The challenges inherent in these problems suggest that research approaches also need to be broad enough to conceive of and incorporate complexity. Community-based research (CBR) is one approach to research in which diverse people from a variety of organizations, universities and communities bring different knowledge, resources, experiences and skill sets to produce knowledge collaboratively. Collaboration has been recognized to bring such advantages and benefit to knowledge production, that some research funding competitions require applicants to demonstrate the use of collaboration in their research proposals.

Distinct from research problems, the literature hints at problems that collaborations experience. Specific references to problems and their consequences or potential to affect or influence the design, implementation and outcomes of research, however, are rare in the literature. Preventing problems or knowing how to act when encountering problems can be of benefit to collaborations. Knowledge of the kinds of problems that CBR collaborations might encounter may also assist collaborations to plan for or avoid them.

“What are the problems that arise in collaborators’ experiences of community-based research governance?” In this paper I describe a qualitative study of members’ experiences of governing CBR collaborations and report their identification and experiences of problems. I refer to the literatures on collaboration, CBR and governance, which provide conceptual underpinnings for the study. Following a brief outline of the methods used to collect and analyze the data, I describe the findings followed by a discussion that revisits the critical theoretical origins of CBR. In conclusion, I propose an approach that encourages systematic and regular reflection as a means of preventing, anticipating and resolving problems of collaboration in CBR.

Literature

Collaboration is a fundamental and defining component of community-based research (Israel et al., 1998; Suarez-Balcazar, Harper & Lewis, 2005). Community-based

research is defined as “a collaborative approach to research that engages partners from a community - geographic or otherwise defined - in all phases of the research process, with a shared goal of producing knowledge that will be translated into action or positive change for the community” (Lantz, Israel, Schulz & Reyes, 2006, p. 239). Definitions of community-based participatory research include taking a collaborative approach to research in which the partners contribute their unique strengths and take on shared responsibilities (Green, George, Daniel, Frankish, Herbert, Bowie, et al., 1995; Israel et al., 1998). Green and colleagues also specifically highlight the substantial collaboration of ‘traditionally defined’ researchers with the community (Green et al., 1995).

Working interdependently, collaboration members achieve objectives better than they could alone by generating “collaborative advantage” (Huxham, 1996; Huxham, 1993; John-Steiner, 2000). Collaborative advantage contributes to collaboration creativity and innovation (Granovetter, 1973; John-Steiner, 2000), and stimulates research on important health issues (Dowsett, 1999). Collaboration also provides opportunities to change traditional and disciplinary-bound ways of undertaking research (Koelen et al., 2001; Labonté & Robertson, 1996; Leung et al., 2004), producing new and different types of knowledge (Gibbons et al., 1994; Israel et al., 1998; John-Steiner, 2000); and supporting community development and empowerment (Florin & Wandersman, 1990; McMillan et al., 1995).

Although community-based research has inherent advantages because it is collaborative (Cornwall & Jewkes, 1995), references are made to problems that collaborations experience in working together. The literature of participatory development research, in particular, has reported problems of participation demonstrated by tokenism and sometimes, exclusion of community members (Cleaver, 1999; Cooke & Kothari, 2001; Koné et al., 2000; Reich & Reich, 2006). Outside this literature, specific problems as they are experienced by community-based research collaborations are referred to less often. Some authors have referred generally to tensions and disagreements which have been identified as arising from unequal power in collaborations or partnerships (Green et al., 2001; Israel et al., 2006). Writing on his experiences of university-community research partnerships in the province of Québec in Canada, Yves Vaillancourt has identified problems of inequality of participants and

participation in community-based research. Building a solid partnership, as Vaillancourt sees it, is “difficult because it implies the confrontation of two organizational cultures (universities and communities) ... which have different concepts of knowledge, of action and also of time” (Vaillancourt, 2007, p. 68). Importantly, problems may be generated as a result of collaboration.

There are resources in the literature that are designed to support members of community-based research collaborations, which include principles and guidelines for community-based research and integrated knowledge translation and exchange, and course materials and curricula for studying community-based research (Centers for Disease Control and Prevention, 1997; Israel et al., 2003; McTaggart, 1991; Parry, Salsberg & Macaulay, 2009; Pinto, Schmidt, Rodriguez, & Solano, 2007; Strand, Marullo, Cutforth, Stoecker & Donohue, 2003; The Examining Community-Institutional Partnerships for Prevention Research Group., 2006). Theoretical approaches to governance in community-based research in which problems may be generated by doing research collaboratively, thus far have received little attention. However, the comparatively recent literature of collaborative governance suggests one theoretical approach. Collaborative governance has been defined as “A governing arrangement where one or more public agencies directly engage non-state stakeholders in a collective decision-making process that is formal, consensus-oriented, and deliberative and that aims to make or implement public policy or manage public programs or assets (Ansell & Gash, 2008, p. 544). Although, Ansell and Gash’s definition of collaborative governance, reveals the authors’ disciplinary origins in public administration, the concept of governance is argued to be flexible enough for application to different ‘species’ of governance, such as in the context of community-based research.

In the absence of a definition of governance applied specifically to community-based research, I used Ansell and Gash’s understanding of collaborative governance as a guide to develop a working definition of governance of community-based research. It is defined as an organized process whereby members of defined communities in collaboration with academic researchers, democratically participate in making decisions towards producing new knowledge from the context and experience of their lives.

Clarification of terms

The terms ‘partnership’ and ‘collaboration’ are used somewhat interchangeably in the literature, but collaboration is used in this paper to maintain the focus of attention on the association of collaboration and its definitions, with community-based research. In some contexts, the notion of partnership suggests a contractual type of relationship where partners may contribute, but not necessarily on an equal basis. University member and academic are used interchangeably. Community member is used to refer to non-academic members of the community-based research collaboration.

Method

A study was designed to describe collaborators’ experiences of governance of community-based research in Canada. A qualitative research design was selected because qualitative research “claims to describe life-worlds ‘from the inside out’, from the point of view of the people who participate” (Flick, von Kardorff & Steinke, 2004, p. 3). The analytic method used was qualitative description which is used to create a low-inference robust description of a phenomenon. Qualitative description may also be used for theoretical development, such as grounded theory, at a later stage (Charmaz, 2006; Morse et al., 2009; Sandelowski, 2000).

Sample

Fifty-four participants who had experience in governance of community-based research participated in a semi-structured interview. The sample consisted of 28 academic and 26 community members engaged in community-based health-related research in Canada. Forty participants were engaged in poverty, homelessness and food insecurity research. The remaining 14 participants were engaged in a variety of community-based health-related research.

Procedures

Respondents were invited to participate in the study by emails distributed through list serves accessible to university and community members engaged in homelessness and food security research. Personal invitations to participate in an interview were also extended by email to individuals associated with community-based research, whose names were publicly available through academic publications and university websites. A

list of thematic questions which was informed by the literature was used in a semi-structured interview. Selected questions can be found in the Appendix. The semi-structured nature of the interview allowed the author to pursue lines of questioning with the respondents and to clarify answers.

Ethics

The study's procedures were approved by the University of Ottawa Research Ethics Board. Informed consent was obtained prior to the interview. Identifying features of respondents' stories, including the focus and location of the research, and individuals and populations implicated in the research, have been removed in the reporting of data as respondents were assured of confidentiality and anonymity.

Analysis

Interviews were transcribed, checked for accuracy, and analyzed on receipt of the transcriptions. The definition of 'problem' as "a doubtful or difficult matter requiring a solution, and something hard to understand or accomplish or deal with", was used as a guide to code and analyze the data.²⁸ Problems were determined from respondents' accounts through: language they used to describe an issue such as the use of negative constructions and vocabulary; expressed uncertainty about an issue; presentation of an issue that they reported was difficult to resolve; description of events or other issues that were identified as needing a solution; and through report of events or issues that respondents thought had led to negative outcomes whether for individual members, the research collaboration, or other parties to the research.

Because of the study focus on governance, problems related to the operational management, coordination and administration of the project such as, for example, staff turnover and replacing project staff, were excluded from the analysis. Also excluded were systemic problems that were identified as outside the reach of collaboration members (Flicker, Travers, Guta, McDonald & Meagher, 2008). Respondents' quotes are used in the text to illustrate the problems. Respondents are identified by their principal affiliation of community or university.

²⁸ The Oxford English Reference Dictionary (1995).

Findings

Problems were categorized under five main headings: disincentives to collaborate; insufficient resources; unequal decision-making; divergent thinking about knowledge; and difficulties in organizing the production and translation of new knowledge.

1. Disincentives to collaborate

1a. Institutional lack of recognition of effort

Compared to ‘traditional’ research, academic members reported that community-based research added extra effort. Doing community-based research with others from outside the academy, for this university member meant: “doing things differently...it requires more support...and to be meaningfully a part of that community means a longer-term investment that extends beyond projects”. For some academics, these differences served as a disincentive to participate in community-based research. For example, academic members often attended community meetings in non-university settings to help facilitate research collaboration relationships. But by participating in these community activities, some academics said they traded off the production of other academic work such as publications, with the time they spent with community-based collaborators. As publications are used as one of the means of indicating academic productivity, some university members reported having to deal with chastisement from their academic supervisors, or other career-related consequences. As one academic reported, “I won’t publish as much as some people so I’ll never become a full professor”.

A general lack of home institution recognition or credit given for community-engaged participation beyond the university walls and in community-based research was therefore reported to serve as a disincentive, and deterring some university members from engaging in community-based research.

1b. Focus of the academic recognition system on individual researchers

With the academic recognition system focused on the productivity of individual researchers, not actually leading a research collaboration and participating only in a supporting role may have acted as a disincentive to some researchers as one university respondent observed: “We wanted other academics to be involved and we were happy to share the data. But people were busy or saw it as not their own”.

1c. Restriction of single organization 'ownership' of a community issue

Although in the literature, collaboration is generally understood as reaping positive results, one community member noted that it can act as a disincentive for some community-based organizations who seek sole credit for their work. As one respondent said, in collaboration, “no single organization can take credit”. Another community respondent referred to this as “jockeying for position” of community agencies because “their survival has depended on their being the (sole) spokespeople for poverty or whatever”.

1d. Unsatisfactory research collaboration and working relationships

Community members reported that previous unsatisfactory experiences with community-university research collaborations served as a disincentive to participate again. In one case, a university member who had made decisions unilaterally deterred a community member from further collaboration in governance of community-based research. In another case, a challenging working relationship that “hadn’t been the easiest in the past” acted as a disincentive for a community member.

2. Insufficient resources

2a. Community organizations' lack of capacity

Participation of community members, organizations and practitioners in community-based research collaboration is largely a voluntary activity that takes place over and above regular workloads. For community organizations that were “already stretched very thinly”, it was a problem to accommodate research within existing workloads. A community respondent noted, “It’s difficult for groups like ours to undertake research...Where do we get the time to write the proposals? Where do we get the proper staffing and where do we get the time to reflect because we’re so busy with other things?” Another community respondent described research participation as “a considerable burden”. One community respondent thought, “people inside the university who haven’t worked with communities don’t understand how difficult it is to run a community organization on no money”.

2b. Lack of funding

Community collaborators bemoaned a lack of research funding to contribute to their organizations’ core costs of rent and administration, in addition to insufficient

program funding. Lack of funding also was reported to impact the ability of individual community members to participate in collaborative governance.

2c. Lack of time

A repeated problem theme for community-based collaborators was time. Lack of time itself was an issue as this community member reported: “there is no protected time in my job per se that’s called ‘research time’”. Additional responsibilities as a result of research activities competed with time allocated to regular tasks. “There’s this student ... they need somebody to supervise them... and that suddenly becomes a drain of time on somebody else’s job who has other things assigned to them”.

3. Unequal decision-making

3a. Control of financial resources by universities

As collaboration members understood it, fund-holding corresponded with power-holding and therefore raised sensitive issues of unequal power in decision-making when universities held research funds. For some collaborations, fund-holding gave academics power to make decisions unilaterally, by placing “power in the hands of the fund-holder to do as they please”. In one collaboration, community members reported “it was basically (an academic principal investigator) that was controlling the research and everything went through that person,” effectively excluding any community participation in decision-making.

3b. Academic control of language

Language spoken in research collaborations was problematic for community-based respondents because it was not the everyday language that community participants used to frame problems and was therefore difficult to understand. As one respondent explained, “there were areas that were over my head, because academics talk academic”. One community respondent gave an example of how this language difference served to separate the university from the community: “There was a woman from my old community. I’m walking down the street and she was asking, “Where are you going?” “Now I’ve got to go to a meeting”. She said, “What’s your meeting about?” I said, “Oh it’s about poverty”. And she says, “What’s poverty?” And I said, “It’s being poor and not having enough”. And she says, “Oh. Like us”. I said, “Yeah exactly like us,” but just the word ‘poverty’ was not part of the vocabulary. It was somebody else’s vocabulary”.

Academics were aware of language differences, and the lack of a shared language that all collaborators could understand. One academic said, “I think the university is an ivory tower and the language that we use on campus is different from language that you use in everyday life”. Another reported having to explain academic language dubbed as “research speak”. This same academic specifically linked the use of language with the holders of power and the imbalances this created for collaboration members: “the major challenge is a huge imbalance in power. Some of us are university profs and a lot of the people don’t have the same standing so they’re at a huge power disadvantage and probably at a huge language disadvantage”. The language that was used had a particular effect of separating community members who represented a researched population from community-based practitioners and academic members of the collaboration. One respondent observed “The academics and the bureaucracy are able to talk to each other better because most of the bureaucracy have been university trained and they have a certain deference or a respect for professors”. In the experience of this respondent, this separation resulted in a hierarchical structure of members in the collaboration’s governance.

3c. Academic control of community members’ participation

In some collaborations, community members felt they were at the beck and call of the academic researcher, and had little control over their participation: “It often seemed like we were being pulled into things to basically give some credibility to whatever their fancy was”. Community members further felt that “they (academics) also feel that they (community members) are not capable to be equal partners”. In one collaboration, the academic fund-holder controlled all aspects of the study. Community-based collaborators were excluded from any decision-making despite appeals to the fund-holder.

4. Divergent thinking about knowledge

4a. Value placed on academic knowledge

Assessments of the value of knowledge were a central problem for the development of equitable relationships. Community members placed higher value on the knowledge of academics than on their own such that a community member observed: “People who are considered very confident and knowledgeable and skilled and

experienced walk into the university and they're quite intimidated. People from the community really do think that university people know more". Community members devalued their own knowledge even though local knowledge was instrumental for the research. Community members also thought academic members valued their own knowledge more highly. One community respondent reported that "people can come from outside thinking that they know better, what's best and not really ready to listen and to accept their expertise and knowledge of their (community members) own condition".

4b. Deference to academic freedom

Access and deference to the methodological and scientific knowledge of academics was important for community members, because the "power of research", as one person described it, gave legitimacy to related community-based actions. However, 'academic freedom' became a problem in one collaboration when community respondents reported it was used as a reason by the principal academic to unilaterally decide on an issue, who also denied their attempts to deliberate or discuss the decision. One university respondent said, "universities are an entity all in themselves. They're like no other institution...if we want to maintain the freedom of having people be able to speak out in a variety of ways, which I see is an important part of the university, then I guess sometimes we have to risk a few problems or failures as some people call them".

5 Difficulties in the production and translation of new knowledge

5a. Different cultures of community and university members

How collaboration members approached knowledge production, how they valued it and what they intended to do with research knowledge, differed depending on members' affiliations with the university or the community. A university member described this state of affairs as, "having two cultures coexist that had different rhythms, different expectations, and frustrations". Another said, "what the community based organizations want to do, what they value the most is different from what academic researchers value the most" setting the conditions for tension, and discord. One community respondent thought that this led to, "Either the community feels it's being completely ripped off and misrepresented or the university feels they completely wasted their money and they're not getting the results that they want". Referring generally to the problems of collaborative governance arising from the different cultures and perspectives

of community and academic members, one respondent felt it was like “walking the tightrope all the time. Like you can’t please two masters and it’s very rarely a win-win situation”.

5b. Lack of community participation in framing the research

The experiences of some respondents suggested problems arose because community members lacked participation when framing the research. Framing the research problem or topic, developing research questions and designing other elements of a study were important discussions for some research collaborations, but not all. As one community respondent noted, research problems had already been framed first, by the funding agencies’ call for proposals, and second, by the researchers’ responses to them, implying that communities had little room to contribute their perspective. Community collaborators’ lack of participation in writing research proposals was perceived to be “pretty common. Researchers have to show that they’ve reached out to the community, but you don’t actually need the active involvement of a (community) partner,” as one community member explained. Some community members discontinued their participation on the basis of disagreement with methods being used because “the methodology we felt was inadequately referencing the community realities”. One community respondent’s experience with collaborative research was a problem in that “the research doesn’t actually answer the questions that are a priority of the sector,” and another said the research “Didn’t add anything...in the sense of new knowledge”.

5c. Lack of knowledge with regard to research and research ethics

Community members were not always privy to steps that university members are obliged to take to conduct research ethically and to protect research data. Their lack of knowledge caused unforeseen problems. For example, in one study, community collaborators had not realized that they were excluded from access to research data: “I was shocked and horrified that after all our monetary and personal and time resources that we had contributed, all that rich data, they were not accessible to us, completely none, because the researcher had promised them confidentiality”.

5d. Incorrect assumptions about research and its use

Academics sometimes found themselves in awkward positions as a result of being a member of a community-based research collaboration. In one instance, a community

organization incorrectly assumed the academic's political involvement, which caused a rift in the relationship. The researcher said: "you can use my data but you're not going to use me...I'm not going to give you my assent or approval over your interpretation of my data".

Some academics also had incorrect assumptions about social action consequent to the research. This academic respondent explained, "There was an assumption ...that once the research was finished ... that the needs and issues that had been identified and captured so well ... that they would take this and run with it. And they didn't".

5e. Overlooked relationship building and maintenance

Overlooking the need to develop and maintain relationships were problems for some collaborations. For instance, one organization reported stepping back from a research project. They had found that the research was "really hard because we hadn't formed those relationships".

5f. Collaborations' failures to define roles and responsibilities

Failing either to delineate members' roles or to carry out agreed-upon tasks and responsibilities were significant problems for collaborations. As one community respondent reported, "The research collaboration had no clear goals, rules or methods. Conflict led to breakdown in relationships". Some community respondents referred to a lack of structure, oversight and accountability for the research collaboration, which produced a subsequent loss of interest: "when things don't get defined very clearly, what everyone expects and what everyone's roles and responsibilities are, how the whole operation is structured, things fall apart and people get disappointed and it doesn't work out exactly how planned and some of the interest dissipates". Failures to fulfil roles and responsibilities as designated, sometimes adversely affected the workloads of community organizations. Community members of one collaboration had the problem of having responsibilities transferred to them for which the organization was unprepared. In another collaboration, a community member said, "We ended up having to do all the components of the research. Deadlines were missed and meetings with partners were missed by the university side which was problematic".

5g. Lack of means of recourse

Even with formal agreements in place, community respondents reported “there wasn’t a remedy for a partner not coming through on their core responsibilities embedded in the governance agreements”. If collaboration structures failed, rather than seeking recourse through university or funding agencies, abandonment seemed preferable to some community members. Further, for some participants, there was a residual sense of let-down and considerable disappointment. Community members felt they had been deprived of participation or misled.

Respondents’ suggestions for resolving collaboration problems

Respondents suggested means of resolving problems through their responses to an interview question, “What arrangements of governance would you suggest would be most helpful to a new community-based research collaboration?” Their solutions were often direct responses to the problem categories. For example, where insufficient resources presented a disincentive for community participation, sufficient resources offered a solution: “You want to have it resourced both in terms of amount and in terms of time allocated...because it’s going to take you a while”. Another respondent suggested: “there should be adequate funding for participation of community low income members ... there has to be a good reciprocal arrangement in terms of making (participation) affordable for them to be there”. Where roles and responsibilities were not defined, suggestions included defining roles and responsibilities. Where there was lack of means of recourse in cases of failure, providing means of recourse was one of the suggestions.

Other suggestions were made to individuals, offering advice as to how individuals should act. For example, a recommendation to academics engaging in community-based research was, “Be more transparent...be more realistic and more practical. Work with, not just in rhetoric but in reality, work with the community. Eat a little humble pie and don’t pretend you know everything”. Another respondent’s exhortation was similar: “not to present themselves as sort of knowing it all or that they were doing anyone a favour...to present yourself as a learner and a helper”.

Some respondents’ suggestions targeted the relationship between community and university members, and building and maintaining the collaboration. According to some respondents relationships were built on trust. As this respondent noted, “It’s important to

have partners that you trust and that trust you”. Ensuring community participation in all aspects of collaboration was repeatedly mentioned. One university respondent suggested that representation from the community should be “at least 51%,” and another said, “The more stakeholders that you bring into this partnership the better”. Practical suggestions included encouraging collaborations to bring along new members of collaboration in governance activities, such as, “Have other people brought in even if they are going to just sit there to be exposed to what’s going on and even offer limited input and almost build their confidence to make contributions”. Community member involvement was also a risk management strategy, “a very good way of mitigating the risk is to have more stakeholders and more people involved”.

One respondent thought “the symmetry of leadership is important...there should be co-leadership as much as possible”. At the same time as there was recognition that community-based research requires participation and representation of community members, and careful shepherding and leadership, it was also recognized that not everyone has the abilities, experience and skills to ensure that these are implemented. In a community-based context which can generate unequal decision-making, some respondents saw, “one of the missing elements is the facilitative piece”. A facilitator, also referred to as an ‘intermediary’ by one respondent, was seen to have particular value in enabling collaboration members to solve problems. Taking on many roles including enabling voice and ensuring participation of community members, “implies that they're there to facilitate, to grease the wheels and make the process work”. Facilitation was seen either as a role or task to be assumed by a principal investigator, or as a role that was produced as a result of collaborators’ becoming immersed in community-based research, and assumed by them. As one respondent claimed, “researchers and the people around this process become facilitators rather than dominant actors”.

Discussion

Despite the availability of literature, principles, course materials, curricula and experienced collaborators to call upon in community-based research, in this study the governance of community-based research collaborations presented problems. In some cases, problems caused conflict between collaborators. In some collaborations, problems

were severe enough that respondents reported that collaborations ceased to operate. Although academics were not immune to problems, the brunt of the problems was experienced by community collaborators at the individual and the group level in all the categories in this study. In the experiences of the majority of respondents in this study, the problems raised in community-based research, were offset by the benefits of collaborating in community-based research, suggesting that attention to collaborative governance itself can offer remedies.

Responding to 'problems'

How can community-based research collaborations respond to problems, and can they be prevented? Some directions have been suggested (Fay, 1987). Theories of collaboration offer one approach. Wood and Gray (1991) have posited a number of elements for a theory of collaboration. These are: a definition or meaning of collaboration; “the role of the convener and auspices for convening” (p. 149); the conditions of environmental complexity and participants’ control over it (p. 155), and the relationship between individual participants’ self-interests and the collective interests of all involved in the collaboration (p. 161) (Wood & Gray, 1991). But although this theory suggests what elements should be in place, in its present form collaboration theory does not offer active means to re-order arrangements, or tools to embrace and solve problems.

Ansell and Gash, building on the basis of collaborative theory see collaborative governance as responding to governance failures (Ansell & Gash, 2008). The authors developed a list of variables that influenced whether collaborative governance would be ‘successful’. These included prior history of conflict or cooperation, the incentives for stakeholders to participate, power and resources imbalances, leadership, and institutional design. Although there is not necessarily a direct relationship of ‘success’ with a lack of problems for all collaborations, the findings of problems in this paper resonate in part with Ansell and Gash’s contingency theory of collaborative governance. For example, their first contingency, “If there are significant power/resource imbalances between stakeholders, such that important stakeholders cannot participate in a meaningful way, then effective collaborative governance requires a commitment to a positive strategy of empowerment and representation of weaker or disadvantaged stakeholders” (Ansell & Gash, 2008, pp. 551-552). To address the identified problem of unequal decision-making

that negatively impacted participation of community members who were disadvantaged in terms of power, and by the language they spoke, Ansell and Gash's logic would suggest "a positive strategy of empowerment and representation" addressed towards community members in collaborative governance. But why power or resource imbalances occur in the first place are not well explained, suggesting that problems can be duplicated or even perpetuated, even when actors think they might be changing the conditions that they thought had brought about the problems in the first place. Other theory or theories which have historical or cultural explanations as well as action components may offer a way to solve problems.

Critical theory and community-based research

Community-based research, particularly that which follows 'Southern' traditions, has its theoretical origins in critical theory. Critical theory is a guide to critique of social relations and power uncovering the causes and consequences of social inequalities, and directing action towards social change (Buzzelli & Veenstra, 2007; Harvey, 1990; Labonté, Polanyi, Muhajarine, McIntosh & Williams, 2005; Labonté, 2005). Fay summarizes critical theory as follows: "(it) presupposes that the social crises it studies must be partly the result of the false consciousness of (some) members of the relevant society, that false consciousness is amenable to education, and that elimination of this false consciousness can lead to fundamental changes in social structure (and personal life-style) (Fay, 1987, p. 45). False consciousness or 'alienation' is the shaping of people's perceptions by power-holders (in a larger societal sense) so that all accept their 'lot in life'. This means that people fail in being able to represent their best interests because they are prevented from fully grasping them and acting on them (Lukes, 2005).

Freire's 'popular education', also adopted in community-based research, demonstrates a critical theoretical approach to education: by reflecting on their assumptions about society (false consciousness) and answering critical questions, citizen learners increase their knowledge and understanding of societal structures and the relations embedded in them, becoming empowered through learning to make social change (Freire, 1970). Another critical approach is the notion of 'critical friends' who act by posing critical questions, and prompting an individual or collective for answers about their work (Costa & Kallick, 1993). Other critical methods include critical reflection on

practice (Argyris & Schön, 1974; Schön, 1983); and adopting ideas of a collective ‘mindfulness’ (Weick, Sutcliffe & Obstfeld, 2010). Ideas of critical ‘theory in practice’ and reflexivity are also taken up in communities of practice and epistemic communities (Wenger, McDermott & Snyder, 2002). These theoretically-based methods all help to open up reflection on problems, and orient action towards problem resolution and social change.

Reflexivity and collaborative governance of community-based research

In this study of problems of collaborative governance of community-based research, community members were seen to be in a less powerful position than university members. Critical theory suggests that community members are constrained in the ways that they are able to represent themselves and participate in decision-making. To address this unequal disposition of power in a research collaboration whose approach to research is intended to address power inequities, a critical theoretical approach suggests collaborators should critically examine their arrangements and practices of decision-making (Fay, 1987). Reflexivity “demands an evaluation of our assumptions, our part in the research process, and the ethical considerations we make during the research process” (Dyck, 1993, p. 53 cited in Reed & McIlveen, 2006). There are a number of possible ways that collaborations can develop and practice critical self-reflection and incorporate it into the setting of governance. First our working definition of collaborative governance of community-based research should be discussed by the research collaboration. Next I propose that collaborations choose and implement methods for analyzing, reflecting on and evaluating the purposes and problems of collaborative governance of community-based research, choosing a method that is theoretically based and accessible, and opening up spaces for deliberation. For example, a ‘critical friend’ or facilitator, and/or collective reflexive practice and self-monitoring of collaboration governance can help to guide deliberation. Through this process, collaborations can orient action to prevent, correct or resolve problems.

Study methods and further research

In this study, qualitative description provided the initial approach and the analytic basis to determine categories. Both the research design and analytical approach to the

data are interpretive, meaning, that the interpretation of the data is assigned to the author. Qualitative interpretive methods do not make any claims to generalizability of the findings. However, “fittingness” is present when a study’s findings “can fit into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences” (Sandelowski, 1986, p. 32). Readers are invited to consider and assess the findings in light of their own experiences. For purposes of confirmability, further research utilizing different research methods is suggested. Ethnographic studies, or case studies of single collaborations in which critical practice is applied to collaborative governance, can provide local evidence of the impact of collaborative governance in creating, preventing and resolving problems in community-based research. Quantitative studies can utilize categories of problems determined here in surveys of research collaborations to determine their applicability. Some preliminary steps have been taken but further investigation of a definition and a theory of collaborative governance in the context of community-based research is necessary.

Summary and conclusion

Respondents in this study reported a number of commonly experienced problems of collaborative governance of community-based research collaborations. Respondents offered some suggestions for new collaborations. Active and critical collaborative governance can offer a space for remedying problems. Critical theory and methods were proposed, and further research suggested. Although theory of collaborative governance in the context of community-based research can be useful for understanding governance and its problems, critical practice is also seen as necessary for addressing them. In general, the experiences of the majority of respondents suggested that any problems raised in governing community-based research, were offset by the apparent benefits of collaborating in community-based research. One response to the question which asked, “Do you have any advice for a new community-based research collaboration member?” summarized the experience of collaborative governance for many respondents. This response, whilst acknowledging the problems but seeing the benefits, is encouraging. “It’s like any other relationship in life, it’s not always going to be easy, it’s not always going to be smooth but my experience is when it’s going well you can’t keep up”.

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Appendix.

Selected questions from the interview:

Thinking about one of the community-based participatory research collaborations that you were involved with

Describe your part in it - how, why did you become involved and what ensued?

By whom, when, where and why were decisions made about how the collaboration was going to govern/ function?

Was there anything in your experience of governance with this collaboration that stood out or was different from other experiences? What were they and why? What would you change and why?

Were there issues that you thought you should have discussed yet didn't?

What were the challenges for the governance of the collaboration?

What arrangements do you think worked well or were helpful and successful for your collaboration's governance? and What arrangements do you think did not work well or were not helpful or successful?

What arrangements of governance would you suggest would be most helpful to a new community-based research collaboration?

Link to the third research paper

The participation of collaboration members in the governance of community-based research collaborations is a critical component of community-based research, yet members' reported experiences of participation vary from full participation to little or no participation. Building from the previous papers' descriptive work, this paper takes an incremental step in proposing a theoretical basis for participation in governance of community-based research collaborations.

CHAPTER 6.

PARTICIPATION OF COMMUNITY MEMBERS IN GOVERNANCE OF COMMUNITY-BASED RESEARCH

Abstract

Built on principles of democratic participation, community-based research is a way of producing new knowledge through integrating the knowledge of lived experience of community members with the scientific and technical knowledge of academics. Despite a burgeoning literature of public participation in governance, there is a paucity of literature that looks at community members' participation in governance of community-based research. A qualitative study of governance of community-based research was undertaken, and analysis conducted to answer a research question, "What are the participation experiences of community members governing community-based research?" Arnstein's theory of participation, was used as theoretical orientation to the study (Arnstein, 1969). Data from 54 semi-structured interviews were analyzed using grounded theory. Participation in governance was shaped by four groups of modifiers. These were pre-existing conditions, arrangements of governance, actions of academic actors, and actions of community actors. Community members' participation in governance was largely contingent on the arrangements, structures and actions of others. Although participation in governance of community-based research provides theorized means to realize democratic goals and knowledge co-production, the highest level of participation that Arnstein envisages is rarely attained, although community members' participation was satisfactory to them. Theoretical propositions and practice implications of participation in governance of community-based research are put forward. Improved understanding of the conceptual purposes of collaborative governance may serve to encourage knowledge co-production and democratic participation through community-based research.

Introduction

Community-based research is increasingly used as an approach to conducting health-related research. Premised on the democratic participation and collaboration of members of the public or community member (Ansley & Gaventa, 1997; McIntyre-Mills, 2009), community-based research has been defined as “a collaborative approach to research that engages partners from a community - geographic or otherwise defined - in all phases of the research process, with a shared goal of producing knowledge that will be translated into action or positive change for the community” (Lantz, Israel, Schulz & Reyes, 2006, p. 239). Participation of community members in governance in the context of community-based research differs from representative democracy in which citizens delegate responsibility and vote, in that they can express their preferences directly through participation in governance processes in which they have a say.

Despite a burgeoning literature on public participation and public participation in governance, there is a paucity of literature addressing theory and practice of participation of community members in governing community-based research. The literature therefore has little to offer in the way of guidance for community-university research collaborations. Knowledge and theory of participation in governance may help to realize democratic and knowledge-producing intentions in the context of community-based research (Cornwall, 2002, p. 28). The first goal of this research paper is to gain some understanding of participation in governance of community-based research through the literature and a study designed for the purpose. The second goal is to build theory of participation in governance of community-based research, because theory can help research collaborations in their governance practices (Rowe & Frewer, 2005).

The paper is outlined as follows: After defining some terms and indicating their usage in this paper, the literatures of public participation and governance are surveyed and linked to governance of community-based research. A major theoretical influence, Arnstein's theory and typology of citizen participation and power, is described (Arnstein, 1969). Findings relating to public participation in governance of community-based research from the study are described and discussed. Theoretical propositions and practice implications for participation in governance of community-based research are

put forward. Grounded theory is compared to existing theory. The paper concludes with suggestions for further research on public participation in governance of community-based research, and increased understanding of the conceptual purposes of collaborative governance.

Clarification of terms

Different terms such as engagement and inclusion are used in the literature to mean participation. In this paper, participation is used as a generic descriptive term following Dietz and Stern's definition which is "any of a variety of mechanisms and processes used to involve and draw on members of the public or their representatives in the activities of public or private-sector organizations that are engaged in informing or making (environmental) assessments or decisions" (Dietz & Stern, 2008, p. 12). The term governance is used as well as decision-making to focus attention on formal collective and collaborative processes. The terms, public, member of the public, lay or local person, and community member or citizen, are used interchangeably across the literature. Some of these terms are also used in this paper, primarily to distinguish lay persons from academics.

Governance, participation, lay knowledge and community-based research

"There are many ways to organize collective decision-making in democracies" (Fung, 2007, p. 445). In the literature, construction and organization of collective decision-making has focused on two concepts. One of these is governance. Descriptions and definitions of governance specify interactive processes and structures found in a miscellany of forms through which decisions regarding sharing, allocating and coordinating responsibilities, resources and knowledge are made (Stoker, 1998). (Flinders, 2002; Kaufmann, Kraay & Zoido-Lobaton, 2000; Sloat, 2003). The second concept important to collective decision-making is participation (Roberts, 2004). Although there are different 'types' of participation, the focus in governance of community-based research is on democratic participation. Democratic participation has been defined as "the processes by which citizens influence or control those who make major decisions affecting them" (Verba, 1967, p. 55).

Participation of the public is seen as a 'good thing' for democracy (Arnstein, 1969). It is viewed as an important ingredient for enhancing societal capability of

solving complex or ‘wicked’ societal problems (Rittel & Webber, 1973). It is also held as a way of promoting equity, and preventing injustice (Hampton, 1999). It is a necessary element of ‘good governance’ (Dobriansky, 2003; Edgar, Marshall & Bassett, 2006; United Nations Economic and Social Commission for Asia and the Pacific, 2007). Public participation in governance is advocated as a means of enhancing democracy and addressing inequity (Callanan, 2005; Hirst, 2000). Such participation is argued to improve the quality of decisions (Beierle & Konisky, 2001); increase relevance of policies and service delivery (Barnes, 1999; Bovaird, 2007); and build capacity to address problems and sustain programs (Dietz & Stern, 2008; Minkler et al., 2006).

Participation, in general, and lay participation in governance in particular, are both viewed as having positive effects in a democratic context. Lack of participation, however is viewed as having negative impacts: “In a society where participation is a value, inability to participate represents a severe deprivation” (Verba, 1967, p. 53). Restricted participation or lack of participation in political, social and economic life has theorized serious consequences that include the “deprivation of human capabilities, setting the context for inequities” (Commission on Social Determinants of Health, 2008, p. 18). Concerns have also been raised with regard to distortions of participatory democracy. For example, Arnstein notes that by participating in governance, members of the public are susceptible to political manipulation (Arnstein, 1969). Governance failures and lack of accountability have been blamed on lack of meaningful participation, and this, in turn, has led to public distrust of governments (Huxham, 2003; Stoker, 1998).

The relationship of governance with participation in the context of community-based research is embedded in definitions of community-based research. These definitions focus on collaboration, which includes community members in all aspects of the research. Their participation is key for the production of new knowledge intended for action and social change (Green et al., 1995; Israel et al., 1998; Lantz et al., 2006). Whereas academics bring scientific and technical forms of knowledge to shape research decision-making, community members have lay or local knowledge which is defined as “the meanings people attach to their experience of places and how this shapes social action” (Popay et al., 1998, p. 636), and as “the scripts, images, narratives, and understandings we use to make sense of the world in which we live” (Corburn, 2005, p.

12). Local knowledge can have the effect of turning researcher and professional attention towards contextual, political, social, community and cultural issues which are of concern to members of researched populations (Fiorino, 1990; Fisher, 2002; Tickner, 2001). Through participating in governance of community-based research, community members can contribute their knowledge.

Although the status and potential contributions of lay or local knowledge are considered by some to be of low value or to negatively impact the quality of research (Ismail, 2009; Popay & Williams, 1996), arguments in favour of lay knowledge and the contribution of ‘public reason’, all refer to its legitimacy, validity and relevance to local situations (Popay et al., 1998; Popay & Williams, 1996; Bohman, 2007). The governance of community-based research, therefore, combines democratic participation and lay, scientific and technical knowledge so that research collaborations can learn together, share knowledge and produce new actionable knowledge (Labonté, Polanyi, Muhajarine, McIntosh & Williams, 2005; Ortiz, 2003; Wallerstein & Duran, 2006; Walter, Nutley & Davies, 2003b). Neglecting lay knowledge therefore comes at the risk of overlooking emerging local critical issues and future health problems (Nyden, 2005; Popay & Williams, 1996).

Theoretical orientation

The theoretical orientation for this study of participation in governance of community-based research is Arnstein’s seminal work on participation. It offers a basis for analyzing the nature or depth of public participation in decision-making and the decision-making power that accompanies it (Arnstein, 1969). Proceeding from the normative basis that participation is good, participation is ‘better’ “when it gives citizens power to influence decisions about their own governance” (Webler & Renn, 1995, p. 22). Arnstein’s typology, or ladder of citizen participation, illustrates steps that correspond “to the extent of citizens’ power in determining the end product” (Arnstein, 1969, p. 217). Higher steps on a continuum of participation indicate active public participation and decision-making by citizens. Power is distributed such that citizens have a direct say in the decisions that affect their lives. On the lower rungs of the ladder of participation when citizens do not participate or are prevented from participating or participate without power, the public is excluded from democratic benefits. Arnstein’s work seems to be

helpful as a barometer for gauging the level of participation of citizens in public decision-making processes. It has been cited extensively and replicated elsewhere, for example in the International Association for Public Participation's continuum or matrix of participation (International Association for Public Participation, 2009).

Method

A study was designed to describe the experiences of respondents who had participated in the governance of community-based research, and to develop grounded theory of participation in governance of community-based research. Potential study participants were community and university members of community-based research collaborations in Canada. They were made aware of the study through announcements on listservs, and through networks and personal contacts, and invited to participate in an interview. Potential study participants either referred themselves in response to the announcements, or indicated agreement to participate in response to an email. Potential participants were then given detailed information about the purpose of the study, the issues that were to be covered in the interview, how they might expect the interview to proceed, any associated risks of participation, and their rights in participating or not participating in the interview. Those who agreed to be interviewed were assured of confidentiality and anonymity in the reporting of the interviews. Interviews were conducted over the telephone or in person by the author where it was feasible. The semi-structured nature of the interview allowed for probing and the pursuit of lines of questioning with the respondents. Questions used to guide the interview are shown in the Appendix. All procedures and documentation were approved by the University of Ottawa Research Ethics Board.

Data analysis

I selected grounded theory as the analytic method to describe and theorize participation in governance of community-based research (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Grounded theory is a systematic approach in which the researcher analyzes qualitative data, and builds theory from the data. As an outcome or product of analysis, grounded theory can be understood as a local theory relating concepts that are constructed from respondents' experiential data.

The following questions were initially used for organizing data, but also because they can indicate answers to the location of control and power at different stages of research, and can suggest the effects of participation on different actors (Cornwall & Jewkes, 1995). These questions are: “Who participates in making decisions?”; “When does participation in governance take place?”; “Where does governance take place?”; “What enables participation in governance?”, and, “How is community participation assured in decision-making?” The analysis presented here came about after multiple readings of the raw and organized data. In vivo quotes from those who were interviewed are used to illustrate the results.

Results

Fifty-four respondents who had had one or more experiences of governance in community-based research collaborations were interviewed. These collaborations of academics and community members were convened to focus on social determinants of health-related research including poverty, food insecurity and homelessness, and other social and health problems which affected particular communities. Collaboration members were academics and community members who included community organization board members, volunteers and workers, and users of community services as well as lay persons and people with lived experience of the issues under study.

Findings

I identified four types of modifiers of the participation by community members in governance of community-based research. These were pre-existing conditions, arrangements of collaborative governance, actions of academic researchers, and actions of community participants. I also identified two sets of circumstances which created different conditions for the participation of community members.

Pre-existing conditions

Funding community participation

Although research funding agencies have formal arrangements with universities in Canada, arrangements with community-based organizations (CBOs) are only possible through certain funding competitions, meaning that the majority of research funds for community-based research are managed and mediated through universities. The ability

of community organizations to participate in research was therefore moderated by pre-established conditions of research funding. Research project money that CBOs receive may not adequately cover research-related costs, which affects participation. As one of the community respondents explained, “the fundamental issue on the community side is no core funding, and short term project money. It’s a real barrier for involvement of community partners and their ongoing participation”.

According to some respondents, arrangements to cover expenses were made in the research proposal to facilitate participation of individual community members in governance. These expenses included practical assistance such as travel and childcare expenses, and costs of communication such as telephone or Internet access. Otherwise, participation in governance was voluntary and unfunded. Some participants suggested a lack of up-front access to funding, or delayed payment of expenses or any transfer of funds to community members and organizations, may have limited community participation.

Arrangements of collaborative governance

Organizing participation

Discussions on arrangements of governance centred around formal structures of governance including membership. Certain structures or arrangements of governance provided descriptive boundaries for members’ roles and responsibilities. Some collaborations used agreements or letters of understanding to describe and clarify expectations regarding the participation of community and academic members. Joint discussions with regard to arrangements of governance provided opportunity to determine and clarify all participants’ positions and preferences. However, these discussions were limited for most collaborations.

Deterring participation

The use of formal governance structures was resisted by some respondents. They were seen to restrict participation particularly for members who may not have had previous exposure to formal governance settings. One respondent thought that formal structures may have had the effect of excluding participants: “go that route of the chair and all that sort of stuff, it excludes anybody else joining”. Another noted “if everything’s formalized ... you also have a very structured and determinative relationship

with your community members,” which was seen as a deterrent to participation. Defined as “a hallmark of participatory research”, flexibility was proposed as an essential ingredient for organizing governance. ‘Flexibility’, in one community-based research collaboration, had the result of ensuring that the community members of a collaboration never met more than once with their academic counterparts despite the community’s ongoing calls for meetings.

Actions of academic researchers

Initiating participation

Although both community and university respondents talked about collaboration development and the work that needed to be done before a research proposal was submitted, they also suggested that community members did not participate in this phase to any great extent. Community members’ participation was often limited to agreeing to participate and expressing support for a research proposal through letters of support. Furthermore, in between submitting a research proposal and hearing about funding decisions, little need was felt for meetings.

Inviting participation and determining representation

How members of the community became participants in governance of community-based research was primarily conditional on a decision and an invitation extended by academics. Academics invited some participants because they had lived experience of being homeless or food insecure, or other experience related to the research problem. These participants were presumed to represent a particular group or community. Their contributions to decision-making were respected as legitimately based on their experience. Other participants, such as community workers, were invited because they provided access and “expertise needed in terms of what types of questions, how to ask, where do you find people to ask these questions to”. As one respondent reflected, “we spend a lot of time thinking, “Well, who should be at that table?” ‘who’ meaning not just what organization but who within an organization should be there. And that’s a key question because do you want people who work in the front line or do you want management? Because they see the situation in different ways. They have different kinds of knowledge, and I’m not privileging one or the other, but you have to think about why would you want a manager there as opposed to the front line worker, or vice versa”.

The invitation of certain community members to participate in governance as representatives of a ‘community’ of individuals with lived experience, raised questions for some participants regarding the true meaning of representation. One community respondent questioned the repeated participation of some community members in different local research projects, who were thought to have been invited “because they can speak the bureaucratic language” not because of their representation of a particular community. Another respondent felt like the selection of representatives of lived experience made the process appear fair to outsiders, but that this did not have any connection to participation: “you could feel as though you’re being used... it looks good to have x number of community representatives sitting on a steering committee, right? I’m just here to guarantee funding”.

Ensuring participation

The participation of people with lived experience, characterized by one respondent as “people who are already dominated in so many aspects of their lives”, required academic members to approach their inclusion with care. Some community members saw themselves as differing in status from academic members, which affected their ‘voice’, or their ability to perceive and present their point of view as important. One community member said, “Well these are not really my peers. These are academics, you know”. One spoke of “the hesitance of some people to get involved in things that they feel are over their heads”. In trying to give “legitimacy to the contributions of people who are living the experience and who may not be as articulate”, some collaborations took positive steps towards assuring people participated as equals: “there wasn’t this sort of either hierarching (sic) the levels of participation in the group or marginalizing the people who were less involved. There was a lot more ethical consideration”. In another collaboration, academics took special steps to ensure community members’ participation because they valued their participation: “we (academics) involve the (community members) in a substantive way. They are the conceptual engines of our project”. On the other hand, some collaborations ensured representation but not participation. One respondent spoke of a lone community representative with lived experience on a governing committee “who was open to give as much expertise from his experience as was required, but was not utilized as effectively as he could have been”.

Enabling participation

In some collaborations, skilled facilitation appeared to be a factor in enabling participation in meetings. As one respondent noted from one collaboration's experience, "...you could see that one or two people were dominating and you have to be quite careful and quite skilled in those situations and not just a nominal facilitator or chair". Academics recognized that "no matter how equitable we try to be there's always a tendency for academic researchers to dominate the discussion or to drive the agenda".

Restraining participation

The amount of time that community members spent voluntarily in meetings was generally treated by academic investigators as a limited resource to be carefully expended. Respondents spoke of carefully planning meetings to ensure participation. One spoke of "a very circumscribed participation in terms of honouring the time that they have", and "to be very clear about what the time commitment is, and to use that very efficiently to draw out the expertise". This protection of time by academic researchers recognized the time and resource restraints on community organizations and other community members.

Community member actions

Weighing up participation

Community members' attitudes towards research influenced their decision to participate in governance of community-based research. Some community members wanted some understanding of research, or needed to value research in order to participate. Others needed to see some benefits to their participation. Some needed to know about the processes they were becoming engaged in, and others adopted a position that research as an end in itself was important for community-based organizations. On occasion, community members and community organizations showed reluctance to participate at all. In one university member's experience, some community members' attitudes towards research were summarized as, "for them there's no need for research. Research is just like a useless task for them".

Bounding participation in governance

Some community members found it helpful to separate the governance or decision-making role from the research operations or as one respondent referred to them,

“the coordination of the scientific side and research side”. This same respondent continued, “They just don’t want to be bothered at that level. They don’t want to have to get called in on the operational stuff”. One academic respondent noted that “we try and involve all people in every kind of decision... but you also get push back from community members and from agencies who say “Well you’re the expert. You propose something and if it sounds good we’ll do that...you take that role, you take that responsibility and that’s fine with us”.

Discontinuing participation

Sometimes community members who initially might have been interested in participating left a research collaboration, because, as this respondent explained, “it winds up being too hard... It's a painstaking process ... it requires a lot of time and effort”. Attitudes towards academic researchers also varied and influenced participation. A small number of community members stated that they would not collaborate with particular academics or universities in the future, because of past negative experiences. The reasons given for these decisions to discontinue were failure to involve community members in decision-making, failure on the part of academics in carrying out responsibilities, and lack of clarity with regard to members’ roles and responsibilities.

Leaving out participating in knowledge translation

Disseminating and translating knowledge after the completion of research was a phase in which community members participated rarely. Participating in this phase by assisting in the production of reports and peer-reviewed academic literature was “not necessarily valued by people in the community sector (even though) we would always invite somebody from the agency to contribute ... but that’s not the business they’re in”, as one academic explained. One community member said, “They (community members) don’t give diddly squat about authorship, order and pure academic journals”, acknowledging that community members expect different outcomes for their participation. This same community member went on to say, “What they (the community) might care about is, what do you need for your work to continue? We know what we need”, referring to the resources necessary to implement programs or interventions suggested by the research findings.

The findings reveal common experiences of participation of community members in governance of community-based research which were contingent or modified by a number of factors. However, exceptions to these experiences which ensured the participation of community members were noted by respondents. The first exception was in peer-conducted research, which is a fully participatory process employing and engaging people with lived experience in all aspects of the research including governance (For examples, see Flicker, 2008; Iman, Fullwood, Paz & Hassan, 2010). The second was when communities and organizations rather than universities hosted research projects and supervised research staff. Some community and university respondents felt that, when a research project was located at the university, the power and culture of the university would dominate community partners, and possibly taint community perspectives. A community respondent said, “We have located in the community deliberately from the very beginning knowing that universities tend to absorb, and you become part of that system”. Located in the community, community member participation was thought to be assured.

Discussion

The types of modifiers of participation identified in this study influenced participation by community-based members in governance of community-based research. The first modifier, pre-existing conditions, determined academic control of research projects supported by institutional arrangements of funding that give universities fund-holding preference. Limited budgets and absence of categories which could assist community organizations or individuals to participate more readily suggested limits placed on participation. The second modifier, arrangements of governance in the form of documentation, membership, bodies and meetings created frameworks for defining and enacting participation in governance, but lack of attention and sometimes resistance to these may have meant that many collaborations did not have the ‘governance discussion’ at any time. The third modifier, actions of academic researchers, suggested many ways in which academic members’ actions affected or influenced participation of community members. Community members’ involvement was initially contingent on being invited, but later, opportunities for participation were also carefully planned by university

members ostensibly to protect community members' time and workloads. This resulted in participation that was controlled by university members, not by the community. Community participants also modified their participation in response to funding arrangements and actions of academics in order to reach a level of participation that was satisfactory to them.

Participation of community members was tied to the acts or decisions of powerful others who set limits on resources, placed constraints on ideally conceived participation, and who were largely responsible for determining arrangements of governance that admitted community members to collaboration, again setting the terms of their participation. Reluctance, "push-back", and occasional refusal by community members to participate demonstrated their rejection of constraints or simply their negative attitudes towards research, but also demonstrated the enactment of personal agency. However, participation in governance that was generally conditional on the structures and actions of others does not seem to offer sufficient explanation of the willingness of many community members to be voluntarily engaged in governance of community-based research.

Given that community members appeared to have little in the way of control, resources or power in participating in governance of community-based research, how can their participation be explained? Their perception of the importance of research and their commitment to the production of knowledge offers one answer. However, community members appear to have resolved this question by participating in governance to a level that they deemed satisfactory and I describe as 'good enough': that is, they determined a level of participation that they were prepared to be satisfied with. In other words even if in their own estimation their contribution was limited, their choices were satisfactory insofar as they did not give rise to conflict, disruption, upset or lack of coherence with the importance that they attached to participation in governance of community-based research.

'Good enough' participation in governance meant that community members were willing to make certain investments in participation of governance of community-based research as long as the returns on investment were judged as proportional to the effort or risk of participating. Community participants determine risks, assess expenditures and

losses of time, money, resources and status, and measure their input into governance to bring about a process that they were satisfied with, not necessarily one that is unreservedly participatory in an ideal sense. As one respondent explained the approach, “it matter(s) more that there be real benefits generated than it does to have some sort of hyper-participation”. Another said, “I don’t care if I participate all the time, every time, on every decision. As long as there’s transparency, as long as I see the money goes where it should go, I’m happy to be a member. I don’t have to be the chair as long as those benefits are flowing. As soon as I see no benefits to my people or my organization I’m going to bail”. As long as benefits were apparent, limited participation in decision-making was therefore, not bad, but ‘good enough’ from community members’ perspectives. Risks taken by participating in decision-making were assessed, but most community participants did not feel they had a lot to lose.

Arnstein’s highest participation levels (citizen control, delegated power and partnership) compared with the experience of the study’s community respondents, were rarely knowingly attained in this study, with the exception of one respondent who recorded comprehensive and direct community control of decision-making, and ownership of decision-making by communities. Most respondents’ experiences of participation suggested middle and lower level participation. What Arnstein refers to as the middle-level ‘placation’ category is where (marginalized/vulnerable) participants, the “have-nots” (or already elected officials), are invited to participate on traditional public advisory boards or bodies and participate in planning governance arrangements. Arnstein suggests that it is not possible for citizens’ participation to have any significant impact on decision-making at this level. At even lower rungs of the ladder, Arnstein uses ‘therapy’ and ‘manipulation’ to describe non-participation. These terms are deliberately metaphorical and euphemistic. Her use of the terms “chicanery” and “sham” for the activities of powerholders that match these categories also suggests that, once exposed to participation in governance where community members are essentially disregarded, community participants who are aware or become aware of the pretence are likely to be twice shy of a future experience of participation, as some of the respondents suggested. For collaborators who expect or consciously seek higher level participation, lack of opportunity to participate is problematic.

Arnstein's ladder and the terminology she employs suggest that middle and lower level participation is an 'unaware' state of participation in which conditions of participation in decision-making are imposed by power-holders. Her explanation suggests that in efforts to maintain power and control there is some sort of furtive manipulation of conditions of participation to maintain power in power-holders' hands. Because participants do not object to the terms of their participation in decision-making, and do, in fact, participate, they are likely unaware of the manipulation. Without awareness of powerholding, lower levels of participation certainly suggest tokenism. However, lack of awareness of a less-than-optimal participation can readily apply to non-reflective power-holders as well. In some contrast to Arnstein's explanation, our findings suggest that most community members were aware of their limited levels of participation, but found a means of justifying the level and adjusting their participation so that participation was good enough.

How to recognize differing levels of participation and their effects on distributing or redistributing power to make decisions, is a challenge using Arnstein's typology. As Arnstein also points out, such a simplistic typology tends to assume homogeneity in (powerless) group composition. Not all scholars would agree that the highest levels of participation necessitate full citizen control. Neither does "more participation necessarily lead to more socially acceptable outcomes or processes" (Reed & McIlveen, 2006, p. 595).

Habermas proposes in his "ideal speech situation" that it is more important to ensure conditions for a fair and competent discourse (Webler, 1995). In such a context, where participants have an equal interest in discourse that ensures communication and agreed-upon outcomes, the best argument as opposed to the most powerful person, prevails. In other words, power holders relinquish their control to the goals of discourse. Perhaps the closest that respondents in this study got to envisaging Habermas' ideal speech situation and their participation in it, was expressed in this respondent's words: "the best thing as a researcher that you could possibly have happen would be a community group say *we* did this research and this is what *we* found (emphasis added). People start to feel that they own the research: that it's about them...and it's theirs".

Other than the distribution of power, the ladder of participation does not offer an analysis of barriers to genuine participation, or suggest theories to address each level of participation. The examples that Arnstein uses as well have yet to be adapted more widely to modern arrangements of citizen participation that include a variety of governance situations where citizens are involved. However, Arnstein's ladder is a basis and a useful tool for describing and uncovering non-authentic participation, and for challenging pretensions by power-holders who make use of lightweight evidence to demonstrate participation in governance.

*Theoretical propositions and practice of participation in governance of
community-based research*

Grounded theory provides a basis for modelling participation in governance of community-based research based on the findings of this study, and informed by the literature and discussion. I suggest the following theoretical propositions with accompanying suggestions for critical practice:

1. Governance of community-based research acknowledges the contribution of different knowledge to knowledge co-production, and the democratic right to participate in decision-making that affects collaborators' lives. In practice all participants need to know the theoretical purposes of participation in governance of community-based research.
2. A theory of participation in governance of community-based research acknowledges that participation is palpable, and consciously and reflectively undertaken. To avoid tokenism, inadvertent or otherwise, and observe respect for all collaboration members, hidden agendas must be exposed. All members have responsibility in respect of each other's authentic participation.
3. There is an ideal theorized participation. In reality those who hold power for conducting research, set the terms that define participation. Knowledge of power-holding should be exchanged, and governance set up to distribute power widely.
4. Participation is necessary for collaborators to exchange, transfer and gain power, knowledge, and resources. In practice, participants need to know what they are going to exchange, transfer and gain from participation in governance of CBR. This is probably one of the more important questions to ask and answer at the beginning of

collaboration governance because it sets the tone for participation, forms the basis for undertaking collaboration, provides means for realistically assessing collaboration progress and checking expectations.

5. Participation is directly related to governance structures, tools and processes which in theory are shaped by all participants. Structures, tools and processes that are adopted in governance directly influence participation by circumscribing it, and enabling, moderating and excluding it. Participants should determine their own governance, and governance in practice requires continual reflection.

6. Coherence and clarity in governance are achieved by separating the decisions of governing from the operational decisions of the work of a collaboration (referred to sometimes as project management or research coordination). Participants need to be aware of possible role conflict, and wear the appropriate ‘hat’ for the appropriate role whilst participating in governance.

Using these propositions, members of community-based research collaborations can approach participation in collaborative governance by developing an agreed-upon style of governance with a level of participation that is coherent with their research mission, values and principles, and resources. This can serve to accommodate ‘good enough’ participation, while preserving ‘ideal’ participation as an intellectual goal. Whilst facilitating clarity of governance, this agreement can then be used for reflection and to assess collaborators’ claims for adherence or non-adherence to principles, and consistency in collaborative governance. To evaluate participation in collaborative governance in community-based research, a further criterion of achievement is member satisfaction derived through participation as he or she defines participation.

‘Good enough’ participation in governance of community-based research suggests a different emphasis from traditional accounts of participation or non-participation in community-based research. Much of the community-based research literature centres on the importance of trust for participants. The exploitation through research of black and racial minority community members in the US, of indigenous peoples throughout the world who have been exposed to ‘helicopter’, ‘drive-by’, ‘safari’ or ‘parachute’ research, and others who have suffered the consequences of different harms brought about by research participation, are examples of oppression which have produced harm and

mistrust (Centers for Disease Control and Prevention, 2008; Horowitz et al., 2009; Myser, 2004; Oberly & Macedo, 2004; Smith, 1999). Attentiveness to developing trusting relationships in community based research is intended to address these problems (Beyrer & Kass, 2002). However, trust that is needed to participate in research as a research participant has a different quality to trust that is needed to participate in governance. Decisions to participate in governance may be more influenced by what potential decision-makers feel they have to gain or lose personally and organizationally, which may relate more closely to issues of assessing ‘risk’, than to issues of trust or assessing potential for harm. This interpretation may have greater relevance to the implementation of governance of community-based research in the north where community actors may have greater standing vis à vis academic counterparts than in developing countries’ collaborations, and community members participating in governance have a feeling that they can choose to participate or not without negative consequences.

Further research

Community-based activities which are intended to deepen university-community relationships are becoming more common in Canada. Community-based research is one expanding area. Given this context, further investigation of research relationships and collaborative governance models could be helpful to academics and community organizations and associations. How people participate in a group setting is a separate yet related area of study. Knowledge of interpersonal behaviour and different cultural approaches to decision-making in governance spaces is important for ensuring participation by people from different multicultural backgrounds. Further theory and description is needed of how decisions are actually made in participation through mechanisms of discourse, debate, discussion, and other decision-taking procedures. Research methods other than those used in this study can be employed to study governance. Case studies of a selection of community-based research collaborations might help for testing the propositions in this study and bringing more attention to theorizing participation in governance of community-based research.

Methods of assessing or evaluating governance of community-based research, and satisfaction with participation, whether employing quantitative or qualitative approaches, can take on board ideas of ‘good enough’ participation to account for the fact that not all participants may be concerned about reaching ideals, but nonetheless are still interested enough to provide a voice of ‘public reason’ in governance of community-based research.

Conclusions

David Beetham argued that the core idea of democracy in classical views is that of popular rule or popular control over collective decision-making (Beetham, 1999 cited in Gaventa, 2006, p. 5). When governance is viewed as a component of the knowledge production process, the participation of citizens in governance broadens the scope of knowledge and improves democratic participation. Participation in governance of community-based research has potential for transformation, by producing research that is more relevant for researched populations than without their participation (Walter, Davies & Nutley, 2003a). Better understanding of the theory and practice of participation in governance of community-based research by all collaborators may serve to increase recognition of the role of governance in enabling knowledge co-production and enhancing democratic participation.

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Appendix

List of question areas to be covered during the interview

Thinking about one of the community-based participatory research collaborations that you were involved with

- 1) Describe your part in it - how, why did you become involved and what ensued?
- 2) What were the arrangements that the collaboration made to govern or lead—such as board and committee structures, written documentation?
- 3) What activities or procedures to lead or govern the community-based research did the collaboration perform?
- 4) By whom, when, where and why were decisions made about how the collaboration was going to govern/function?
- 5) How were decisions made as to the development of arrangements of governance that you just described?
- 6) Was there anything in your experience of governance with this collaboration that stood out or was different from other experiences? What were they and why? What would you change and why?
- 7) In your experience, what were the issues that required leadership which you discussed? Were there issues that you thought you should have discussed yet didn't?
- 8) What were the challenges for the governance of the collaboration?
- 9) What arrangements do you think worked well or were helpful and successful for your collaboration's governance?
- 10) What arrangements do you think did not work well or were not helpful or successful?
- 11) Were you satisfied with the arrangements that were made to govern the collaboration? Why or why not?
- 12) What arrangements of governance would you suggest would be most helpful to a new community-based research collaboration?

CHAPTER 7 DISCUSSION AND CONCLUSION: EXPERIENCES OF GOVERNANCE IN THE CONTEXT OF COMMUNITY-BASED RESEARCH: STRUCTURES, PROBLEMS AND THEORY

In this thesis, I have reviewed the literature of governance, and considered the governance of community-based research as a population health topic. I have found out about the governing experiences of members in some Canadian community-based research collaborations, and learned from their problems and perspectives. In this concluding chapter I review the project on governance in the context of community-based research through a summary of the three research papers and raising some aspects that are worthy of note for research collaborations and research governance. I propose specific contributions which this thesis has made towards the body of knowledge that population health encompasses, and a strategy for knowledge translation. I point out some limitations of the thesis, as well as suggest potential directions for furthering governance research. In closing, I revisit the relationship of democratization and governance in the context of the knowledge process, and envision the future with respect to governance and knowledge production.

Governance and community-based research

Descriptions and theories of governance span from public models of governance, private sector models including networked corporate governance models, to global and international governing bodies whose powers extend beyond the single nation state and multinational corporations in an increasingly ‘globalized’ world. Civil society organizations, such as Civicus: World Alliance for Citizen Participation²⁹, which advocates for citizen participation as an essential component of governance and

²⁹ <http://www.civicus.org/who-we-are>

democracy worldwide, and organizations such as the People's Health Movement, have highlighted a role of governance by promoting "new ways of participatory and self-governing practices within consensual rules and processes of governance where marginalised communities and social movements may play a stronger role in building more equitable health systems (Lee, Koivusalo, Ollila, Labonté, Schrecker, Schuftan, et al., 2007, p. 15). Work at the global level towards ensuring participation of citizens in governance takes place at a different level and scale than the participation of citizens or local people in the governance of community-based research, but the central issues of governance appear similar. 'Classic' questions of politics on which the study of governance has been based, "Who shall decide?" "What to decide?" and "How to decide?" are still relevant today for different levels of governance (Kingdon, 2003; Lasswell, 1950; Verba, 1967).

Governance offers spaces for coordinating interests and solving problems. Its arrangements are designed for making decisions concerning sharing, allocating and coordinating responsibilities, resources and knowledge (Stoker, 1998). Despite similarities and commonalities of governance, contexts influence governance. The case for including lay knowledge and the 'voice' of researched populations has been made democratically, normatively and morally (Bohman, 2007; Jasanoff, 2007). But because community-based research creates opportunities for the insertion of different conceptions of knowledge and knowledge holders who are not part of the formal knowledge system, it also presents a challenge to their incorporation and acceptability within formal existing structures of governance. Configuring structures, or alternatively, creating new structures to support the participation, contributions and knowledge of lay people in the production of new knowledge, may be required.

Structures

What arrangements research collaborations make to govern has received marginal attention in the literature although community-based research is increasingly becoming an important participatory means of producing social and health-related knowledge. The lack of description seems to be an important gap, for individual collaborations, for the governance literature, for participatory approaches in democracies, and within the context of knowledge production. In response to this lack, the first task of the inquiry was to

research arrangements of governance that community-based research collaborations selected or developed, and members' experiences of them. The first research paper described governance structures and tools that were used within community-based research collaborations. Collaborations established different structures, such as steering committees, which served as mechanisms for organizing decision-making.

Documentation that collaboration members developed together, such as terms of agreement, served as records for guiding collaboration. Arranging governance was regarded as a necessary step, but accorded little attention by collaborations. Moreover, where discussions with respect to organizing governance were cursory or even absent, collaborations were unstable. Where governance was absent, potential contributions of community members and on occasion, some university members, were put aside.

Problems

Advantages and benefits of partnership and collaboration have been well documented in the literature. Collaborative working is theorized to bring added value to a group of people organized for the purpose, through combining different skills, forms of knowledge and resources. The literature of collaboration, particularly the participatory development literature, indicates that the course of collaboration is not always smooth. In Northern settings, however, problems that collaborators experience in governing community-based research, have received little attention. Whatever the reasons for this apparent absence of problems or lack of attention to them in the literature, experiences of governing community-based research collaboration described in the second paper revealed a number of problems. The main categories of problems brought to light were disincentives to collaborate; insufficient resources; unequal decision-making; divergent thinking about knowledge; and difficulties in organizing the production and translation of new knowledge. Transferring learning about the kinds of governance problems that community-based research collaborations may encounter might permit research collaborations to anticipate or avoid them. Making use of arrangements of governance, as described in the first paper, is offered as a first step. But identifying and avoiding governance-related problems, while offering a logical approach, lacked theory.

Theory

Collaborative governance theory provides guidance for identifying principal components of a theory of governance, but it is not a theory of action (Ansell & Gash, 2008). Community-based research however, is rooted in critical theory which is a theory of action. Critical theory can act on problems by deconstructing structures that are taken-for-granted and exposing relationships of power and domination (Foucault, 1980; Labonté, Polanyi, Muhajarine, McIntosh & Williams, 2005; Labonté, 2005). A general direction of critical theory such as Freire's 'popular education' (Freire, 1970) which is coherent with community-based research and held as a major theoretical influence on community-based research, repositions those who possess lower authority and influence than their more powerful counterparts, so that they can ask questions of power and act on their findings, in effect bringing about social change. Critical theory therefore acts as a guide for action. There are a number of ways through which change might be achieved in collaborative governance. These include critically reflecting on practice (Argyris & Schön, 1974; Schön, 1983); and developing collective 'mindfulness' (Weick, Sutcliffe & Obstfeld, 2010). Critical reflection and collective mindfulness are also used in other forms of organization than collaborative governance, such as communities of practice and epistemic communities (Wenger, McDermott & Snyder, 2002). Elsewhere in the literature, governance itself has been envisaged as a mechanism for re-organizing power and re-modelling political change in democratic societies, "d'une nouvelle ambition: celle de se présenter comme une solution de rechange à l'organisation du pouvoir... et comme une réponse efficace aux transformations en cours du politique dans les sociétés démocratique" (Cardinal & Andrew, 2001, p. 1 and back cover).³⁰

Theories of collaboration and governance, collaborative governance and participatory governance all have contributions to make towards understanding of participatory processes in the context of governance (Chhotray & Stoker, 2009; Fischer, 2006; Gaventa, 1980; Gaventa & Cornwall, 2001). However, theory that might be

³⁰ "A new aspiration (for governance): presenting itself as a solution to the reform of power, and as an effective response to political changes taking place in democratic societies" (tr. by author).

applied to participation in governance does not address the specific context of community-based research. Using Arnstein's theory of participation as the theoretical orientation, the third paper studied participation experiences in governance of community-based research with an intention of building grounded theory (Arnstein, 1969). Respondents' experiences of participation were shaped by four modifiers: pre-existing and institutionalized structures, governance structures that research collaborations set up, actions of academic actors, and actions of community actors. These modifiers provided a framework for understanding participation in governance, but whilst academic actors had control or input over all modifiers except for actions of community actors, these same three modifiers (pre-existing structures, the collaboration's governance structures, and actions of academic actors) were outside the control of community respondents, and only amenable to input or change in some cases. However, although community members had little power and control over participation in decision-making, they adapted their participation. Agreeing to participate, community members appeared to find a level of participation that was 'good enough' or satisfactory to them. Rather than using ethical concepts of harm which are tied to participation in community-based research, the findings suggested that community members assessed their governance participation on the basis of risk and return. Determining that higher levels of participation were not worth the risk for the return, community members opted for low levels. Low participation in governance of much community-based research presents a challenge for the vitality, authenticity and meaningfulness of community-based research.

Critiques of participation in the literature have been directed at the inequalities or power imbalances experienced by community members. Acknowledging one group's unequal or lesser power however, implicates an 'Other's' position of greater power or dominance. "Participatory acts refer to inter-actions between citizens and decision-makers. This means that to understand participation and its effects, one must study both the participants and the decision-makers" (Verba, 1967, p. 56). Foucault's understanding of power and knowledge as inseparable, and necessarily a theory of relations, is also in agreement with Verba's assertion: to paraphrase, one should not study one party without studying the other which is in relation to it. The findings of the third paper revealed inequalities in participation that mostly affected community participants, not their

university counterparts. The findings permitted the development of a number of propositions that are theoretically based directed towards both academic power-holders and community members which help to ensure equitable relations and suggest related practices in governance of community-based research.

Is governance a solution to problems in the context of community-based research, and necessary for authentic research and meaningful results? With a focus on governance in this study, it might appear that governance is a panacea, and that “good” community-based research is dependent on governance. Indeed, attention is paid to governance in myriad contexts because it is increasingly seen as a solution to problems such as sagging corporate bottom lines, or corruption. Looking further, it is not that governance is so much a solution to problems, but that it provides the means of achieving order, and organizing or coordinating interests. Governance is also an opportunity for knowledge production, albeit producing different forms of knowledge than research outcomes. Lack of governance, and lack of participation in governance, are therefore missed opportunities for knowledge co-production. Further, whilst no one theory (of collaboration, participation, or collaborative governance) can claim common acceptance, nor offers an entirely satisfactory explanation of governance and participation, governance itself is a mechanism for attaining the level of participation that is necessary for authentic research and meaningful results.

In the literature review I gave some examples of definitions of governance alongside their context of application. Rather than adopt a global definition for governance, in Chapter 5 I proposed a contextually specific working definition for governance of community-based research as “an organized process whereby members of defined communities, in collaboration with academic researchers, democratically participate in making decisions towards producing new knowledge from the context and experience of their lives”. This definition captures the membership, the form and implied nature of the relationship of members (in collaboration), the attribution of power of members in relation to each other (‘democratically’ implying equals) and the purpose of the organized process (making decisions towards producing new knowledge) whilst indicating the knowledge from which members draw to make their decisions (from the context and experience of their lives). This definition also helps to clarify that

governance of community-based research and community-based research, although connected, are different phenomena. Although definitions of community-based research consistently include the notion of member participation in all aspects or phases of the research process, the study findings suggested that definitions of community-based research were not specific enough to incorporate governance, and a definition of governance for the context of community-based research is desirable for ensuring this aspect does not go unnoticed.

Participation in governance appears to revolve around three questions which collaboration members can democratically and collectively address and answer themselves. These are, what are the purposes of participation in governance; who participates in governance; and how can participants make decisions, that is, what mechanisms and procedures and modes of discussion can they utilize. The purposes of participation in governance are not necessarily reflected on, or are assumed. Some instrumental purposes, relate directly to the research for example, include to gain access to research populations, to gain access to scientific knowledge, or to lend a helping hand to a colleague. Others may not be related to research such as participating for prestige or simply for the experience. ‘Who participates?’ is a question of selection that also comprises issues of representation. But it is only through discussion that assumptions about representation are laid open, determining which people are best at representing populations and generating knowledge, thus paving the way for appropriate selection of potential participants in governance. There is often overlap between the three questions. For example, the third question of how a collaboration determines its structures, mechanisms and procedural tools of governance soon shows that membership is not a stand-alone structure or item, but is closely tied to participation and representation in collaborative governance.

None of the classic questions of governance specifically address participants and others’ expectations of participation nor ramifications for the quality of participation in governance. Because the literature of governance and the thesis inquiry have suggested that failures of governance occur when participation is not ideal, coming to agreement within a collaboration about the meaning of quality of participation seems important. Quality of participation can be related to the quality of the discussion or discourse that

takes place in research collaborations. Fung and Wright's notion of Empowered Participatory Governance is linked to Habermas's work in the sense that 'fair and competent discourse' and the best argument 'win(s) the day'. Empowered Participatory Governance is one design where the means and ends of governance are co-created through discourse, deliberation and planning (Fung & Olin Wright, 2003). However, more participation in terms of quantity as well as quality, although desired as an ideal, is sometimes not possible. Taking on the idea of 'good enough' participation in governance permits participants to think pragmatically, and make adjustments and accommodations that are acceptable.

Research governance and governance of community-based research

At this point in time, research governance in Canada appears to be undergoing significant redevelopment and change. One of the developments is the publication in 2010 of a new Tri-Council Policy Statement (TCPS2) on human research ethics (Canadian Institutes of Health Research et al., 2010). Chapter 6 of the TCPS2 deals with the governance of research ethics review, giving directions to university research ethics boards. Community-based research collaborations must conform to institutional REB requirements now based on the TCPS2. These directions and requirements place some boundaries on the extent of decision-making permissible by community-based research collaborations. A further development in the TCPS2 concerns the conduct of research involving the First Nations, Inuit and Métis Peoples of Canada which is separately addressed in Chapter 9. The chapter specifically recognizes different knowledge, including traditional and indigenous knowledge, but importantly, from the perspective of this thesis, the chapter is a recognition of a need to adapt governance of research for specific contexts. This also has implications for definitions of governance in other contexts of research.

Other research governance developments include steps taken by Canadian research funding agencies to engage citizens in agency work. At CIHR, citizen

engagement is defined as the “meaningful involvement of individual citizens in policy or program development” in which citizens “play an active role in defining issues, considering solutions, and identifying resources or priorities for action”.³¹ CIHR's Framework for Citizen Engagement identifies areas of focus for citizen engagement which include, in addition to public outreach and knowledge dissemination programs such as Cafés Scientifiques, “integrated knowledge translation”, which incorporates community-based research, as well as “collaborative research, participatory research, action-oriented research and co-production of knowledge” (Tetroe, 2007, p. 6), representation on CIHR's Boards and Committees, and involvement in the development of corporate and Institutes' strategic plans, priorities, policies, and guidelines. Other activities include the creation of opportunities for funding, such as for example, the CIHR's HIV/AIDS Research Initiative, which specifies the inclusion of “equal representation from experts and community representatives, including patients and community organizations, on its merit review committee”.³²

Whilst NSERC's Partnership Programs which “foster collaborations between university researchers, colleges and other sectors, including government and industry” do not appear to involve members of the public, the Social Sciences and Humanities Research Council of Canada (SSHRC), which originated the Community-University Research Alliance (CURA) funding program, is undergoing revisions of program architecture that have implications for public engagement and governance. New partnership programs are formalized requiring evidence of commitment from non-academic partners which may include, “an agreed-upon governance and/or management structure, a mutually determined methodological approach with established roles and responsibilities, a memorandum of understanding, or other sources of evidence endorsed by the partners”. The text goes on to say, “While the formality of partnerships may vary, a formal partnership is grounded in trust and mutual respect, with partners contributing in a meaningful way to the success of the endeavour. This may include, for example,

³¹ <http://www.cihr.ca/e/41592.html>. Accessed April 19, 2011.

³² <http://www.cihr-irsc.gc.ca/e/41287.html>. Accessed April 19, 2011.

sharing in intellectual leadership or providing expertise. The partner is also expected to provide cash and/or in-kind contributions”.³³ Current revisions of program architecture ask for greater demonstration of partnership and commitment from community partners than previously required. The size of recent CURA awards and research teams also suggest that it is likely only large community organizations that can donate in-kind resources to community-based research projects, thus excluding the participation of smaller organizations, as respondents in the thesis study also intimated as possibilities. Additionally, any studies of governance or community-based research which focus on the subject matter of health are no longer funded by SSHRC.³⁴

At the same time as new directions unfold at research funding agencies, there is greater emphasis in Canadian universities on public outreach, the development of university partnerships with private and public sectors, and citizen engagement in a number of different ways. However, a general lack of home institution recognition or credit given to academics engaged with research-related community activities beyond the university walls, reported in the thesis study as a disincentive to participation, suggests a barrier to optimizing academic participation but also with the consequences of limiting community members’ participation in governance activities associated with community-based research.

A CIHR-authored discussion about citizen participation has stated, “the vehicles already exist ... but a new way of thinking is needed to ensure inclusiveness and fair representation of citizens in CIHR's decision-making structures and in its research programs”.³⁵ This statement demonstrates a recognition not only of citizen participation but also the importance of governance for the research funding agency. In this statement, governance is not presented as a solution to problems, but as a democratic mechanism which is only as good as the extent to which it is used.

³³ <http://www.sshrc-crsh.gc.ca/funding-financement/programs-programmes/definitions-eng.aspx#a10>. Accessed April 19, 2011.

³⁴ http://www.sshrc-crsh.gc.ca/funding-financement/apply-demande/background-renseignements/selecting_agency-choisir_organisme_subventionnaire-eng.aspx. Accessed April 19, 2011.

³⁵ <http://www.cihr-irsc.gc.ca/e/41293.html>. Accessed April 19, 2011.

Contributions of the thesis

Contribution to the population health literature

Making a new contribution to disciplinary knowledge through this thesis is both an academic and a personal goal. Although population health does not have formal status as a discipline in the organization of knowledge, population health is my primary affiliation, and the source of my training and theoretical leanings. The work of this thesis is therefore intended as a contribution to the population health literature. It is an analysis of one component of the knowledge process, governance, and extends thinking about the role of decision-making in the knowledge process, but particularly within the phase of knowledge production through research collaboration.

Research papers

A study of governance of community-based research from the perspectives of participants has not previously been undertaken, and the three research papers of this thesis are all original contributions.

Conceptual framework

A conceptual framework has been contributed through the thesis. The conceptual framework for a review of the literature in Chapter 3, suggested two main pathways that connect different disciplinary literatures to form a literature of governance of community-based research. This conceptual framework linking governance theory to knowledge production as community-based research and relating the democratic characteristics of both has not been articulated elsewhere.

Knowledge translation

Additional contributions are planned although they have yet to be implemented. The translation of the findings into a product or products that can be used by community and university members governing community-based research collaborations has been proposed as a practical project. With the participation of other interested parties, I plan to publish a handbook on governance of community-based research written in plain language to be distributed through the University of Ottawa website, and elsewhere as applicable, such as the CES4Health (Community-Engaged Scholarship for Health) of the Community-Campus Partnerships for Health. The second proposed contribution is an academic meeting with community leaders and university researchers to discuss

governance of community-based research. An application is planned through the CIHR Meetings, Planning and Dissemination grants program.

Study limitations and suggestions for future research

In this section I propose some limitations of the thesis, and make some suggestions as to future research. The reflection on method limitations is brief. A detailed account of the methods with some associated discussion can be found in an earlier chapter.

Apart from the literature review, the research design utilized a single method (interviews) for data collection. A single qualitative research method used to generate findings could be thought to restrict a researcher's discussion and interpretation, as well as any extrapolation to different contexts. Any one qualitative method such as interviews, however, can provide rich data. These data can be descriptive, and also act as a springboard for theory development, discussion and further research. In this study, the wide basis of experience from which respondents drew, and the depth of the interviews, has provided rich data for analysis and discussion, and a basis from which to suggest further work. Revealing information about individual community-based research collaborations and the individuals involved in them has potential to breach anonymity, and is unethical. The protection of respondents in the reporting of the data has resulted in a limitation that restricted the ability of the researcher to relate identifying features of the respondents, the studies that they were involved with and full explanation of some of the examples given. Additionally, when specificity in description is not possible nor desirable, terms are employed as they would be in day-to-day usage. The total sample size is known to readers, so 'many' respondents, for example, is an expression of an experience that was common for respondents.

Limitations on identity and description can be addressed in other ways. Reconstruction of a number of individual cases to make one or several stories which can be validated for their truthfulness through the feedback of respondents or others who have had similar experience, is one method (Papadopoulos, Scanlon & Lees, 2002). The method of seeking to validate reconstructed stories with research respondents also has the

benefit of providing feedback directly to researchers and respondents. Although desirable, reconstruction was not carried out for this study.

In the first research paper, Chapter 4 in the thesis, respondents made references to collaboration documentation. Although some respondents provided documentation to the researcher, systematic collection of documentation did not take place. Documents provide an adjunct to interviews, and may have provided additional data for analysis, and support (or not) for interpretation. Documentation has particular value in research designs that use multiple forms of data, including interviews and document (texts) for data analysis, such as in case studies and ethnographic research (Smith, 2007; Stake, 1995; Yin, 2007). A case study approach to study the social organization of knowledge production is possible: Thurston, for example, used a case study approach and a postal survey to model public participation in regional health policy (Thurston et al., 2005).

Future research

A number of questions have been raised through the conduct and the findings of this study, and some selected issues are suggested here for future investigations. These are using the qualitative findings to inform quantitative work in mixed methods research; further research and testing of the study's theory-based practice guidelines for governance and transfer to other contexts, development of measurements of governance and participation, and conceptualizing governance and population health.

Mixed methods research has gained significant support in recent years (Tashakkori & Teddlie, 2003; Westhues, Ochocka, Jacobson, Simich, Maiter, Janzen, et al., 2008). A claim that is made for mixed methods research is that it is "more than collecting and analyzing both kinds of data: it also involves the use of both approaches in tandem so that the overall strength of a study is greater than either qualitative or quantitative research" (Creswell, 2010, p. 4). I suggest that this qualitative study and its findings can be used as a basis for developing questions for use in survey research.

For the development of a model of collaboration the literature has provided an example using quantitative methods. Using structural equation modeling, Thomson, Perry and Miller (2009) have developed a model of collaboration in which assumptions are made about the operation and interactions of components, directly observed variables and those that are measured indirectly (Thomson, Perry & Miller, 2009). Although the

components are possibly transferable to collaborations in different contexts, the model itself may not reflect the theoretical versatility of governance, and the measurement of collaboration has a different sense to that of participation. As Thomson, Perry and Miller suggest, their contribution is one such model in a “terrain for a family of models on collaboration” (Thomson, Perry & Miller, 2009, p. 49). In terms of building a theory of collaborative governance, consideration of collaborations in a full range of sectors, including the non-profit sector warrants further study.

As noted earlier in the thesis, the literature of community-based research is accompanied by principles that prescribe how collaborations should proceed. The findings suggest that such principles are ideal-types, which can act as a default in the absence of collaboration-developed guidelines, but they are not necessarily suited to all collaborations. For governance of community-based research collaborations to be effective for knowledge co-production, and legitimate in a democratic sense, prescriptions for governance need to be debated, discussed and determined by all collaboration members, bearing in mind that what is determined as ‘good enough’ may set the bar. The issue of theory-based practice guidelines for governance, as I have framed them, requires further research and confirmation.

Some theoretical findings of this study may be transferable to other governance contexts where participation by non-institutional actors in collaboration with institutional actors is required, but this requires further research and testing. Green and colleagues have developed a survey intended to be used by reviewers assessing the participatory nature of research collaborations (Green, George, Daniel, Frankish, Herbert, Bowie, et al., 1995). This survey is a useful tool for collaborations, but makes some assumptions based on uniformity in governance. As our research has suggested, individual research collaborations have sometimes developed their governance autonomously and participation is variable, therefore the survey needs to be adapted and adaptable to a variety of collaborations.

Measuring governance and aspects of governance are just as difficult as the definitions of governance are “slippery” (Chhotray & Stoker, 2009). The development of measurements that can support the ‘classic’ qualitative questions of governance are no

doubt helpful, but must be accompanied by an underlying contextual theory that can explain why the findings can or should deserve an attribution of ‘good’ governance.

Some questions related to the thesis that bear further investigation in relation to the area of population health, while outside the remit of this project, offer important ideas for future research. These include: “How do the governing arrangements of research affect the population’s health? Can improved participation in governance of community-based research collaborations improve population health? How can effective governance of community-based research collaborations contribute to improving the health of communities and populations?” Participatory activities have been argued as health-enhancing or health promoting. Public participation in decision-making, theories of participation and participatory research (Freire, 1970), and theories of participatory governance (Chhotray & Stoker, 2009; Cornwall & Coelho, 2007; Steyn, 2010) have all been linked to positive impacts related to health including: personal empowerment of individuals (Wallerstein & Duran, 2003; Wallerstein & Duran, 2006), and social and community change including examples of participatory budgeting and participatory government in Puerto Alegre and Kerala (Chhotray & Stoker, 2009; Fischer, 1993). Governance in the context of community-based research is a new focus. The generation of related questions and empirical research to this topic could benefit from the collective thinking and input of community and university members.

Conclusion

In setting the context for a recent book that looked at different disciplinary takes on governance, Chhotray and Stoker claim that the rapid increase in study of governance is not an academic fashion but a response to a changed world marked by globalization and democratization. Chhotray and Stoker believe that it is citizens’ own expectations of influencing decisions that affect them that have served to increase the pressure on institutionalized systems of decision-making to include them (Chhotray & Stoker, 2009). Changing, reforming or even establishing shared decision-making for the first time in some political contexts to increase legitimacy and effectiveness is complex. As the experience of the respondents in this study has suggested, an assured and positive

relationship of citizenship and democratic participation across contexts of governance is an ideal, rather than something that simply emerges from collaboration.

The interrelationships of democratization and the contexts of governance of knowledge production, have yet to be fully conceptually mapped. The organization or governance of knowledge production through local community-based research is but a small contributor in the total picture. However I suggest that the ‘classic’ questions of governance and the study’s findings can start this conceptualization, encouraging a critical and reflective view of governance and its arrangements for knowledge co-production. There is growing recognition of the value of local and lay knowledge as a legitimate basis for participation in governance, and positive steps to give governing roles and voice to those who are also affected by the knowledge that is generated by research. These trends suggesting an increasing democratic orientation in knowledge production are encouraging.

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APPENDIX A STUDY DOCUMENTATION

Recruitment text

Date

Dear (name)

I am writing to you in your capacity as an experienced community-based research collaborator with a request for a personal interview for a research study, “Arrangements of governance in community-university research collaborations in Canada” that is being conducted by me, Vivien Runnels, working with the Centre of Governance at the University of Ottawa.

I am trying to determine how community-university research collaborations make arrangements to govern research collaborations, what arrangements they make and how collaborators experience and judge the outcomes of the arrangements. The people that I hope to interview will be community and university or college members of research collaborations in food insecurity and homelessness from across Canada.

The information that will be gained from this study we believe will be helpful to members of research collaborations who are engaged or about to become involved in social determinants of health research, including food insecurity and homelessness, within the Canadian context.

Would you please participate in an interview? I can assure you of confidentiality in taking part in the interview as well as anonymity in the reporting of results. I expect the interviews to last no longer than 45 minutes to an hour. Taking part in an interview is a voluntary activity, and you are under no obligation to participate.

In preparation for a possible interview, I have attached a consent form which is a document that outlines your rights as a participant. I have also attached a brief description of the study and a list of the question areas that we will talk about during the interview. If you would prefer to receive the consent documents and study information by regular mail or fax, please let me know. You will be contacted by telephone to set up an appointment.

Oversight of the study's ethical conduct is by the University of Ottawa Research Ethics Board which has approved the conduct of the study. My research is being supervised by Dr. Caroline Andrew (e-mail address removed) of the Centre of Governance at the University of Ottawa. I have been funded in part through a doctoral award from the Social Sciences and Humanities Research Council of Canada, and a University of Ottawa Scholarship of Excellence.

Would you please participate in an interview? I would very much appreciate your agreement. Please would you indicate your involvement by reading, signing and returning the attached form by fax, regular mail or electronic mail (with electronic signature attached)?

If you have any further questions or would like to discuss this research in person, please contact me, Vivien Runnels, by e-mail (e-mail address removed) or by telephone at (telephone number removed).

Thank you very much. We really look forward to talking with you.

Sincerely

Vivien Runnels

Researcher/PhD candidate

Vivien Runnels

Institutional address: Centre on Governance

55, Laurier Avenue East

Desmarais Building, Room 3172

Ottawa, Ontario, Canada

K1N 6N5

Fax: (fax number removed)

Email: (e-mail address removed)

Description of study

Community-based participatory research (CBPR) or community-based research, emerged as an approach to research in the second half of the 20th century. The approach challenged the rationale for and conduct of research by single discipline researchers. It provided grounds to link the scientific knowledge of universities, societies' traditional holders of knowledge, with the lay or local knowledge of communities, and it made the case that authentic and meaningful community-based research needed to be conducted by researchers in collaboration with members of the community. Now widely used, CBPR appears in a variety of formats and settings to answer a variety of research topics, and is increasingly documented.

The arrangements that the collaboration makes, to share, allocate and coordinate responsibilities, resources and knowledge, however are not well described or documented. These arrangements are distinct from the work or implementation of the research or project management, and conveyed through the term “governance”. Arrangements of governance have implications for the conduct of research. The literature also suggests that the arrangements of governance have effects on the degree of participation of collaboration members and the community in general, and the authenticity, meaning and utilization of the research to effect social change. Through personal interviews with community and university members of collaborations who are researching homelessness and food insecurity, we will gain some insights into how community-university research collaborations make arrangements to govern research

collaborations, what sort of arrangements they make and how collaborators experience and judge the arrangements. By describing arrangements of governance and publishing the findings in peer-reviewed publications and plain language formats, we expect to invite consideration of arrangements of governance in discussions of CBPR and collaboration building by collaboration members and other stakeholders.

List of question areas to be covered during the interview

Thinking about one of the community-based participatory research collaborations that you were involved with

- 1) Describe your part in it - how, why did you become involved and what ensued?
- 2) What were the arrangements that the collaboration made to govern or lead—such as board and committee structures, written documentation?
- 3) By whom, when, where and why were decisions made about how the collaboration was going to govern/ function?
- 4) What activities or procedures to lead or govern the community-based research did the collaboration perform?
- 5) How were decisions made as to the development of arrangements of governance that you just described?
- 6) Was there anything in your experience of governance with this collaboration that stood out or was different from other experiences? What were they and why? What would you change and why?
- 7) In your experience, what were the issues that required leadership which you discussed? Were there issues that you thought you should have discussed yet didn't?
- 8) What were the challenges for the governance of the collaboration?
- 9) What arrangements do you think worked well or were helpful and successful for your collaboration's governance?
- 10) What arrangements do you think did not work well or were not helpful or successful?
- 11) Were you satisfied with the arrangements that were made to govern the collaboration? Why or why not?

12) What arrangements of governance would you suggest would be most helpful to a new community-based research collaboration?

Setting up an appointment to interview – telephone script

Hello.(Name of potential participant)

My name is Vivien Runnels. I am a PhD student at the University of Ottawa. I am calling to ask you to participate in an interview for a research study that is looking at governance of community-based research collaborations.

Do you recall receiving an email from me about the study? You may remember I sent you some information about the study and consent forms for your possible participation.

(OR My name isand I am calling on behalf of Vivien Runnels of the Centre on Governance at the University of Ottawa, and I am calling to ask you about participating in an interview for a research study that is looking at governance of community-based research collaborations. Have you received the email from Vivien Runnels? You may remember she sent you some information about the study and consent forms for your possible participation?)

IF YES, Will you participate in an interview please?

IF YES, Can we set up a time and date for an interview, please? When would be convenient for you?

(If potential interviewee is in Ottawa and area, ask “Would you prefer to be interviewed over the phone or in-person?") Set up a time and date for an interview.

(If NO i.e. potential participant did not receive the email, I can send you this information by email today. Can I tell you something about the study now and why we are asking for your participation? (If YES, after giving the information, ask “Will you participate in an interview please?” IF the answer to this question is NO, say “Thank you very much for your time. By all means, please contact me (Vivien Runnels) if you have any questions. Goodbye.)

(IF NO to participating in an interview say “thank you very much for your time. By all means, please contact me (Vivien Runnels) if you have any questions at any time. Goodbye”.)

Thank you. Before we close could I please ask you to return the signed consent forms to me please prior to the interview? If there is any change to the interview plans, feel free to contact me at (telephone number removed) to make those changes.

Do you have any questions?

Thank you very much for agreeing to participate in an interview. I (I know Vivien will..) look forward to talking to you on (Repeat day, date and time. Be sure to confirm the time zone of the participants.)

Goodbye.

Contact information for mailing consent

Vivien Runnels

Institutional address:

Centre on Governance 55, Laurier Avenue East

Desmarais Building, Room 3172

Ottawa, Ontario, Canada

K1N 6N5

Fax: (Fax number removed)

Email: (e-mail address removed)

OR by scanning the signed copy and sending it to Vivien Runnels electronically.
(e-mail address removed)

Or by fax (Fax number removed)

Consent Form

“Arrangements of governance in community-university research collaborations in Canada”

I am invited to participate in the above-mentioned research study conducted by Vivien Runnels (researcher/PhD candidate) and supervised by Professor Caroline Andrew (e-mail address removed) at the University of Ottawa. Vivien Runnels is funded in part by the Social Sciences and Humanities Research Council of Canada, and the University of Ottawa. The study will start in 2008 and end in 2009. Interviews will be held in 2008.

Study purpose: This study aims to describe how community-university research collaborations make arrangements to govern the collaboration, what arrangements collaborations make to govern a research collaboration, and how collaborators experience and judge these arrangements.

The personal interviews will involve community and university or college collaborators from community-based research collaborations researching homelessness and food insecurity. Some of those interviewed will be members of publicly-funded research collaborations.

My role as a participant in this research study will be to offer information that will assist the researcher in answering her questions about how community-university research collaborations govern. I will be asked about my experience and my personal opinions.

Participation:

Interview: My participation will consist of participating in a single one-on-one interview with Vivien Runnels or her appointed research assistant. The interview will last approximately 45-60 minutes.

As part of the invitation to be interviewed, I will have received a list of the question areas to be covered in the interview, in sufficient time before the interview so that I have time to consider them.

I may at any time during the interview ask the researcher any question about any part of the research study that is being conducted.

The interview content will be transcribed and analyzed by the researcher for the purpose of the study.

Follow up to interview: No formal debriefing will be conducted at the end of the interview. I may agree or disagree to consider follow-up questions after the interview to clarify any points of information.

Anonymity of responses: I understand that the contents of the interview may be used for anonymous citation in the study's findings.

Opportunity to give feedback: In the last phase of the study in 2009 I and all other individuals interviewed will be invited to provide feedback on the study's findings, presented in the form of a plain language document intended for use by community-university research collaborations.

I can choose to receive a summary of the study findings whether I provide feedback or not.

At the end of the interview, I will be asked to give permission or not to the researcher to contact me after the interview to clarify any points of information.

Risks of participation: No deception is involved in the study and no risk to participants is anticipated. Participants are being interviewed on the basis of their membership of a community-based research collaboration. All participants are adults, many of whom have considerable life experience: issues of vulnerability and power differentials do not arise between the interviewer and the participants.

Benefits: My participation in this study will provide greater insight into how, community-university research collaborations make arrangements to govern research collaborations, what sort of arrangements they make and how collaborators experience and judge the outcomes of the arrangements. Combined with other interviews the findings will possibly be of assistance to other research collaborations. I may gain personal benefit through personal reflection on the questions posed during the interview.

Confidentiality: I have received assurance from the researcher that my participation in this study is strictly confidential to her and the research supervisor. The contents will be used for the purposes of the research study, the production of research literature and the researcher's doctoral thesis, and plain language materials for distribution to community-based research collaborations for their information.

Anonymity: Anonymity will be protected by removing any personal identifiers from transcripts. In the reporting of results, direct quotations may be used and any identifiers removed. Those being interviewed are involved in community-based research of homelessness and food insecurity. The large numbers of community-based participants and university researchers in Canada who are involved in such research will ensure anonymity. Anonymity of all participants will also be ensured by removing any geographical identifiers

Conservation of data: Interviews will be digitally recorded. The data will be transcribed into text. Digital and electronic text files will be stored on password-protected sites of Vivien Runnels' personal computer. Hard copies of transcripts will be kept locked by Vivien Runnels in her private home office (also the location where the interviews will be privately conducted) , until 2013 at which time the necessity of continuing to store data will be reviewed. Hard copies will be shredded and digital files erased. Only the researcher Vivien Runnels and her supervisor, Dr. Andrew will have access to the raw data.

Voluntary Participation: I am under no obligation to participate. If I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions. If I choose to withdraw, all data gathered until the time of withdrawal will be destroyed unless I indicate otherwise.

Consent Form – Arrangements of governance in community-university research collaborations in Canada

Acceptance: I, _____ (*Name of participant*), understand the consent form and I agree to participate in an interview which will be conducted by Vivien Runnels or her designate, and to the digital recording of an interview in the research study named above. I understand that the contents of the interview may be used for anonymous citation.

I, _____ (*Name of participant*), would like /would not like (*please delete as applicable*) to receive a summary of the study's findings and include my address for this purpose. (*email address or mailing address*):

Where hard copies of the consent form are used, there are two copies of the consent form, one of which is mine to keep. –

Signature of Participant:

Date:

Signature of Researcher:

Date:

If I have any questions about the study, I may contact the Researcher or her supervisor as follows:

Vivien Runnels (Doctoral Researcher) OR Caroline Andrew (Supervisor) (e-mail address removed)

Institutional address: Centre on Governance 55, Laurier Avenue East
Desmarais Building, Room 3172
Ottawa, Ontario, K1N 6N5 Canada
Fax: Fax number removed

Email: e-mail address removed

If I have any questions or complaints regarding the ethical conduct of this study, I may also contact:

Institutional position and address

Protocol Officer for Ethics in Research, University of Ottawa,
Tabaret Hall, 550 Cumberland Street, Room 159,

Ottawa, ON, K1N 6N5,

Tel.: email address and telephone number removed

Please sign the consent form and mail, fax or scan and email it to

Vivien Runnels

Institutional address: Centre on Governance

55, Laurier Avenue East

Desmarais Building, Room 3172

Ottawa, Ontario, K1N 6N5 Canada

Fax: Fax number removed

Email: e-mail address removed

Thank you very much for your time and cooperation!

Letter to colleagues

Dear (colleague)

I am writing to ask you if you would be willing to help me with my research study for my doctoral thesis.

My thesis focuses on the study of governance of community-university research collaborations (or community-based participatory research collaborations), in particular, collaborations which study homelessness or food insecurity. I would like to personally interview members of community-based research collaborations who are members of the community and the university.

In order to get the process started, I will be creating a database of community-based participatory research collaborations working on homelessness and food insecurity in Canada. Would you be willing to let me know of any collaborations which you know about, and/or would you be willing to promote the study through your network or website? Although your website contains a list of members that is publicly accessible, I would be very appreciative if you would let me know of any research collaborations who conduct community-based research.

After I have completed the interviews, the research findings drawn from the interviews and the research literature will be synthesized in order to produce a plain language document on governance of community-based participatory research collaborations, that is intended to be useable by a wide range of members of the public, and which I hope will be useful for research collaborations. Research participants themselves will have the opportunity to provide feedback on the study findings and comment on the production of the documents and on knowledge transfer. I hope that several participants will choose to share their comments.

In the future, I also plan on organizing focus groups with people who have taken part in community based participatory research studies on homelessness and food insecurity in order to validate the findings and conclusions and to determine if the documents will be useful (or not, if this is the case) for other research collaborations. I hope that you are willing to share your knowledge with me and help me to develop a database of community-based participatory research collaborations of homelessness and food insecurity in Canada.

Sincerely

Vivien Runnels

Message de recrutement

La date:

Madame, Monsieur,

Par la présente, je souhaite vous inviter à participer à la recherche « Arrangements of governance in community-university research collaborations in Canada ». C'est une recherche que je (Vivien Runnels) mène en collaboration avec le Centre d'études en gouvernance de l'Université d'Ottawa. Vous possédez une longue expérience en tant que collaborateur/trice en recherche communautaire, et c'est à ce titre que nous aimerions vous inviter à participer à une entrevue.

L'objectif de la recherche est de comprendre comment les ententes qui gouvernent les alliances ou partenariats de recherche universités-communautés sont conclues, comprendre la nature des ententes, et finalement, comprendre l'expérience des partenaires relativement à ces ententes et l'évaluation qu'ils en font. Mon intention est de tenir des entrevues avec des membres de la communauté, des universitaires et des enseignants du niveau collégial qui participent à des projets de recherche concertés qui portent sur l'insécurité alimentaire et l'itinérance au Canada.

Nous estimons que l'information qui découlera de l'étude sera utile et pourra aider les partenaires de projets de recherche concertés qui sont engagés ou sur le point d'être engagés dans une recherche qui porte sur les déterminants sociaux de la santé, ce qui comprend l'insécurité alimentaire et l'itinérance, dans le contexte canadien.

Accepteriez-vous, s'il vous plaît, de participer à une entrevue? Votre confidentialité sera assurée lors de l'entrevue et votre anonymat sera respecté lors de la publication des résultats de la recherche. L'entrevue sera d'une durée de 45 minutes à 60

minutes, tout au plus. La participation à une entrevue est un choix volontaire, vous n'êtes aucunement obligé de participer.

Afin de préparer une éventuelle entrevue, vous trouverez ci-joint un formulaire de consentement qui explique vos droits en tant que participant. Vous trouverez aussi en pièce jointe une brève description de l'étude ainsi qu'une liste des questions et sujets qui seront abordés pendant l'entrevue. Si vous préférez recevoir les documents de consentement et l'information au sujet de l'étude par la poste ou par télécopieur, n'hésitez pas à me le signaler. Vous serez contacté par téléphone afin de fixer un rendez-vous.

L'étude a obtenu l'approbation du comité de déontologie de l'Université d'Ottawa qui s'assure du déroulement éthique de la recherche. Ma recherche est dirigée par Caroline Andrew, directrice du Centre d'études en gouvernance de l'Université d'Ottawa. Mes études sont en partie financées par une bourse d'études doctorale du Conseil de recherche en sciences humaines du Canada (CRSH) et par une bourse d'excellence de l'Université d'Ottawa.

Votre consentement serait fort apprécié. Auriez-vous l'obligeance de me faire part de votre participation en lisant, en signant et en retournant le formulaire ci-joint par télécopieur, la poste ou par courriel (en y joignant votre signature électronique)?

Si vous avez des questions ou si vous souhaitez discuter de la recherche en personne, n'hésitez pas à me contacter, Vivien Runnels, par courriel ou par téléphone. Je vous remercie et au plaisir de faire votre connaissance.

Salutations distinguées,

Vivien Runnels

Centre d'études en gouvernance
 55, avenue Laurier Est
 Pavillon Desmarais, pièce 3172
 Ottawa (Ontario) K1N 6N5
 Télécopieur :
 Courriel :

Description de l'étude

La recherche communautaire (community-based participatory research (CBPR)) émerge comme voie de recherche pendant la deuxième moitié du 20^e siècle. L'approche remet en question la justification pour la recherche menée par des chercheurs provenant d'une seule discipline. De plus, l'approche fournit des motifs pour lier la connaissance scientifique du milieu universitaire, le lieu traditionnel de la connaissance des sociétés, avec la connaissance locale des communautés. Finalement, cette voie de recherche fait la preuve que pour être authentique et significative, la recherche communautaire doit être menée par des chercheurs en collaboration avec les membres de la communauté. La recherche communautaire est une approche qui a largement été adoptée, elle est utilisée dans de multiples contextes et prend différentes formes afin de répondre à une grande variété de questions de recherche. Par ailleurs, cette méthode de recherche est de plus en plus documentée.

Cependant, les ententes que les alliances ou partenariats de recherche adoptent en ce qui concerne le partage, l'attribution et la coordination des responsabilités, des ressources et de la connaissance, ne sont pas adéquatement décrites ni documentées. Ces ententes diffèrent du travail, de la mise en œuvre de la recherche, ou encore de la gestion de projet. C'est ce qui est entendu par le terme « gouvernance ». Les ententes de gouvernance ont des implications pour le déroulement de la recherche. De plus, la littérature scientifique suggère que les ententes de gouvernance ont des effets sur le degré de participation des partenaires et de la communauté en général ainsi que sur

l'authenticité, le sens et l'utilisation qui est faite de la recherche pour promouvoir le changement social. La tenue d'entrevues avec des partenaires issus de la communauté et du monde universitaire, et qui participent à des projets de recherche communautaire qui portent sur l'itinérance et l'insécurité alimentaire, permettra de mieux comprendre comment les participants à ces alliances de recherche universités-communautés concluent les ententes qui gouvernent les projets de recherche concertés, de comprendre la nature des ententes et finalement de comprendre l'expérience que les collaborateurs font des ententes et comment ils les évaluent. La description qui sera faite des ententes de gouvernance ainsi que la publication des conclusions de la recherche dans des revues scientifiques et sous forme de publications rédigées dans un langage clair, simple et accessible à la communauté et au grand public permettra de tenir compte de la question des ententes de gouvernance lorsqu'il sera question de recherche communautaire et de faire la promotion de la collaboration auprès des partenaires et d'autres parties prenantes.

Questions et sujets qui seront abordés pendant l'entrevue

En vous référant à une recherche communautaire à laquelle vous avez déjà participé...

1) Veuillez décrire votre rôle dans la recherche communautaire. Comment et pourquoi avez-vous décidé d'y participer? Que s'est-il ensuivi?

2) Quelles ententes furent prises par le partenariat pour gouverner ou faire preuve de leadership? Par exemple, au niveau de la composition du conseil d'administration et du comité, de la documentation écrite?

3) Par qui, quand, où et pourquoi les décisions au sujet du fonctionnement et de la gouvernance du partenariat furent-elles prises?

4) Quelles activités ou procédures pour mener ou gouverner la recherche communautaire ont été exécutées ou accomplies par le partenariat?

5) Comment les décisions relatives au développement d'ententes de gouvernance que vous venez de décrire furent-elles prises?

6) Il y a-t-il un aspect de votre expérience de la gouvernance de ce partenariat qui se démarque ou qui diffère de vos autres expériences? Quelles sont ces différences? Pourquoi cette expérience est-elle différente? Que changeriez-vous et pourquoi?

7) Selon votre expérience, quels étaient les sujets qui nécessitaient un leadership et qui ont fait l'objet de discussion? Il y avait-il des sujets qui, selon vous, auraient dû faire l'objet de discussion, mais qui ne l'ont pas été?

8) À quels défis était confrontée la gouvernance du partenariat?

9) Selon vous, quelles ententes ont bien fonctionné, ou furent efficaces et une réussite pour la gouvernance du partenariat?

10) Selon vous, quelles ententes n'ont pas bien fonctionné ou ne furent ni utiles, ni une réussite pour la gouvernance du partenariat?

11) Étiez-vous satisfait des ententes prises pour gouverner le partenariat? Si oui, pourquoi? Sinon, pourquoi?

12) Selon vous, quelles seraient les ententes de gouvernance les plus utiles pour un nouveau projet de recherche communautaire concerté?

Organisation d'un rendez-vous – scripte pour appel téléphonique

Bonjour (nom du participant potentiel),

Je m'appelle Vivien Runnels. Je suis candidate au doctorat à l'Université d'Ottawa. Je vous téléphone pour vous inviter à participer à une entrevue dans le cadre d'un projet de recherche qui porte sur la gouvernance des projets de recherche communautaire concertés.

Vous vous souvenez peut-être du courriel que je vous ai fait parvenir au sujet de l'étude? Je vous avais fait parvenir de l'information au sujet de l'étude ainsi que des formulaires de consentement en vue de votre éventuelle participation.

(OU, Mon nom est... et je vous appelle de la part de Vivien Runnels du Centre d'études en gouvernance de l'Université d'Ottawa. Je vous appelle pour vous inviter à participer à une entrevue dans le cadre d'une étude qui porte sur la gouvernance des projets de recherche communautaire concertés. Avez-vous reçu le courriel de Vivien Runnels à cet effet? Elle vous a fait parvenir de l'information au sujet de l'étude ainsi que des formulaires de consentement en vue de votre éventuelle participation.).

SI OUI, Acceptez-vous de nous accorder une entrevue?

SI OUI, Peut-on fixer la date et l'heure de l'entrevue? Quel moment vous conviendrait? (Si le participant potentiel habite Ottawa ou la région, leur demander « Préférez-vous que l'entretien ait lieu en personne ou par téléphone? »). Fixer la date et l'heure de l'entrevue.

(SINON, c.-à-d. que le participant potentiel n'a pas reçu le courriel (l'informer) je peux vous faire parvenir l'information par courriel aujourd'hui. Est-ce que je peux brièvement vous parler de l'étude et vous expliquer pourquoi vous êtes invité à y

participer? (SI OUI, après avoir donné cette information, demander « Acceptez-vous de nous accorder une entrevue? ». Si la réponse à cette question est NON, dire « Merci beaucoup pour le temps que vous nous avez accordé. Si vous avez des questions, n'hésitez pas à me contacter (Vivien Runnels). Au revoir».).

(SINON, la personne refuse de nous accorder une entrevue, dire « Merci beaucoup pour le temps que vous nous avez accordé. Si vous avez des questions, n'hésitez pas à me contacter (Vivien Runnels). Au revoir».).

Merci. Avant de raccrocher, est-ce que je pourrais vous demander de me retourner les formulaires de consentement signés avant l'entrevue? Si vous souhaitez modifier la date et/ou l'heure de l'entrevue, n'hésitez pas à me contacter au (no. de téléphone).

Avez-vous des questions?

Merci beaucoup de nous accorder une entrevue. Au plaisir de discuter avec vous le (répéter le jour, la date et l'heure. S'assurer de confirmer le fuseau horaire des participants).

Au revoir.

Adresse postale pour l'envoi des formulaires de consentement par courrier :

Vivien Runnels
Centre d'études en gouvernance
55, avenue Laurier Est
Pavillon Desmarais, pièce 3172
Ottawa (Ontario) K1N 6N5
Télécopieur :
Courriel :

Vous pouvez numériser (scanner) le formulaire signé et le faire parvenir à Vivien Runnels par courriel à :

Vous pouvez aussi nous faire parvenir le formulaire signé par télécopieur au (no. du télécopieur).

Formulaire de consentement

“Arrangements of governance in community-university research collaborations in Canada”

(Dispositions de la gouvernance dans les alliances de recherche universités-communautés au Canada)

Invitation à participer : Je suis invité à participer à la recherche nommée ci-haut qui est menée par Vivien Runnels (chercheure et candidate au doctorat) et dirigée par la professeure Caroline Andrew de l’Université d’Ottawa. Les études doctorales de Vivien Runnels sont financées en partie par le Conseil de recherche en sciences humaines du Canada (CRSH) et l’Université d’Ottawa. L’étude débutera en 2008 et prendra fin à l’automne 2009. Les entrevues auront lieu en 2008.

But de l’étude : Les objectifs de l’étude sont les suivants : décrire comment les projets de recherche communautaire concertés établissent des ententes qui gouvernent le partenariat; décrire les ententes conclues par les partenaires de recherche pour gouverner le partenariat de recherche, et décrire l’expérience que font les partenaires des ententes et comment ils les évaluent.

Les entrevues se feront avec des partenaires de projets de recherche communautaire concertés qui portent sur l’itinérance et l’insécurité alimentaire. Ces personnes sont issues du milieu universitaire et collégial ainsi que de la communauté. Au nombre des participants seront des membres de projets de recherche communautaire concertés dont la recherche est subventionnée par le secteur public.

Participation : Ma participation consistera essentiellement à fournir de l’information et ainsi aider la chercheure à répondre aux questions de recherche qu’elle

s'est fixées quant à la façon dont les alliances de recherche universités-communautés établissent les ententes qui gouvernent les alliances ou partenariats, et comprendre la nature des ententes et l'expérience que font les partenaires des ententes et l'évaluation qu'ils font des résultats. On me demandera de parler de mon expérience et de mes opinions personnelles.

Entrevue : Ma participation consistera à participer à une entrevue d'une durée de 45 à 60 minutes avec Vivien Runnels ou son assistant de recherche désigné.

La chercheure m'a fait parvenir une liste des questions et des sujets qui seront abordés pendant l'entrevue au moment de m'inviter à participer à la recherche et donc suffisamment de temps à l'avance pour me permettre d'entamer une réflexion.

Je peux poser des questions à la chercheure à tout moment pendant l'entrevue au sujet de n'importe quel aspect de l'étude.

Le contenu de l'entrevue sera transcrit et analysé par la chercheure aux fins de l'étude.

Suivi : Aucune séance d'évaluation (de débriefage) n'aura lieu à la fin de l'entrevue. Je peux choisir de répondre ou non à des questions complémentaires ou de suivi dont le but serait de clarifier certaines informations à la suite à l'entrevue.

Anonymat des réponses : Je comprends que le contenu des entrevues pourrait être cité dans les publications qui découlent de l'étude.

Possibilité de rétroaction : Pendant la dernière phase de l'étude (2009), toutes les personnes qui ont participé à une entrevue seront invitées à fournir de la rétroaction aux conclusions de l'étude qui seront présentées dans une publication rédigée dans un langage clair, simple et accessible pour les alliances de recherche universités-communautés.

J'ai fait part de mon intérêt à recevoir ce document sommaire à la fin de ce formulaire de consentement. Je peux recevoir le document, même si je choisis de ne pas fournir de la rétroaction.

À la fin de l'entrevue, on me demandera si j'accorde ou non la permission à la chercheuse de me contacter à nouveau après l'entrevue afin de clarifier certaines informations.

Risques : L'étude n'implique aucune déception et aucun risque pour les participants n'est anticipé. Les participants sont interrogés en leur qualité de membre d'un projet de recherche communautaire concerté. Tous les participants sont adultes et plusieurs d'entre eux ont une grande expérience de vie : des questions de vulnérabilité et de différence de pouvoir entre la chercheuse et les participants ne se posent pas.

Bienfaits : Ma participation à cette recherche permettra de mieux comprendre comment les alliances de recherche universités-communautés établissent des ententes pour gouverner les alliances ou partenariats de recherche, de comprendre la nature des ententes et l'expérience que font les partenaires des ententes et l'évaluation qu'ils en font. En conjonction avec d'autres entrevues, les conclusions de l'étude pourront être bénéfiques pour d'autres alliances de recherche. La réflexion que suscitera l'entrevue pourrait m'être enrichissante.

Confidentialité : J'ai l'assurance de la chercheuse que l'information que je partagerai avec elle restera strictement confidentielle et ne sera partagée qu'avec sa directrice de thèse de doctorat. Le contenu ne sera utilisé qu'aux fins de l'étude, la production de publications scientifiques et la thèse de doctorat de la chercheuse ainsi que la production de publications rédigées dans un langage clair, simple et accessible et destinées aux projets de recherche communautaire concertés à titre d'information.

Anonymat : L'anonymat du participant est garanti de la façon suivante : tout renseignement qui pourrait identifier le participant sera retiré des transcriptions. En ce qui concerne la publication des conclusions de l'étude, les propos du participant pourront être cités, mais tout renseignement qui pourrait l'identifier sera retiré. Les participants à l'étude collaborent à des projets de recherche communautaire qui portent sur l'itinérance et l'insécurité alimentaire. Le nombre important de participants communautaires et de chercheurs universitaires qui mènent ce genre de recherche assure l'anonymat. L'anonymat des participants est aussi assuré du fait que les identificateurs géographiques seront retirés.

Conservation des données : Les entrevues seront enregistrées sur un support numérique. Leur contenu sera transcrit sous forme de texte. Les fichiers de texte et numériques seront conservés sur l'ordinateur personnel de Vivien Runnels dans un lieu sûr protégé par un mot de passe. Les copies papier des transcriptions seront conservées sous clé dans le bureau privé de Vivien Runnels situé à son domicile (c'est aussi le lieu où les entrevues seront menées de façon confidentielle), jusqu'en 2013, à laquelle date la nécessité de continuer à conserver les données sera réévaluée. Les copies papier des données seront déchiquetées et les fichiers numériques effacés. Seules Vivien Runnels et sa directrice de thèse, la professeure Caroline Andrew, auront accès aux données brutes.

Participation volontaire : Ma participation à la recherche est volontaire et je suis libre de me retirer en tout temps, et/ou refuser de répondre à certaines questions, sans subir de conséquences négatives. Si je choisis de me retirer, les données recueillies jusqu'à ce moment seront détruites à moins que j'accorde la permission à la chercheuse de les conserver.

*Formulaire de consentement – « Arrangements of governance in
community-university research collaborations in Canada »*

(Dispositions de la gouvernance dans les alliances de recherche universités-
communautés au Canada)

Acceptation : Je,(nom du participant),
comprends le formulaire de consentement et j'accepte de participer à une entrevue qui
sera menée par Vivien Runnels ou par un assistant de recherche désigné. J'accepte aussi
que l'entrevue soit enregistrée sur un support numérique. Je comprends que le contenu
de l'entrevue pourrait être utilisé pour des fins de citation anonyme.

Je, (nom du participant),
souhaite/ne souhaite pas (s.v.p., indiquer votre choix) recevoir un document sommaire
des conclusions de la recherche et j'inclus mon adresse pour cette fin. (*adresse courriel
ou postale*) :

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Dans le cas où des copies papier du formulaire de consentement sont utilisées, il y
a deux copies du formulaire de consentement, dont une copie que je peux garder.

La signature du participant/e

Date:

La signature de la chercheuse

Date:

Pour tout renseignement additionnel concernant cette étude, je peux communiquer avec la chercheuse ou sa directrice de thèse à l'adresse suivante :

Vivien Runnels (chercheuse et candidate au doctorat) OU Caroline Andrew
(directrice de thèse)

Centre d'études en gouvernance

55, avenue Laurier Est

Pavillon Desmarais, pièce 3172

Ottawa (Ontario) K1N 6N5

Télécopieur :

Courriel de Vivien Runnels:

Courriel de Caroline Andrew :

Pour tout renseignement sur les aspects éthiques de cette recherche, je peux m'adresser au :

Responsable de l'éthique en recherche

Université d'Ottawa

Pavillon Tabaret

550, rue Cumberland, salle 159

Ottawa (Ontario) K1N 6N5

Tél. :

Courriel :

Je vous prie de bien vouloir signer le formulaire de consentement et le poster, le télécopier, le numériser (scanner) ou le faire parvenir par courriel à :

Centre d'études en gouvernance

55, avenue Laurier Est

Pavillon Desmarais, pièce 3172

Ottawa (Ontario) K1N 6N5

Télécopieur : Courriel de Vivien Runnels:

Je vous remercie pour votre temps et pour votre collaboration!

Lettre destinée aux collègues pour le recrutement de participants

Cher collègue,

Je vous écris pour vous demander si vous seriez en mesure de m'aider avec mon projet de recherche doctorale.

Ma thèse de doctorat s'intéresse à la gouvernance aux alliances ou partenariats de recherche universités-communautés, plus particulièrement les alliances qui étudient l'itinérance et l'insécurité alimentaire. J'aimerais m'entretenir personnellement avec des membres d'alliances de recherche qui sont membres de la communauté et des universitaires.

Afin de démarrer le processus, je dois créer une base de données d'alliances de recherche universités-communautés qui portent sur l'itinérance et l'insécurité alimentaire au Canada. Seriez-vous en mesure de me renseigner au sujet d'alliances de recherche dont vous avez connaissance, et/ou faire connaître l'étude par l'entremise de vos réseaux et sites d'affichage électronique? Bien que votre site web contienne une liste de membres accessible au public, je vous serais reconnaissante si vous pouviez m'indiquer les alliances de recherche qui mènent des recherches communautaires.

À une date ultérieure, lorsque les entrevues seront complétées, les informations obtenues des entrevues et les conclusions tirées de la documentation sur la gouvernance seront consolidées afin de produire une publication rédigée dans un langage clair, simple et accessible au grand public et qui, je l'espère, sera utile pour les alliances de recherche. Les participants à l'étude auront l'opportunité de fournir de la rétroaction par rapport aux conclusions de la recherche et commenter les publications qui seront produites. J'espère que plusieurs participants choisiront de me faire part de leurs commentaires. J'organiserai aussi des groupes de discussion avec des personnes qui ont participé à des études comme la nôtre par le passé afin de valider (ou non, le cas échéant) les

conclusions et déterminer si les documents seront utiles pour d'autres alliances de recherche. J'espère que vous pourrez partager vos connaissances et m'aider à mettre sur pied une base de données canadienne.

Salutations distinguées,

Vivien Runnels

Certificate of Ethical Clearance – Social Sciences and Humanities Ethics Committee,
University of Ottawa

A copy of the Certificate of Ethical Approval File #06-08-37 is lodged with the
Research Grants and Ethics Services, University of Ottawa.