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Visualizing and Interacting With Social Determinants of Health

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Graduate Program in Health Information Science

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Abstract

**Purpose:** The purpose of this study is to examine the use of information visualization to represent specific social determinants of health, and to examine the benefits of such representation for health policymaking. **Methods:** The study developed a prototype for a visualization tool (www.healthvisualization.ca), which represents the conceptual framework for the social determinants of health (CSDH) and new ways to represent related health equity indicators. This tool was used by study participants. The experience of these participants and the usability of the tool were evaluated using qualitative semi-structured interviews. **Results:** Visualizing the CSDH framework helps to present the social determinants of health more effectively, allowing better visualization of indicators. Communicating healthcare indicators to policymakers is a complex task because of the complexity of these indicators. **Conclusions:** The contribution of information visualization to policymaking could only be understood by taking into consideration the different factors that impact health decision-making and evidence uptake.

**Keywords**

Information Visualization, Social Determinants of Health, Conceptual Framework, Health Policymaking, Health Equity, Knowledge Translation, Healthcare Indicators, Health Indicator Representation, Complexity of Knowledge Communication, Knowledge Misinterpretation.
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## List of Abbreviations

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<th>Description</th>
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<tbody>
<tr>
<td>KT</td>
<td>Knowledge Translation</td>
</tr>
<tr>
<td>SDoH</td>
<td>The Social Determinants of Health</td>
</tr>
<tr>
<td>HCI</td>
<td>Human-Computer Interaction</td>
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Chapter 1

1 Introduction

Health indicators are measurable characteristics of people or environments which can be used to describe specific aspects of health and healthcare systems (Nutbeam, 1998). In 2010, the Institute of Medicine in the USA conducted a study to evaluate the effectiveness of the national healthcare quality and disparities reports, which are published yearly by the Agency for Healthcare Research and Quality (AHRQ). The study argued that, while the significance of health indicators is high, these indicators were not presented effectively enough to provoke policy action (Bruno, Burke, & Ulmer, 2010).

Health equity is “the absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically or geographically” (World Health Organization, 2005, as cited in Solar & Irwin, 2010, p. 12). Several factors have a direct or indirect impact on health equity, and they are known as the social determinants of health (SDoH). These are the conditions in which people are born, grow, live, work and age. These conditions are shaped by the distribution of money, power, and resources at global, national and local levels. (Solar & Irwin, 2010)

Health equity has emerged as a major challenge for health policymakers. While health equity might not be a top policy objective in many countries, the impact of public policies on health equity should always be monitored (WHO, 2014). Marmot et al. (2008) assert that action on SDoH should aim to achieve several objectives, including improving daily living and working conditions and tackling the inequitable distribution of power, money, and resources. Measuring and understanding health equity problems, and expanding the knowledge base of health equity are also important parts of this action. This knowledge base includes data systems and tools that facilitate problem understanding, solving and decision-making.

However, there are many factors that hinder planning and design of policy interventions for solving health equity problems, including the political system, the economic conditions, and public opinion. These factors affect all public policies. However, there
are other factors that could have a direct impact on health policy decision-making in particular, including health system complexity, decision makers’ bounded rationality and cognitive needs, and knowledge translation barriers.

Information visualization is “the use of computer-supported, interactive, visual representations of abstract data to amplify cognition” (Card, Mackinlay, & Shneiderman 1999). Information visualization has been used to support decision-making in many domains, including business and urban planning. However, there is a dearth of research on information visualization, and there are many knowledge gaps, including how information visualization impacts complex cognitive activities such as decision-making and problem solving (Sedig & Parsons, 2013). While information visualization is inevitable for analyzing and presenting the huge and growing amount of healthcare data and understanding the complexity of health systems, there is scant literature on using information visualization in healthcare (Steenstra & Erkoyuncu, 2014). Further research on visualizing heterogeneous data such as healthcare data, which include electronic medical records, public health indicators, prescription data, and insurance data, is also needed (Liu, Cui, Wu, & Liu, 2014).

1.1 Purpose of the Thesis

The purpose of this thesis is to examine the use of information visualization to represent the social determinants of health and health equity indicators, and to examine the benefits of this representation for health policymaking.

In this thesis, I have developed a prototype for a visualization tool (http://www.healthvisualization.ca), which represents health equity indicators and the conceptual framework for the social determinants of health (CSDH). The CSDH framework was developed by Solar and Irwin (2010) to explain the social determinants of health and provide a theoretical lens through which policy action could be analyzed. The framework is shown in Figure 1. Different visualization techniques were used to represent spatial and temporal properties of health indicators.
This tool was used by study participants, and I evaluated their user experience and the usability of the tool by using qualitative semi-structured interviews.

Figure 1: CSDH Framework


1.2 Research Question

This research has an overarching purpose of examining the use of information visualization to represent the social determinants of health. Additionally, the study aims to evaluate the value of a specific design construct, which is the visualized framework. Therefore, this study is conducted to answer the following research question:

What is the perceived utility of visualizing a conceptual framework for the social determinants of health in performing complex cognitive activities such as analyzing health equity problems?

1.3 Significance of This Research

This research is timely for several reasons:
1. It sheds light on the utility of information visualization in health policymaking.

2. It explores the use of information visualization in knowledge translation.

3. It is the first part of a larger empirical research study on the representation of healthcare indicators, and decision support tools, which will be part of my P.h.D program.

4. It will inform the development of the next version of the visualization tool.

### 1.4 Conceptual Framework of This Thesis

Miles and Huberman (1994) define a conceptual framework as a setup that contains the “intellectual bins,” which are the main concepts identified by a researcher. This setup has many functions:

> It explains either graphically or in narrative form, the main things to be studied—the key factors, constructs, or variables—and the presumed relationships among them. (p. 18)

Although it is not in the scope of my thesis to develop a framework, I have created the framework represented in Figure 2 to guide my literature review and data analysis. This framework provides me with the theoretical lens, which I have used to interpret my research findings and to validate my interpretation. It is also a communication tool, which I have used to explain my work to my supervisor, my committee, and my peers. I have also updated this framework in the Discussion Chapter to reflect the change in my understanding of the core concepts in this thesis, and to accommodate the new concepts that have emerged.

This framework is not related to CSDH framework created by Solar and Irwin (2010) to explain the social determinants of health and was visualized in the tool. While CSDH framework aims to represent the social determinants of health, the conceptual framework of this thesis explains a possible use of information visualization to represent the social determinants of health.
Figure 2: The Conceptual Framework Used in This Thesis

This framework shows that the social determinants of health impact population health. Health indicators reflect the social determinants of health and describe the status of the health system and population health. These indicators are used by researchers and other knowledge producers to generate evidence. Evidence goes through different knowledge translation processes and then it might be used in health policymaking to design policy interventions, which impact the health system and population health. Health Indicators can also be represented using static graphics or information visualization. Information visualization may enhance health policymaking by providing more information processing capabilities and allowing the user to interact with the presented information.
Chapter 2

2 Literature Review

2.1 Definitions

In this section, I provide definitions for the key concepts used in this thesis to help the reader to understand the theoretical underpinnings of this study.

These key concepts include health system, health policy, policymaking, decision making, health indicator, and complex system.

**Health System:** According to Blank and Burau (2013), this concept refers to:

> The people, institutions and resources, arranged together in accordance with established policies, to improve the health of the population they serve, while responding to people’s legitimate expectations and protecting them against the cost of ill-health through a variety of activities whose primary intent is to improve health. Health system is the set of elements and their relations in a complex whole, designed to serve the health needs of the population. (p. 256)

In my thesis, I have used health system, healthcare, and healthcare system interchangeably.

**Health Policy:** According to Buse, Mays, and Walt (2012), Health policy refers to:

> Courses of action (and inaction) that affect the set of institutions, organizations, services and funding arrangements of the health system. It includes policy made in the public sector (by government) as well as policies in the private sector. (p. 6)

According to Frenk (1994), there are four levels of health policy, including the systemic level, the programmatic level, the organizational level, and the instrumental level. The systemic level policy focuses on health system aspects, such as the funding model and the government’s responsibilities for healthcare provision. The programmatic level policy focuses on healthcare objectives, priorities and resource allocation. The organizational
level policy focuses on healthcare settings and healthcare quality. The instrumental level policy focuses on the human resources, information systems, and health promotion tools that are needed to achieve policy objectives at the systemic, programmatic, and organizational levels (Frenk, 1994, as cited in Barker, 1996).

According to Barker (1996), health policy decision-making is a complex process:

 Often decisions are not single identifiable entities but the result of an incremental process. This complexity in the nature of decisions makes it difficult to say that a decision is ever purely technical (p. 5). Decisions are the product of those people who get to have a say in making them, of the process by which the decision is made, and of the distribution of power between the different parties involved. (p. 6)

Different actors participate in health policymaking, including individuals, groups, and organizations, who use their powers to influence the policy and to achieve specific goals. Health policy is also affected by contextual factors, including political, economic and social factors at national and international levels (Buse, Mays, & Walt, 2012). Dente (2014) describes five actors in public policymaking. Political actors participate in policymaking because the citizens elected them to do so. Bureaucratic actors are public servants in top positions, and they hold legal powers that entitle them to participate in decision-making. Special interest actors, such as pharmaceutical companies and food companies, influence specific areas in public policy to protect their interests. General interest actors are advocates for some public issues, such as environmentalists, and human rights activists. Lastly, expert actors have the technical expertise and policy area expertise that enable them to analyze policy problems and suggest solutions. Scharpf (1997) talks about policy-area experts and political experts, and the same concept can be found in George (1994).

Accordingly, in this thesis, I have used the term expert to refer to expert actors who have the technical knowledge in healthcare and health system issues, including researchers, epidemiologists, and data analysts. I have also used the terms policymakers and decision makers interchangeably to refer to bureaucratic actors who have the authority to make
final decisions with regards to health policy interventions and resource allocations. Those bureaucratic actors may or may not have the technical area expertise. However, in healthcare systems, most of them have such expertise by education. This conceptualization of policy actors is consistent with the views of my research participants, which is presented in Chapter 5 (the results chapter).

**Policymaking:** According to Buse, Mays, and Walt (2012), this concept refers to:

> The process in which policies are initiated, developed or formulated, negotiated, communicated, implemented and evaluated. (p. 13)

**Decision Making:** According to Furby and Beyth-Marom (1992), this concept refers to:

> The process of making choices among competing courses of actions. The normative models of decision theory prescribe the processes that people should follow in order to have the best chance of maximizing their well-being, given their beliefs and values. These processes include identification of possible decision options, identification of the possible consequences of each option, identification of the desirability of each consequence, assessing the likelihood of each consequence, and using some rules to identify the best option and make a rational decision (p. 3). One common rule for making a rational choice is to select that option which has the greatest subjective expected utility. (p. 4)

**Health Indicator:** According to Bosch-Capblanch (2011), This concept refers to:

> A quantitative or qualitative factor or variable that provides a simple and reliable means to measure achievement, to reflect the changes connected to an intervention, or to help assess the performance. (p. A-5)

Nutbeam (1998) describes different kinds of health indicators. Health indicators are used to describe public health issues, healthcare programs’ outcomes, diseases, social, economic and environmental conditions, health literacy, and health policy.

**Complex System:** According to Cilliers (1998), “A system is said to be complex when the whole cannot be fully understood by analyzing its components” (Cilliers, 1998, as

I have used the concept of complexity in my literature review and data analysis and to describe specific themes in my data. However, it is out of the scope of this thesis to use complexity theory and systems thinking to interpret the research findings.

**Conceptual Framework:** Miles and Huberman (1994) define a conceptual framework as a setup that contains the “intellectual bins” identified by a researcher. This setup has many functions:

> It explains either graphically or in narrative form, the main things to be studied—the key factors, constructs, or variables—and the presumed relationships among them. (p. 18)

In Chapter 5 (the results chapter), I use the term “knowledge construct” to denote to this definition.

**Knowledge Communication:** Eppler (2007) defines knowledge communication as:

> The (deliberate) activity of interactively conveying and co-constructing insights, assessments, experiences, or skills through verbal and non-verbal means. It designates the successful transfer of know-how, know-why, know-what, and know-who through face-to-face or media-based (virtual) interactions. (p. 291)

In the context of my thesis, I have used this term to refer to communicating healthcare information by experts to policymakers and other users, including laypeople, and journalists.
2.2 Introduction

The conceptual framework of this thesis, which is described in section 1.4 and illustrated in Figure 2 represents the core concepts used in this thesis and the potential relationships among them. Therefore, this literature review should be read in light of this framework.

Accordingly, my literature review includes three topics: Healthcare systems, health indicators, the social determinants of health, health policy, and information visualization. My aim is to review the available body of research that covers the relationship between the complexity of healthcare systems and health policy; and how information visualization can support decision-making. In my review, I have underlined some sentences in the quotations for emphasis.

2.3 Complexity of Healthcare Systems

According to the Institute of Medicine (US) (2001), the healthcare system is a complex adaptive system that is composed of interdependent and interconnected components. It is adaptive because it is composed of individuals who can learn and change as they gain experience. Those individuals deliver healthcare in an unpredictable way that increases the complexity of the system and impacts the quality of its services. This complex adaptive system is a dynamic network of many agents, such as healthcare providers, administrators, payers, vendors, and information technology experts that continuously act and react to each other’s behavior in a non-linear way (Sturmberg & Martin, 2013). At a macro level, healthcare is provided through a set of independent and interconnected organizations that each forms a system by its own. These subsystems include the systems of healthcare financing, healthcare provision, healthcare regulation, and health promotion (Hsiao, 1992, as cited in Atun & Menabde, 2008).

2.4 Complexity of Health Indicators

Healthcare systems rely on accurate, reliable, and valid indicators that reflect the quality and cost of care, and the burden of diseases. Alper, Sanders, and Saunders (2013) assert that healthcare indicators should be represented in a way that provokes actions and supports a learning health system where “science, informatics, incentives and culture are
aligned to create a continuous learning loop” (p. 3). However, there are several challenges for benefiting from health indicators, including the huge number of indicators produced by different players in the healthcare system, and the disagreement over the appropriate indicators to use. Other challenges include the differences in measurement methods used for the same metric concept, and the diversity of data sources (Alper, Sanders, & Saunders, 2013).

Conceptual frameworks for health indicators show specific healthcare perspectives. These frameworks define each indicator and represent relationships among indicators. Many indicators are standards such as infant mortality and quality of life. However, the frameworks themselves are not standards because they represent different dimensions of healthcare, and they reflect the priorities of healthcare systems and subsystems. For example, according to the Canadian Institute for Health Information (CIHI) (2016), several provinces in Canada produce specific primary healthcare indicators that fit their needs, including Ontario, British Colombia, and Alberta. Additionally, there are twelve Canadian research teams who use some CIHI indicators and also produce other healthcare indicators. There are also many indicator frameworks, such as the chronic disease indicator framework developed by the Public Health Agency of Canada, the health indicators framework developed by Statistics Canada, the Healthy Canadian framework developed by Health Canada, and the health indicators framework developed by the Canadian Institute for Health Information.

I believe that if according to Alper et al. (2013), the main goal of health indicators is to improve health and healthcare, then this multiplicity of indicator frameworks necessitates the use of proper presentation techniques and tools to enable stakeholders to use these indicators effectively and efficiently.

2.5 Complexity of the Social Determinants of Health

The complexity of health equity and the social determinants of health is due to the multiple levels of these determinants and the multiple pathways through which they affect individual and population health. What amplifies this complexity is the fact that the effects of these determinants might accumulate over a long period and impact generations
of disadvantaged people (Mahamoud, Roche, & Homer, 2013). According to Tsouros (2003):

The field of the social determinants of health is perhaps the most complex and challenging of all. It is concerned with key aspects of people’s living and working circumstances and with their lifestyles. It is concerned with the health implications of economic and social policies, as well as with the benefits that investing in health policies can bring. (p. 5)

This complexity makes it necessary to use systems science to understand the dynamics of health equity (Mahamoud, Roche, & Homer, 2013). Ostlin, Schrecker, and Sadana (2009) state that SDoH research has focused primarily on the “problem space” by describing and suggesting relationships between SDoH and poor health. Nevertheless, a “third wave” of research that focuses on the “solution space,” including examining, explaining and adapting strategies to reduce health disparities has started. Additionally, Ostlin et al. identify four research priorities for the SDoH:

1. The global factors that affect health equity, including globalization, free trade, financial crises, environmental change and immigration.
2. Pathways to health or illness in a given context and over a life span.
3. Healthcare system factors that affect health equity; including healthcare service costs, accessibility, and availability.
4. Implementing and evaluating effective policy interventions to reduce health inequity.

According to Solar and Irwin (2010), the CSDH framework was developed by the World Health Organization’s Commission on social determinant of health to help in the analysis and communication of the complex phenomenon of the social determinants of health:

A key aim of the framework is to highlight the difference between levels of causation, distinguishing between the mechanisms by which social hierarchies are created, and the conditions of daily life which then result. (p. 4)
The CSDH framework identifies two types of determinants: The structural determinants and the intermediary determinants. The structural determinants of health include the sociopolitical context represented by the social values, public policies and the political system that impact a set of “structural mechanisms”, such as people’s income, education, and occupation. These structural mechanisms reinforce and help in maintaining the social stratification in the society and determine and reinforce people’s power and privileges. The sociopolitical context and the structural mechanisms are the social determinants of health inequity. These determinants impact another group of determinants, which are the intermediary determinants of health. The intermediary determinants include the following:

1. Material factors: Housing and neighborhood quality, and the work environment.
2. Psychosocial circumstances: Psychosocial stressors and stressful living circumstances.
5. The healthcare system factors, including service availability, accessibility, and cost.

These intermediary determinants are, according to the framework, the social determinants of health, and they cause unequal exposure and vulnerability to health-damaging factors, such as the availability of clean drinking water, the low-quality food, and the unhealthy living conditions (Solar & Irwin, 2010).

2.6 Health Policy

Complexity should be taken into consideration when introducing innovations, delivering new healthcare services, and designing policy interventions. Innovations in healthcare include new technologies, drugs, or treatment. Adoption of innovations in healthcare
systems is influenced by contextual factors, the complexity of these systems, and the interaction of the different subsystems within these systems (Atun, 2012). Murray & Frenk (2000) assert that the performance of health system is linked to the performance of its subsystems. However the performance of health system is not the sum of performance of these subsystems:

The performance of the entire health system must be related to the performance of various subcomponents or even organizations such as hospitals, within the health system. Ultimately, it may not be possible or even useful to try to define [a linear] relationship between overall performance and the performance of various subsystems or organizations. (p. 723)

A simplistic view of health systems and the use of unsophisticated tools for health system analysis and decision-making can lead to bounded rationality of decision makers (Atun, 2012). Bounded rationality describes decision-making under complex conditions, including the lack of information and uncertainty, which impact the mental capabilities of decision makers. Under such conditions, humans make decisions by searching for satisfactory alternatives that may or may not be the best ones, and they lower or raise their aspiration levels and goals accordingly (Dequech, 2001). Information visualization has been used to support decision-making and enhance decision makers’ understanding of problems and potential solutions (Pfeffermann, Minshall, & Mortara, 2014).

2.6.1 Health Policy and Health Equity

Achieving health equity is a major goal for primary healthcare reform (World Health Organization, 2008). While there is enough evidence about the relation between the social determinants of health and health (in)equity, designing and implementing the appropriate policy interventions require more research (Lofters & O’Campo, 2012). Policy interventions for addressing health equity are complex because they require “complex social, economic, and political change”, and this multifaceted change requires cross-program and cross-sector coordination (Commission on Social Determinants of Health, 2008, p. 116). Evidence to support this multifaceted change is not always
available, and producing such evidence requires a change of the criteria of what counts as good evidence:

**Generating evidence** on what works to reduce health inequities is a complex process. Randomized controlled trials are often not practically and/or ethically feasible. Moreover, evidence on the social determinants of health can be context-dependent. Understanding the impact that context has on health inequities and the effectiveness of interventions requires a rich evidence base that includes both qualitative and quantitative data. Evidence needs to be judged on fitness for purpose—that is, does it convincingly answer the question asked—rather than on the basis of strict traditional hierarchies of evidence. (MEKN, 2007, as cited by Commission on Social Determinants of Health, 2008, p. 179)

Delivering health services requires allocating financial and human resources, setting up service infrastructure and operating care delivery efficiently and effectively. These tasks always generate competing demands and require prioritization of policy goals. Additionally, intervention outcomes could take a long time to appear or to be evident, which makes intervention evaluation difficult to perform (Braveman, Egerter, & Williams, 2011).

### 2.6.2 Decision Makers’ Information Needs

Healthcare decision makers require knowledge and information about different aspects of health policy issues, including the context of the problems, possible solutions, implementation guidelines, priorities, and stakeholders’ needs (Nutley, Walter, & Davies, 2003). Decision makers require current and updated information. They also need transparent information that reflects the context of policy issues and interventions and shows the cost, efficiency, and effectiveness of interventions. Using information technology to deliver information and evidence is the preferred method by decision makers (Dobbins, DeCorby, & Twiddy, 2004). Additionally, there are two challenges that impact evidence uptake: 1) access to evidence by policymakers, and 2) translating it correctly to design effective interventions (Dobbins, DeCorby, & Twiddy, 2004).
However, despite knowledge availability and accessibility, there are other factors that impact knowledge use by decision makers. These factors are discussed in the next section.

### 2.6.3 Decision Makers’ Information Representation Needs

Bruno, Burke, and Ulmer (2010) present a study conducted by the Institute of Medicine in the USA in 2010. The study aimed to evaluate and enhance the effectiveness of the national healthcare quality (NHQR) and disparities (NHDR) reports, which are published yearly by the Agency for Healthcare Research and Quality (AHRQ). The study argues that while the significance of health indicators and findings is high, those indicators are not presented effectively enough to provoke actions:

> While the NHQR and NHDR monitor a large number of measures, there is no sense from the report findings that the nation is improving or worsening its performance in the areas that matter most or in areas that can make the greatest difference. The significance of the findings is not relayed in a manner that evokes action from its readers. This led to the committee’s conclusion regarding the importance of telling a story through the NHQR and NHDR. (p. 211)

The study identifies several problems in the NHQR and NHDR reports, including the difficulty to get an aggregated view of any topic and the unreliability of data to respond to different stakeholders’ needs. Graphics used in these reports are cluttered with information and less informative, and they do not represent priority areas, performance indicators, and policy interventions. These reports should also address different stakeholders’ needs. The study recommends publishing these reports online and making them customizable and more usable. More importantly, the study suggests using the framework for healthcare quality to organize and present the information in these reports (Bruno et al., 2010). While this study does not specifically advocate for the use of information visualization, I believe that its recommendation can be achieved using information visualization.
Pega, Valentine, Matheson, and Rasanathan (2014) examine New Zealand’s national project to monitor and report the social determinants of health, which took place from 2000 to 2008. These researchers argue that while the reporting and monitoring increased the awareness about the social determinants of health, they produced limited policy action to solve health inequities. The study recommends several strategies for effective reporting of social determinants of health. These strategies include creating a conceptual framework to represent the interrelationship and causality relationships between SDoH on one side, and health and economic outcomes on the other side. The framework should be included in SDoH reports because it helps policymakers to realize inequities and health outcomes and create effective interventions:

This framework would provide policy-makers with the rationale and guidance for targeted intersectoral policy and action. It could prevent the denial, indifference or mental block arising from professional, political and organizational divisions and potentially preventing translation of social reports’ evidence into action. (p. 67)

Quay and Hutanuwatr (2009) discuss visualization techniques for representing sustainability indicators to support policymakers, and they demonstrate a visualization tool that represents a framework of sustainability indicators, which organizes these indicators categorically, spatially, and temporally. Additionally, according to these researchers, there is a dearth of research on indicator organization and visualization.

2.7 Knowledge Translation

Knowledge translation (KT) is defined as:

A dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically-sound application of knowledge to improve health, provide more effective health services and products and strengthen the healthcare system. This process takes place within a complex system of interactions between researchers and knowledge users which may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the
needs of the particular knowledge user (Canadian Institutes of Health Research, 2010).

Despite its success in medicine and healthcare, several researchers adopt a skeptical stance toward KT’s approaches in health policy. For example, Greenhalgh and Wieringa (2011) criticize the knowledge translation metaphor which represents knowledge as a set of objective facts:

> The notion of knowledge as objective, context-free scientific facts which need to be ‘translated’ (summarized, packaged, prioritized, and presented in a form understandable and usable by practitioners) competes in the wider literature with a number of other conceptualizations of what knowledge is and how it is circulated and used. (p. 503)

Bridging the gap between knowledge and practice—the know-do gap—in both health policymaking and clinical practice requires far more than a set of “evidence-based and actionable messages.” It requires judgment and reflexivity that build the tacit knowledge of policymakers and practitioners:

> Policymakers have many legitimate goals other than clinical effectiveness, and research findings may serve to challenge general ideologies and assumptions as much as to inform specific decisions. Furthermore, policy-making may be best viewed not as a rational exercise in decision science (for which clear, actionable evidence on ‘what works’ would be the perfect substrate) but as a process of argumentation to decide what is right and reasonable goals. (p. 507)

### 2.7.1 Knowledge Translation and Health Inequity

Masuda, Zupancic, Crighton, Muhajarine, and Phipps (2014) criticize KT approaches to address health inequity problems. These approaches are based on the assumption that health inequities are caused by knowledge gaps and resource deficiency, and, therefore, to solve these problems; researchers should convey “the right amount of the right facts … to the right people” (p. 458). However, Masuda et al. call for using critical lenses to examine the root causes of health inequity problems and analyze stakeholders’ powers
and interests, which could hinder or support policy actions to address health inequities. Murphy and Fafard (2012) take the same stance:

Strategies based on a conventional KT framework are often ineffective for helping health equity research to have policy impact. Specifically, KT conceptualizes research utilization in terms of the technical implementation of scientific findings, on the part of individual decision-makers (or individual decision-maker groups, such as a particular type of professionals) who can be “targeted” for a KT intervention, in a context that appears to be absent of political interests. (p. 724)

2.7.2 Barriers to Evidence Uptake in Health Policy

There might be several barriers for using evidence in health policy contexts, including the complexity of decision-making process, stakeholders’ influence, and the role of politics and power in public policy (Murphy & Fafard, 2012). Braveman, Egerter, and Williams (2011) argue that knowledge gaps on SDoH are not always the main barrier to policy interventions, and state that it is the political will that pushes or halts these interventions. Other barriers include educational background, professional expertise, and political beliefs of policymakers (Smith & Joyce, 2012). Thomas et al. (2014) suggest that knowledge use in healthcare is a learning process and argue that knowledge is not a packaged static object that can be delivered to prospective users, but rather, it is dynamic and shaped by knowledge producers and knowledge users. Nutley, Walter, and Davies (2003) assert the need for using individual and organizational learning theories to understand research and evidence use.

On the other hand, other researchers take a more positive stance toward KT and agree on a potential benefit for evidence in health policy, but call for adopting approaches that acknowledge user needs and contextual impact. Graham et al. (2006) agree that it is “complex and challenging” to achieve action that is based only on knowledge. They proposed knowledge to action framework that takes into consideration the local context and organizational barriers to ensure knowledge uptake.
Lavis (2006) asserts that public policymaking includes a set of non-linear processes where prioritization of issues and designing of interventions and implementing them take place in a complex context where evidence is just one factor among other factors:

Debates about which issues warrant governmental action, about how best to frame problems and design an appropriate policy response, and about policy implementation take place in the context of a complex array of institutional arrangements, interests, and ideas that are animated by individuals and occasionally profoundly influenced by external events, including elections and recession. Research evidence then effectively competes with other forms of evidence (e.g., budgetary constraints and the legal code) and with values (e.g., public opinion about the role of government versus the market). (p. 39)

Lavis (2006) adds another factor that could impact evidence uptake by policymakers, which is the availability of rigorous evidence at the right time. Research and policymaking are “often distinct and typically asynchronous processes” (p. 39). However, Lavis asserts that in Canada, some researchers have been able to provide enough evidence in the right time to policymakers regarding issues of high impact on public health and health system in Canada:

During the fact-finding phase of the Commission on the Future of Healthcare in Canada, which faced significant pressure to open up the Canadian hospital sector to for-profit corporations, a team of researchers rapidly conducted a systematic review to compare the mortality rates of patients treated in for-profit and not-for-profit hospitals. The result directly informed the Commission’s final report. (p. 39)

2.7.3 Knowledge Translation Methods

Lavis (2006) suggests that knowledge translation can “build bridges” between research and policymaking. He describes several KT methods and gave real examples from Canada:

1. Producing systematic reviews in response to public policy issues identified by policymakers.
2. Researchers’ “push efforts”, where they communicate evidence to policymakers to make them aware of certain issues.


4. Exchange efforts, where policymakers and researchers work together to set research agenda and find evidence.

Lavis describes another method, which includes the “efforts to facilitate user pull” where researchers make high-quality evidence available and accessible to policymakers and provide feasible services to locate such evidence. For example, the Canadian Cochrane Network offers low-cost licensing for provinces. Another example described by Lavis is the “friendly front ends for systematic reviews”, which is discussed in the next section.

Other knowledge translation methods that are targeted towards health policymakers include health system guidance and policy briefs (Bosch-Capblanch, 2011). Lavis et al. (2012) provide the following definitions for these methods. Health systems guidance is defined as:

A set of systematically developed statements created at the global or national level to assist decisions about options for addressing a health system problem in a range of settings and to assist with implementation and with monitoring and evaluation. (Lavis et al., 2012, Appendix S1)

A policy brief is health system guidance that is developed at national or sub-national levels. Researchers and experts, who prepare these KT products, should analyze and summarize three types of contextual factors that impact health policymaking, including governance, financial, and delivery factors. Governance factors are factors related to stakeholders’ authorities and powers. Stakeholders include governments, medical associations, physicians, and consumers. Financial factors are factors related to how health services’ cost is covered. Delivery factors are related to how health services are provided (Lavis et al., 2012). Health policy guidance and briefs could be delivered in different formats and through different kinds of media, including print and audiovisual formats. Bosch-Capblanch (2011) asserts that guidance should be written using a simple
language and could include illustrations to help the users to understand it. Bosch-Capblanch also identifies many advantages for using websites to deliver health systems guidance. Advantages include providing different types of information for different user groups, and interaction capabilities. However, websites may also contain misleading information:

Web sites are very popular and provide versatile ways of storing and displaying information. They have great possibilities, such as redirecting the user to different sections using internal and external links and hosting nested information that could be used to successively access more complex aspects of guidance, such as the risk of biased assessments. Web sites can also host sections that allow interaction with users, such as ‘blogs,’ comments or forums. However, they can also contain irrelevant and misleading information. (p. 103)

The Agency for Healthcare Research and Quality (AHRQ) (2014) asserts the importance of disseminating research findings to bridge the gap between research and practice. This dissemination should represent the strengths and weaknesses of the evidence, and the effectiveness of interventions, and should be tailored to the needs of different audiences, including policymakers, physicians, and patients. AHRQ develops summary guides to disseminate research findings and systematic reviews using plain-language.

However, Dobbins et al. (2009) conduct a randomized controlled trial study on different KT strategies and argue that online evidence repositories can be effective if they are accompanied by KT push methods that deliver the evidence to the intended users. These methods should use communication techniques that are sensitive to the contextual factors affecting the reception and use of knowledge:

Tailored, targeted messages plus website informational materials can be an effective strategy for facilitating evidence-informed decision making. In addition, simply having access to an online registry of research evidence appears to have no impact on evidence-informed decision making. (p. 10)
2.7.3.1 Friendly Front Ends for Systematic Reviews

Lavis (2006) describes a knowledge translation method called “friendly front ends for systematic reviews”, and he classified this method as a user pull method:

Friendly front ends for systematic reviews, which use a graded-entry format (e.g., page of take-home messages, a 3-page executive summary, and a 25-page report) offer promise as an element of both push efforts and efforts to facilitate “user pull”. (p. 40)

Tugwell, Robinson, Grimshaw, and Santesso (2006) propose an evidence-based framework for equity-oriented knowledge translation. This framework includes using systematic reviews to assess impeding and enabling factors, and identify possible interventions. It also includes outcome evaluation, and knowledge dissemination and sharing, which could be achieved by using KT methods such as the development of a friendly front end for sharing equity indicators:

Methods to develop a friendly front end for equity measures are needed to assist knowledge management and sharing. For example, the concentration index and Gini coefficient are neither intuitive nor user-friendly. (p. 648)

Santesso et al. (2006) provide more insights about the friendly front ends that are developed by the Cochrane Musculoskeletal Group (CMSG). These front ends are “summaries that are understandable, readable, and usable and address the concerns of clinicians and consumers with musculoskeletal conditions” (p. 2312). They are also decision aids that help to transfer the Cochrane systematic reviews into a format that is understandable by the end users, including physicians, and patients. The friendly front ends developed by CMSG include the following elements:

1. Physicians’ clinical relevance tables for treatments. All statistics or figures in these tables are represented as percentages. This representation is user-friendly.

2. Face figures, which are used by physicians to graphically represent treatment outcomes to patients.
3. Patients’ summaries for the reviews, which are written in a plain language. These summaries are prepared in four versions with varying degree of detail. They include summaries that could be read in 1 minute, five minutes, 15 minutes, and 45 minutes. These reviews can be used by patients to help them making informed decisions about their health condition.

Santesso et al.’s (2006) study suggest that these front ends are available only in PDF format at http://decisionaid.ohri.ca. However, a study by Rader et al. (2014) suggests that the CMSG has created some new types of these frontends and that target physicians, patients, policymakers, the press, and laypeople. The new types of front ends include “press releases, clinical scenarios, medical journals, frequently asked questions, podcasts, Twitter messages, Journal Club materials, and the use of storytelling and narratives to support continuing medical education.” (Rader et al., 2014, p. 206)

2.8 Information Visualization

The evolution of powerful and affordable computers has sparked a revolution in information and communication technology, which resulted in the development of computer programs that are considered essential in our life, including desktop applications and internet browsers. Some of these computer programs have been used to perform “complex cognitive activities,” such as decision-making, learning, and problem-solving (Sedig & Parsons, 2013). Complex cognitive activities impose high cognitive overload on the person performing them. According to Paas and Van Merriënboer (1994), these activities have two main characteristics: 1) they require a high number of complex skills to perform, and 2) they require a complex set of goals to be achieved to complete an activity. Additionally, these activities are performed in complex work environments (Marmaras and Pavard, 1999).

Computer artifacts that support performing the complex cognitive activities are called cognitive activity support tools because they “can partner, distribute, augment, amplify, canalize, guide, offload, cognize with, shape, and/or transform human activities and thinking.” (Sedig & Parsons, 2013, p. 85). For example, financial analysis software, health informatics software, risk modeling software, and information visualization tools
are all cognitive activity support tools. These tools have a visual interface, which enables human-computer interaction, and allows the user to organize and change how and how much information is displayed to maximize the tool’s “epistemic utility” (Sedig & Parsons, 2013).

Information visualization tools act as “external cognition aids”, which enhance cognitive task performance by increasing the user’s information processing power (Fekete, Van Wijk, Stasko, & North, 2008). Sedig, Parsons, Dittmer, Haworth, (2014) assert that it is the quality of interaction—interactivity of a visualization tool—which determines the usefulness of visualization tools as cognitive aids:

One way to make visualization tools human-centered is to make them interactive. Although interaction allows a user to adjust the features of the tool to suit his or her cognitive and contextual needs, it is the quality of interaction that largely determines how well complex cognitive activities are supported. (p. 717)

However, Sedig et al. (2014) assert that a conceptualization for the visualization tool’s interactivity is still challenging, and the discussion about interactivity in literature is “often vague.” Sedig et al. present a framework that could help in such conceptualization, which can lead to a more user-centered design for visualization tools.

2.8.1 Theory of Distributed Cognition

Several theories have been used to study human computer interaction, including activity theory, the theory of distributed cognition, and situated action theory (Nardi, 1997). However, in the information visualization field, the theory of distributed cognition has been used to study visualization artifacts (Parsons & Sedig, 2014). It has also been used to study human-computer interaction and measure its effectiveness (Hollan, Hutchins, & Kirsh, 2000).

Edwin Hutchins developed this theory in 1995. According to Hollan, Hutchins, and Kirsh (2000), this theory has the following principles:
1. An individual's brain does not bound cognitive processes, and they could extend to include other people and the external environment.

2. The learning mechanisms and events that take place during learning are both internal and external to the learner’s brain.

3. During a cognitive process, people coordinate their internal learning mechanisms and the external environment and try to off-load more cognitive activities to the external environment.


This theory has been used to understand the impact of information visualization on user cognition (Parsons & Sedig, 2014). According to Sedig, Parsons, Dittmer, Haworth (2014), when performing a cognitive action such as analyzing a problem using an interactive visualization tool, a coupling between the internal representations and processes of the user, and external representations and processes of the visualization tool will be created. However, a less effective coupling is created when the user uses a static image in the cognitive action:

Although working with a static representation to support cognitive activities engages external cognition and creates a coupling, the coupling is not very strong. During the performance of complex cognitive activities, users are forced to adapt to the characteristics of static representations and to make extrapolations regarding information that is not encoded. When representations are made interactive, however, there is potential for strong coupling, and users can adjust the visual representation to meet their contextual and cognitive needs. (p. 722)

Therefore, the high interactivity of the visualization tool creates a strong coupling between the user and the tool. This coupling leads to a better performance of complex cognitive activities (Sedig, Parsons, Dittmer, Haworth, 2014).
2.8.2 Information Visualization and Health Information

Healthcare data comes from different and disconnected sources including, for example, electronic medical records, population and global health indicators, prescription data, and insurance data (Shneiderman, Plaisant, & Hesse, 2013).

In the healthcare domain, the challenge of information visualization lies in representing complex and large-scale data without putting too much of a cognitive overload on users or reducing the usability of the visualization tool (Carroll et al., 2014). Information visualization can help decision makers to organize and analyze this data and make decisions about a variety of healthcare aspects, including, among others, quality of care, epidemics, drug safety, personalized care, and health equity. Information visualization can support knowledge discovery and sense making of problems through “contextual reasoning,” which can be facilitated by representing spatial and temporal perspectives of complex and multifaceted problems (Tomaszewski & MacEachren, 2012).

Xu, Jewell, Steed, and Schryver (2012) suggest that healthcare indicator databases should provide sophisticated tools rather than just listing and presenting indicators. These tools should enable comparing multiple indicators and analyzing the correlation between multiple indicators over a period or in specific geographic regions, and the impact of this correlation on the quality of care and population health. Information visualization tools equipped with “intelligent user interface” could be an effective solution for presenting health indicators and achieving such functionality (Xu et al., 2012).

Carroll et al. (2014) present a systematic review conducted to analyze information needs of public health professionals and review existing information visualization tools for monitoring and analyzing infectious diseases. The review included 88 studies published from 1980 to 2013 and found that while there is an agreement on the value of interactive visualization, static graphics were the main form of visualization used to represent health data:

Despite results from studies with users emphasizing the value of dynamic, interactive graphics to facilitate data exploration and abstraction, existing tools are
largely still static. And while static graphics are extremely useful, pairing them with interactive features may give users more freedom to explore and learn from their data. (p. 294)

Carroll et al.’s study identifies the following themes:

1. Public health professionals require high quality, timely, and relevant data.

2. Accuracy and transparency of data are important for correctly interpreting the data.

3. Misinterpretation of graphics and cognitive overload could result from displaying complex graphs that are difficult to understand or to interact with, by the users.

4. Software tools that are difficult to use could result in creating flawed and inconsistent charts.

5. Using visualization tools requires user satisfaction, organizational support, and proper training. Visualization tools should also integrate with existing work processes.

6. To analyze the complex health data, public health professionals use three main types of visualization tools, including geographic information systems (GIS), molecular epidemiologic data visualization tools, and social networks visualization tools.

7. Interactive knowledge discovery is the main reason for using information visualization tools.

8. Some GIS maps could lead to misinterpretation of information.

9. Encoding marks such as colors and shapes could either help users to interpret the data correctly or could lead to misinterpretation of data.

10. There is a trade-off between ease of use and sophistication of the analytical capabilities of visualization tools.
Carroll et al.’s study asserts that visualization tools are expected to facilitate knowledge discovery, comprehension, communication, and decision-making, and they should enable users to interact with the graphics and review different perspectives and different levels of data detail. Representing geographic data in multiple layers of detail is also important. The study also emphasizes the importance of engaging users in the design of these tools; otherwise, these tools could be of limited value. The study suggests that providing adequate training on statistics would enable users to analyze and interpret their data correctly (Carroll et al., 2014).

2.9 Summary

The complexity of healthcare systems, health equity, and healthcare indicators has a negative impact on health policymaking. Additionally, health policy is subject to several contextual factors that may also affect decision-making, including public policy priorities, healthcare system priorities, stakeholders’ powers and priorities, and financial resource constraints. Decision-making may also be affected by the bounded rationality of decision makers and their information and cognitive needs.

By supporting distributed cognition, information visualization can help decision makers to make better decisions in different domains including business, healthcare, and urban planning. However, there is a paucity of literature about the application of information visualization in different domains including healthcare and health policymaking.
Chapter 3

3 Searching for a Research Methodology

The purpose of this chapter is to describe research methodologies that can be used to evaluate information visualization tools. This review represents my efforts to find an appropriate research methodology that can fulfill my thesis’ needs, and for selecting the specific methodology used in this thesis.

There is a fundamental principle that guides my thinking, my goals, and my approach in this study. It is the user-centered design principle, which involves, according to Freitas, Pimenta, and Scapin (2014):

…making real users and their goals the driving forces behind software development. [It] tries to optimize the user interface around how people can, want, or need to work, rather than forcing the users to change how they work to accommodate the system or function. (p. 316)

It is also an iterative and evolutionary process, which is informed by continuous evaluation that takes into consideration the users, their goals, and the tasks that they want to accomplish by using the artifact (Freitas, Pimenta, & Scapin, 2014).

3.1 Background

3.1.1 The IT Artifact

The IT artifact, according to Benbasat and Zmud (2006), is:

The application of IT to enable or support some task(s) embedded within a structure(s) that itself is embedded within a context(s). Here, the hardware/software design of the IT artifact encapsulates the structures, routines, norms, and values implicit in the rich contexts within which the artifact is embedded. (p. 58)

The tasks to be supported are activities performed by the users of the IT artifact to achieve specific goals. In organizational settings, these activities are governed by
organizational processes and policies. The context is the context of use, which includes the technical, physical, social and organizational environments where the artifact will be used. It also includes the users, who engage in social and organizational interactions to perform specific tasks and to achieve personal and organizational goals (Eshet & Bouwman, 2015).

For example, in a public health unit, a data analyst is tasked to prepare a monthly report on the communicable diseases in a specific geographic area (the task). The data analyst uses some computer programs (the IT artifacts) to organize the data and write the report. The data analyst follows a specific policy for report preparation and s/he sends the report to the communication department (the structure). The communication department’s director reviews the report and evaluates potential political and social consequences of it (the context), and based on this evaluation, the director agrees to publish the report.

Each artifact has a life cycle that includes planning, designing, developing, using, and assessing impact. Research on IT artifacts aims to understand and evaluate different stages of this life cycle, and the different aspects of the artifact, including the task, the user, the structure, and the context (Benbasat & Zmud, 2006). According to Rowe, Truex III, and Kvasny (2004), Information systems field focuses on IT artifact evaluation, which takes place at different stages of artifact life cycle:

[Information systems field] is distinct in the way it helps develop evaluation methods at each stage of evolution of the IT artefact (proposal, development, implementation, post-implementation, routine operations), and at the same time takes into account the role, importance, and interaction of social actors, the structures of organizations, strategies, and tasks among a host of other issues. (p. 88)
3.1.2 Human-Computer Interaction

Human-computer interaction (HCI) is “a discipline concerned with the design, evaluation and implementation of interactive computing systems for human use and with the study of major phenomena surrounding them.” (Hewett et al., 1996, as cited in Ritter, Baxter, and Churchill, 2014). HCI aims to identify the features and standards for producing “useful, usable, and aesthetically pleasing software and hardware” (Olson & Olson, 2003). The HCI field studies different kinds of software users, including individuals, groups, organizations, the industry, and the society. It is a multidisciplinary field, and it uses cognitive science, ergonomics, computer science, information systems and psychology. These different fields have a common “unit of analysis,” which is the “user of computer-based information systems” (Emurian, 2004).

Usability and user experience are two essential concepts in HCI. The ISO 9241-11 standard defines the concept of Usability as “the extent to which a product can be used by specific users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use” (Ritter, Baxter, & Churchill, 2014). The ISO 9241-210 standard defines the user experience concept as “a person's perceptions and responses that result from the use or anticipated use of a product, system or service” (Green & Pearson, 2006). Usability and user experience focus on two different aspects of HCI. Usability focuses on task completion, whereas user experience focuses on user’s “emotions, perceptions, physical and psychological responses, behaviors, and accomplishments” that take place upon using the computer (Ritter et al., 2014, p. 44). Usability and user experience concepts reflect an evolution from focusing on designing products that can be used effectively and efficiently, to designing products that are pleasing and aesthetic (Karapanos, 2013).

3.1.2.1 The HCI Shift from Usability to User Experience

According to Fallman (2011), HCI has evolved in three waves. In each wave, HCI had a different focus, different theoretical underpinnings, and different research methodology. In early 1980, the emergence of the personal computer boosted the evolution of many IT related fields, including HCI. At that time, HCI focused on software usability—how to
design computer programs to be useful and capable of achieving specific goals effectively and efficiently. Cognitive psychology helped HCI scientists to understand and model how people learn and understand. HCI scientists created guidelines that helped designers and developers to create software interfaces that facilitate information processing, which at that time was the most important reason for using the computer. Computer interfaces were evaluated by how much they support performing specific tasks.

In the early 1990s, the focus of HCI shifted from the single user to the team of users collaborating and interacting with each other and with the computer to achieve specific goals in specific work environments. HCI researchers used ethnography, phenomenology, and participatory action research to understand the users and the tasks in the field—the real world. The dependence on cognitive psychology started to decrease, and HCI researchers started using other theories, including activity theory, ecological psychology, and distributed cognition. In this wave, HCI focused more on the human/social aspects and less on the technological aspects. However, usability and task completion were still the core of evaluation (Fallman, 2011).

The third wave of HCI started in the 2000s. Ubiquitous computing and Internet access meant that workplaces and work teams have become virtual entities, with members from different locales and even countries working together. Many people worldwide have had internet access and computers of various kinds. Information technology has been used for many purposes that are far beyond work related purposes. People have been using IT for social networking, education, and entertainment. These factors meant that HCI needs to have a broader scope that could help to fulfill the needs of computer users who have different cultural backgrounds, speak different languages, have different values, and are using the computer for different reasons. HCI has started paying closer attention to the phenomenological aspects of the human-computer interaction, as described by Fallman (2011):

> HCI became rapidly interested in issues such as meaning, complexity, culture, emotion, lived experiences, engagement, motivation, and experience. (p. 1052)
The user experience concept has become the focus of HCI. However, this interest in user experience demands more creativity and innovation in the design of computer interfaces to meet user needs (Fallman, 2011). This shift in HCI does not mean that certain concepts and research methodologies have expired. For example, Cairns and Cox (2008) discuss research methods for human-computer interaction and provided guidelines on how to do a task analysis, formal evaluation, user experience evaluation, and other methods. They also encouraged researchers to be aware of the different research methods and to choose the ones that suit their research questions.

Reeves (2013) also identifies a shift in HCI approaches to conceptualizing the user. There have been two approaches to conceptualizing the user in HCI: the cognitive approach and the social approach. The cognitive approach focuses on an individual user interacting with the computer to perform some tasks and achieve specific goals. It is possible to analyze and understand how a user represents the world internally, using cognitive psychology, and, therefore, HCI can design the interfaces that facilitate user interaction and user task completion. The social approach, which relies on social sciences, focuses not only on the user but also on the context where the human-computer interaction occurs. This approach has boosted the use of ethnographic research, which focuses on studying the workplace where users are collaborating to achieve specific goals. People’s interaction with computer artifacts is “a fundamentally socially organized phenomenon” (p. 415). While the user experience is still the core focus of HCI, analyzing the user experience and designing for the user experience should take into consideration not only the computer interface but also social and organizational factors. (Kuniavsky, 2007; Reeves, 2013).

### 3.2 Human-Computer Interaction Research Methods

In their reference work titled “Research Methods for Human-Computer Interaction”, Cairns et al. (2008) discuss several methods for HCI research, including methods that provide an objective evaluation, such as controlled experiments and eye tracking. There are also methods that provide a subjective evaluation, such as surveys, and qualitative methods.
Controlled experiments are quantitative methods, which can be used to evaluate artifact interface, user interaction behavior, and user cognition processes. They study the artifact features and their outcomes. These experiments are costly, and, therefore, they are used mostly for research purposes but not for business and software development purposes.

Eye tracking methods use special devices (eye trackers), to record eye movements and track what people are looking at during their interaction with the artifacts to perform specific tasks. Researchers and software developers have used this method for usability evaluation, and websites and computer game design. Eye trackers can generate movies that show user’s eye focus over time, and they can also generate data about the user’s artifact areas of interest and the time spent in each area. The researcher can analyze and interpret this data using qualitative or quantitative research.

Additionally, there are methods used to evaluate the usability of IT artifacts, including quantitative and qualitative methods. These methods are introduced in the next section.

3.2.1 Usability and User Experience Evaluation in HCI

Usability is defined by the ISO 9241-11 as “the extent to which a product can be used by specific users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use.” However, this definition has been subject to much criticism (Green & Pearson, 2006). Quesenbery (2003) argues that usability evaluation has focused on task completion where users use the artifact to complete a set of predefined tasks. Therefore, usability evaluation includes different measures for task effectiveness and efficiency, such as task completion time, the number of errors, and the number of clicks. These task-related measures are difficult to use when tasks are difficult to define. Satisfaction attribute is also difficult to define (Quesenbery, 2003, as cited in Green & Pearson, 2006).

According to Albert and Tullis (2013), user’s subjective evaluation of the IT artifact gives important information about its usability. They suggest several measures, including ease of use, usefulness, satisfaction, and expectation, and present several questionnaires
to evaluate these measures using some rating scales (e.g., Likert scales) and open-ended questions.

Several methods are used to evaluate usability, including surveys, usability inspection, and empirical user studies. Survey method is used in HCI research to collect subjective feedback of samples of users (Cairns et al., 2008). According to Müller, Sedley, and Ferrall-Nunge (2014), this method is used to assess user’s attitudes regarding specific features of the artifact, and to evaluate certain aspects of the user experience, including satisfaction and happiness. It can also be used to collect general demographic information about users. However, surveys are not suitable for some research areas, including user’s interactive behavior, and artifact usability. Qualitative research methodologies such as ethnography provide better insights in these research areas (Cairns et al., 2008; Müller et al., 2014).

Usability inspection refers to the evaluation of artifact to find usability problems and errors. This inspection is performed by software usability experts. (Rosson & Carroll, 2002). One popular usability inspection method is the heuristic evaluation, which is an informal and cost-effective method that has been used in HCI to evaluate prototypes and finished products. In this method, usability experts use the artifact to perform specific tasks, and while doing so, they can discover many usability issues and problems (Nielsen & Molich, 1990; Freitas, Pimenta, & Scapin, 2014).

Empirical user studies are the gold standard in usability evaluation. They rely on evaluating the experience of the real users—the end users—of the artifact (Rosson & Carroll, 2002). These studies can be formal studies, which are quantitative studies such as controlled experiments, and informal studies, which are qualitative studies such as field observation, interviews, and prototype evaluation (Rosson & Carroll, 2002). However, Höök et al. (2011) assert that usability evaluation should not be “paradigm bound”, and that researchers can use different methods to understand the different aspects of usability.
3.2.2 Qualitative Research in HCI

Hevener, March, Park and Ram (2004) argue that, through innovative design, artifacts can use computer power to address existing issues and bring new opportunities for people and organizations. Researchers can develop new artifacts to understand and examine the use of information systems. Different quantitative methods could be used to evaluate the new innovative artifacts, including laboratory tests, and simulation experiments. However, because these new artifacts are meant to solve specific problems, they can also be evaluated using qualitative research, which provides researchers with many methodologies to explore different aspects of the artifact in its context:

The rich phenomena that emerge from the interaction of people, organizations, and technology may need to be qualitatively assessed to yield an understanding of the phenomena adequate for theory development or problem solving. (Hevener et al., 2004, p. 77)

Courage, Redish, and Wixon (2009) assert that designing information technology products requires there types of analysis, including context, user, and tasks analyses. Different research methods could be used to understand users’ lives at work, and work processes. These methods include “naturalistic observations, interviews, shadowing users, doing day in the life of studies, conducting ethnographic interviews, and observing and listening to users doing specific tasks” (Courage et al., 2009, p. 955).

Qualitative research has been used in HCI to explore and understand the context where human-computer interaction takes place—the artifact context, which affects how people perceive and interact with technology. Qualitative research methodologies can be used to understand different aspects of user experience, including emotional and social aspects, and analyze the factors that impact the user experience. While other HCI methods, such as controlled experiments and eye tracking provide objective evaluation for the usability of the artifact, qualitative research provides subjective evaluation for other factors that impact artifact usability and the user experience, including user’s values, motivations, and needs. Qualitative research methodologies that have been used in HCI include ethnography, grounded theory, action research, and expert interviews.
3.2.2.1 Ethnography in HCI Research

According to Blomberg and Burrell (2008), ethnography is the qualitative methodology of choice for HCI researchers in academia and the computer industry. Researchers use ethnography to inform the development of software and other technology products that respond to existing problems and fulfill specific user needs. It is used in different stages of the product development process, including requirement gathering and user needs specification, prototype evaluation, and quality and usability evaluation (Millen, 2000). Designers use ethnography to get insights about the artifact’s context of use, user needs, and work tasks (Blomberg & Burrell, 2008).

According to Nardi (1997), by exploring different aspects of the culture of the prospective users and the context where the artifact will be used, ethnography can generate ideas for designing, developing, evaluating, and even marketing new products. Ethnography is also more effective than the controlled experiments for evaluating artifacts in their real context and examining how users are using them to perform different tasks. Ethnography can also be used to explore different phenomena surrounding the use of IT artifacts and human-computer interaction (Nardi, 1997).

Because traditional ethnography requires long field studies and comprehensive analysis of the culture, researchers have developed some time saving ethnographic methods, including the quick ethnography for HCI research, and the rapid assessment procedures for public health services (Nardi, 1997; Pink & Morgan, 2013). Quick ethnography is characterized by intensive encounters with people and short trips into their life. It can benefit from different media, such as video observation and online communication to enrich the ethnographic engagement beyond field observation (Pink & Morgan, 2013). Quick ethnography is mainly used in the computer industry, where there is always a need for time saving and cost-effective research methods (Nardi, 1997). However, the literature is scarce on such focused and quick ethnographic studies in HCI.

3.2.2.2 Grounded Theory in HCI Research

According to Creswell (2007), grounded theory is:
A qualitative research design in which the inquirer generates a general explanation—a theory—of a process, action, or interaction shaped by the views of a large number of participants… The theory is grounded in data from participants who have experienced the process. (p. 63)

To be able to develop the theory, researchers might need to conduct from 20 to 60 interviews in the field (Creswell, 2007).

Adams, Lunt, and Cairns (2008) argue that HCI is a fairly new science, and HCI researchers lack a strong knowledge base, which can be used to inform their research. HCI needs to examine users’ emotional and social needs, expectations, and values, and link these concepts to users’ work and community. HCI can rely on qualitative research and use grounded theory methodology to examine these complex phenomena and to generate theories and create frameworks that inform the design and development of new information systems and applications (Adams et al., 2008).

### 3.2.2.3 Action Research in HCI Research

According to Kidd and Kral (2005), participatory action research is:

> A process in which people (researchers and participants) develop goals and methods, participate in the gathering and analysis of data, and implement the results in a way that will raise critical consciousness and promote change in the lives of those involved. (p. 187)

In HCI, action research is a participatory approach where researchers and participants from the organization work together to analyze and solve problems in application design, development, and use (Hayes, 2014). The output of action research includes not only creating technical solutions—artifacts, but also creating new policies, or changing organizational processes.

Hayes (2014) asserts that action research brings to HCI “a systematic, collaborative approach to conducting research in HCI that satisfies both the need for scientific rigor and promotion of sustainable social change.”(p. 49).
3.2.3 Expert Interviews

Field studies play an important role in ethnography, action research, and grounded theory methodologies. These methodologies include interviewing or observing users in their context of work. They also include deploying a prototype in a workplace and having the prospective users test it *in situ*. However, according to Bichard, Greene, Ramster, and Staples (2013), when direct field observations are not possible, researchers can use different tools, including simple games, computer games, software prototypes, and other software to mimic the context of use and draw out the user’s interactive behavior.

Millen (2000) talks about the condensed interview method, which includes using semi-structured interviews and asking very specific questions about work processes. This method can replace the open-ended interviews and field observation (Millen, 2000).

Lazar, Feng, and Hochheiser (2010) contend that interviews are effective tools in HCI research. Interviews allow researchers to collect subjective feedback from existing and prospective users. This feedback enables researchers to understand the requirements, views, preferences and practices of users. Therefore, interviews might be as effective as ethnographic studies. Lazar et al. (2010) compare interviews to surveys and state that:

> Interviews are subjective and more open-ended, often providing deeper insights similar to those associated with ethnographies and case studies. HCI researchers can use interviews in almost any phase of a project, from initial exploration to requirements gathering, evaluation of prototypes, and summative evaluation of completed products. (p. 180)

However, Lazar et al. (2010) advise researchers conducting interviews for prototype evaluation to be skeptical about positive feedback and to favor critical user opinions, because users might be inclined to give positive feedback if they were aware of the purpose of the interviews.

Lam, Bertini, Isenberg, Plaisant, and Carpendale (2012) conducted a systematic review of 850 information visualization empirical research papers and identified seven different categories of methods for evaluating information visualization artifacts. These categories
include methods for evaluating user performance, user experience, tool support for reasoning, and tool support for team collaboration. The user experience category was of particular interest for my study. According to the researchers, user experience could be evaluated using the following methods:

1. **Informal evaluation method**, where the domain experts are allowed to use and play with the tool and their feedback is collected through interviews.

2. **Usability testing method**, where users perform predefined tasks and the researcher collects their feedback using structured interviews or surveys.

3. **Field observation method**, which is similar to usability testing, however, the observation takes place in the real world, and the users are not required to perform predefined tasks. Instead, they can use the tool freely, and the researcher collects their feedback using structured interviews or surveys.

4. **A Questionnaire method**, where users are asked to fill out a questionnaire that includes different questions about artifact effectiveness and user satisfaction.

According to Lam et al. (2012), the *informal evaluation method* is a popular method in visualization research:

> It is the simplest kind of evaluation, and it is, probably for this reason, extremely common. These types of evaluations have been used to assess intuitiveness and functionality, probe for utility and usability, identify design flaws and users’ subjective preferences, evaluate and improve implementation of the ideas, or to solicit ideas for improvements and enhancements. (p. 1530)

Lam et al. (2012) suggest the use of structured interviews in the informal evaluation method because they help the researcher in getting feedbacks that are relevant to researchers’ interest and priorities. However, I decided to use semi-structured interviews, which, according to Lazar et al. (2010), give researchers “the possibility of exploring
topics in a depth and breadth that may be harder to achieve with fully structured interviews” (p. 190).

Isenberg, Isenberg, Chen, Sedlmair, and Moller (2013) conducted a systematic review of 581 visualization evaluation studies that were published in IEEE Visualization conference in the years 1997, 2000, 2003, and 2006-2012. This review analyzed the main characteristics of information visualization evaluation research, including evaluation goals, methods, and quality criteria. According to this review, studies that used qualitative research methodologies used a low number of participants ranging from five to twenty participants.

### 3.3 My Study Design at the Crossroad

Selecting an appropriate research methodology was based on my research purpose, which is to examine the use of information visualization to represent the social determinants of health and health equity indicators, and to evaluate the benefits of such representation for health policymaking. Additionally, methodology selection took into consideration the fact that the tool that I have created is not responding to existing demand from prospective users nor does it solve an already identified problem in the context of health policymaking, and, therefore, testing it *in situ* will be difficult to achieve.

Grounded theory methodology was not suitable, at this stage of my research, because I wanted to evaluate a prototype and test several visualization constructs rather than create a theory about decision-making in healthcare policy. Participatory action research responds to existing demand from users, and in my case, I am not responding to user demands nor do I have any partnership with any organization to develop a solution for an existing problem. Ethnography, is used to design solutions to solve existing problems, and it is used to explore different phenomena surrounding the use of IT artifacts, and neither is a purpose of my research.

Therefore, I have selected the **informal user experience evaluation methodology**, which includes expert interviews. This methodology is described in section 3.2.3 and the Methodology Chapter.
The following table summarizes the research methodologies identified above and shows the advantages and disadvantages of each methodology. It also shows the selected methodology (second row):

**Table 1: HCI Qualitative Research Methodologies**

<table>
<thead>
<tr>
<th>Research Purpose</th>
<th>Methodologies</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Designing a solution to respond to user demands and solve existing problems in workplaces.</td>
<td>Ethnography • Action Research • Interviews in the field • Usability Testing • User experience evaluation</td>
<td>Full support from users and organizations. Access to the field is guaranteed.</td>
<td></td>
</tr>
<tr>
<td>2. Evaluating an innovative prototype of new software that is developed based on the developer’s research, but without a direct demand from prospective users.</td>
<td>Expert Interviews • Usability Testing • Informal user experience evaluation</td>
<td>If the new software was successful, it could be very rewarding for the developer.</td>
<td>Prospective users might not be cooperative. Access to the field is not guaranteed.</td>
</tr>
<tr>
<td>3. Conducting research to explore different phenomena in workplaces.</td>
<td>Ethnography • Grounded Theory.</td>
<td></td>
<td>Prospective users might not be cooperative. Access to the field is not guaranteed.</td>
</tr>
</tbody>
</table>
Chapter 4

4 Study Design

In this chapter, I describe the design of my study.

4.1 Research Approach and Worldview

This research uses a qualitative approach as described by Denzin and Lincoln (2005):

Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that makes the world visible. These practices transform the world. They turn the world into a series of representations including field notes, interviews, conversations, photographs, recordings and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them. (p. 3)

In this study, I situated myself within the postpositivist paradigm. According to Ballinger (2006), this paradigm accepts the existence of a single reality. However, it also accepts that different parties might have different explanations about it:

This perspective acknowledges that there is an underlying single reality that is to be explored but argues that the various parties or players will have different views and explanations about what is happening. The job of the researcher is to explore aspects of the underlying truth through accessing these various explanations. The initial research question is, therefore, likely to be much more open than that found in realist research and the role of the researcher is more prominent. (p. 238)

Guba and Lincoln (1994) identify the essential characteristics of post-positivism. From an ontological perspective, post-positivism asserts that reality is “assumed to exist” but it can only be “imperfectly apprehendable because of basically flawed human intellectual mechanisms and the fundamentally intractable nature of phenomena” (p. 110).
Epistemologically, it is difficult to keep a distance between the researcher and the informants. The researcher’s objectivity remains an ideal target. However, the researcher should use “external guardians of objectivity”, including the fit of findings with preexisting knowledge, and the engagement of critical community (i.e., peers, editors, and referees) in reviewing the findings. Qualitative research under this paradigm could be used to collect “more situational information” and understand the “emic viewpoints” which will enable researchers to know “the meanings and purposes that people ascribe to their actions.” (Guba & Lincoln, 1994, p. 110). The emic viewpoints refer to ungeneralizable “constructs or behaviors that are unique to an individual or a socio-cultural context.” (Ponterotto, 2005, p. 128). Additionally, and according to Lincoln and Guba (1985), qualitative research studies cannot be value free because of the following reasons:

Inquiries are influenced by inquirer values as expressed in the choice of a problem, or evaluand, and in the framing and focusing of that problem. They are also influenced by the choice of the paradigm that guides the investigation, and by the choice of the substantive theory utilized to guide the collection and analysis of data and in the interpretation of findings. (p. 38)

Therefore, acknowledging that objectivity is an ideal goal, and that this thesis may not be value-free, I have described in section 4.2.1 (The role of the researcher) how my values, perspectives, and expertise have influenced or impacted certain aspects of my thesis.

My research paradigm governs the kind of knowledge that this thesis produces and how this knowledge is produced. It also governs my quality assurance practices.

My thesis aims to create a tool that helps to present the social determinants of health, and I have designed and developed the prototype of this tool to achieve this goal. However, I believe that my research participants, who are the field experts, can help me to identify a set of features and visualization constructs that make my tool useful and effective.
4.2 Methodology

This study used the informal user experience evaluation methodology, which is described in section 3.2.3. The informal user experience evaluation aims to collect the subjective feedback of the users of an IT artifact. A detailed discussion, including my justification for using this methodology, is provided in Chapter 3.

For my study, I have developed a prototype for a computer program—a visualization tool or an IT artifact—that represented a set of indicators about the social determinants of health. The study participants used this tool and explored its features. I used the informal user experience evaluation methodology to examine the usability of the tool. I also examined the IT Artifact aspects of my tool, including the tasks, the users, and the context of use. Three measures of usability were evaluated: The perceived ease of use, the perceived usefulness of the tool, and user satisfaction. For this stage of my work, I did not use other usability measures, including task-oriented measures, because my tool is still in an early stage, and my top priorities are to evaluate the usefulness of the tool, understanding users’ needs, and exploring the context of use.

The steps included in this methodology are summarized in the following table:

<table>
<thead>
<tr>
<th>Step</th>
<th>Name</th>
<th>Description</th>
<th>Actors</th>
<th>Location</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Demonstration</td>
<td>The researcher will present the tool to the participant</td>
<td>The researcher.</td>
<td>Participant workplace</td>
<td>One hour</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A participant.</td>
<td>A participant.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Exploration</td>
<td>A participant explores the tool and performs any tasks on it freely and without the attendance of the researcher.</td>
<td>A participant.</td>
<td>Participant workplace</td>
<td>Open as per the participant’s convenience</td>
</tr>
<tr>
<td>3</td>
<td>Feedback Interview</td>
<td>The researcher will interview the participant and ask him/her a set of open-ended questions to evaluate the perceived utility of the visualization tool.</td>
<td>The researcher.</td>
<td>Participant workplace</td>
<td>One session. Expected duration is one to two hours.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A participant.</td>
<td>A participant.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Hudson and Mankoff (2014) identify six methods for demonstrating new IT artifacts. These demonstration methods have different degrees of effectiveness. The following list shows these methods ordered from the most effective to the least effective:

1. Deployment of the artifact for independent use by the users
2. Examining the artifact with users
3. Live demonstration of the artifact by the developers
4. Video demonstration of the artifact by the developers
5. Presenting the artifact using photos and screenshots
6. A written description of the artifact

In this research study, I have used methods 1, 2, 3, and 4 to demonstrate my tool. Although I did not deploy my artifact per se, my tool is a web-based tool and research participants were able to use it independently.

Collecting the user feedback was done through semi-structured interviews. A detailed explanation of this method is provided in section 4.2.2 (the method section).

4.2.1 The Role of the Researcher

I would like to talk about my professional experience and the influence it had on this study. After I had finished my dentistry studies, I practiced as a dentist in rural areas in Syria, and I had the chance to live closely with some disadvantaged groups and to observe many problems and aspects of socio-economic inequities. I saw how poverty, illiteracy, and health were interrelated. As a fresh graduate, my experience lacked a deep scientific understanding of the social determinants of health and health equity; however, it has greatly shaped my beliefs and motivations. Many years later, during my study in the health information science program at Western University, I was able to benefit from that experience to understand some complex aspects of health policy and health equity.

I have also been a certified computer programmer since 2001, and I earned a dozen top professional programming certificates between 2001 and 2012. I also developed and managed an award-winning online library, which had over 300,000 subscribers, between
These experiences enhance my knowledge, perception, and sensitivity to the research problem and assist me in working with the study participants.

There are two possible areas of bias in my work. The first one is my bias towards health equity. I believe that health equity is a major aspect of healthcare quality, and achieving it is a supreme goal. While my bias toward health equity did not have any impact on participant selection and interviewing, it might have influenced the framing of some of the questions used in the interviews, and my interpretation for the data. It might have also influenced the studies that I have selected to represent health inequity in Canada.

Another area of bias is related to my role as a developer and designer for the visualization tool. Usually, designers are biased toward their work. However, I believe in the user-centered design principle, and I highly valued the feedback of my research participants about the design and the value of my tool.

4.2.2 Method

I used a semi-structured interview method to collect my data. I created an interview guide (Appendix A), which has evolved during my data collection stage. After interviewing each participant I reflected on the questions that I used during the interview, and many times I used these reflections to update my interview guide by adding more questions or by rephrasing some of the existing questions. As a result, I ended up having four versions of my interview guide. The semi-structured interview method necessitated that I focus my questions on points related to my research question and objectives. However, all the questions that I asked were open-ended. In times when I received short answers, including “yes” and “no” answers, I asked my participants to explain more, or I rephrased the question. There were some questions that I called strategic questions. Some participants gave me very deep answers to these questions, and I used these as exemplars in my discussion with other participants, while also clearly informing my participants that some other participants had different opinions or views. However, in my interviews, I was careful not to impose my views, and I always informed my participants that they were the experts.
I used three techniques to conduct the interviews. These techniques are face to face, web conferencing, and telephone interviews. I used face to face interview with two participants, and I think that it is the most effective technique, because my participants and I were able to use the tool directly to clarify many points during the interview. I used web conferencing mainly to interview participants who lived outside my city. While this technique enables screen sharing, a feature that can be used to do a live presentation, I did not have to use screen sharing nor did any of my interviewees. I also used the telephone interview technique with two participants, and I think that this form of interview is more difficult to use and record.

The transcription process for the interviews took place in parallel with the interviews, and this helped me discover new perspectives on my research topic, and to realize important aspects that I need to focus on in my next interviews. I tried to create verbatim transcripts of each interview. However, on some rare occasions and for some interviews that were done via Skype, there were some words which were not clear due to internet disruptions, and I had to interpret these words based on the general direction of the conversation.

4.2.3 Setting and Participants

I used a purposeful sampling strategy. Purposefully selected participants enable the researcher to learn more about the local conditions, values and the context of the phenomenon (Lincoln & Guba, 1985). According to Creswell (2012), purposeful sampling is used in qualitative research because:

> The inquirer selects individuals and sites for study because they can purposefully inform an understanding of the research problem and central phenomenon in the study. (p. 125)

I planned to recruit five to ten participants who participate in health policymaking. As I have explained in section 2.1 (definitions), different actors participate in public policymaking, including political actors, bureaucratic actors, special interest actors, general interest actors, and expert actors. However, in my thesis, I have focused on bureaucratic actors and expert actors. Bureaucratic actors are public servants in top
positions, and they hold legal powers that entitle them to participate in decision-making. These actors have the authority to make final decisions with regards to health policy interventions and resource allocations. Expert actors have the technical knowledge in healthcare and health system issues. Expert actors include researchers, epidemiologists, and data analysts.

I wanted to recruit expert actors and bureaucratic actors at the local health planning bodies (Local Health Integration Networks), public health units, hospitals, research centers, and community care access centers. However, during the planning stage, a committee member advised me to change my target sample because policymakers will not have the time to engage in a study that requires a fairly long commitment to do the training on using the tool, using the tool, and attending interviews. Therefore, my research participants were all policy experts as illustrated in Table 3.

Demographic characteristics of the participants were not important for my study, and, therefore, they were ignored. Five of my seven participants were interested in the social determinants of health and were working on projects and research linked to health equity. Additionally, all of the participants used computers and information technology in their work.

I used two recruitment methods: advertisement and snowball sampling. I identified several organizations that might include prospective participants, such as the public health units in Ontario and several research institutes in Canada and worldwide. I contacted these organizations by email and informed them about my research and asked them to circulate my research poster internally. My supervisor and my committee member also circulated my research poster through their networks. I also used snowball sampling, and I was able to recruit some participants with the help of one participant.

To present the tool, I did a live presentation for some of the participants, and I had to rely on a video presentation for the other participants. The type of presentation was determined by several factors, including participant’s choice, and my capability to travel outside the city where I live. After the presentation, participants were granted access to the tool, and they were able to explore it for some time. Participants were not asked to
perform specific tasks with the tool, but in the demonstration I have explained the possible tasks that could be performed. In all the cases, I contacted each participant again and asked him/her for an interview. All of my participants did explore the tool, and I was able to verify that they had done that during the interview.

In addition to the seven participants, one participant did not provide sufficient data; another person who initially agreed did not have time for an interview. These two persons were excluded from the study.

The following table provides a clear description of the research participants:

<table>
<thead>
<tr>
<th>ID</th>
<th>Alias Name</th>
<th>Professional Position</th>
<th>Organization</th>
<th>Education</th>
<th>Demonstration Method</th>
<th>Interview Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Participant#1</td>
<td>Data Analyst</td>
<td>ICES Ontario</td>
<td>Ph.D., Master Degree in Epidemiology</td>
<td>Live</td>
<td>In Person</td>
</tr>
<tr>
<td>2</td>
<td>Participant#2</td>
<td>Researcher</td>
<td>A Health research institute in Canada</td>
<td>RN, Ph.D.</td>
<td>Live</td>
<td>Skype</td>
</tr>
<tr>
<td>3</td>
<td>Participant#3</td>
<td>Ph.D. Student and University Instructor</td>
<td>A Canadian university</td>
<td>RN</td>
<td>Video</td>
<td>Telephone</td>
</tr>
<tr>
<td>4</td>
<td>Participant#4</td>
<td>Program Manager</td>
<td>A public health unit in Ontario</td>
<td>Master Degree in Epidemiology</td>
<td>Video</td>
<td>Skype</td>
</tr>
<tr>
<td>5</td>
<td>Participant#5</td>
<td>Assistant Professor</td>
<td>A Canadian university</td>
<td>BScN, Ph.D.</td>
<td>Live</td>
<td>In Person</td>
</tr>
<tr>
<td>6</td>
<td>Participant#6</td>
<td>Health Records and Business Analyst</td>
<td>Community care access center in Ontario</td>
<td>Master Degree in Health Science</td>
<td>Video</td>
<td>In Person</td>
</tr>
</tbody>
</table>
4.2.4 Data Analysis

Data analysis in qualitative research is inductive in nature and allows the emergence of general themes from the particular data (Creswell, 2012). Patton (2002) describes the core aspects of qualitative data analysis:

The strategy of inductive designs is to allow for important analysis dimensions to emerge from patterns found in the cases under study without presupposing in advance what the important dimensions will be. The qualitative analyst seeks to understand the multiple interrelationships among dimensions that emerge from the data without making prior assumptions or specifying hypotheses about the linear or correlative relationships among narrowly defined, operationalized variables. (p. 56)

Creswell (2014) suggests that qualitative data analysis should include the following steps:

1. Organizing and preparing the data for analysis.
2. Reading the data and identifying general meanings and ideas.
3. Coding the data.
5. Interpreting the meanings of themes.

Although this process sounds linear, in reality, it is an interactive and spiral process, where researchers move back and forth among these steps (Creswell, 2012; Creswell, 2014). Additionally, because qualitative research is an emergent practice, and the researcher is expected to analyze the collected data while he/she is still collecting other data, I started my data analysis after completing my first interview. I continued data analysis while I was still interviewing other participants, and I updated my interview
guide every time I felt that I needed to probe for a potentially important meaning that was brought up by other participants.

While researchers can start data analysis with *a priori* codes, they should be open to emerging codes (Creswell, 2012). Miles and Huberman (1994) suggest the creation of a list of codes before data analysis:

This list comes from the conceptual framework, list of research questions, hypotheses, problem areas, and/or key variables that the researcher brings to the study. (p. 58)

From a postpositivist stance, starting with a set of predefined codes could enhance the quality of the study (Lazar, Feng, & Hochheiser, 2010). Green et al. (2007) assert that theme generation and interpretation should be examined against the conceptual framework, relevant theories, and the data. Such examination enhances the quality of the study. In my data analysis, I adopted this position. I developed a list of codes that reflect the core aspects of usability and user experience. As I explain later in this section, I started with an initial list of categories and codes, and that list evolved into a more compact one in which I have used the IT artifact concept, which I have explained in Chapter 3, section 3.1.1. From this perspective, the IT artifact is the tool that is used by research participants to perform specific tasks in a specific context of use. Most of these codes were mentioned in Carroll et al.’s (2014) study, which I have reviewed in my literature review chapter.

Figure 3 represents a mind-map diagram of these codes. The codes are in the leaf nodes, which are the green and purple nodes.
Figure 3: The Codes Used in Data Analysis

To analyze the data, I used a qualitative data analysis software product called QDA Miner Lite (http://provalisresearch.com/products/qualitative-data-analysis-software/). This product has some of the standard features of qualitative data analysis software, including code definition, text coding and highlighting, multiple coding, text search, and data extraction.

I started data analysis process by creating a set of categories of concepts that I expected to find in the data. These categories were based on my conceptual framework (Figure 2), and in each category I put a few codes. The following list represents my initial category list along with the relevant codes:

- **Usability**
  - Effectiveness
  - Efficiency
  - Satisfaction
  - Ease of Use
  - Learnability

- **Visualization Quality**
  - Encoding Techniques
- Interactivity
  - Tooltips
  - Encoding Marks

- Knowledge Translation
  - Time Constraint
  - Applicability
  - Training
  - Timing
  - Resource Constraints
  - Accessibility to Evidence

- Quality of Information
  - Credibility
  - Reliability
  - Transparency
  - Validity
  - Understandability
  - Interpretability
  - Limitations

- Complexity
  - Complex Problem
  - Complex Information
  - Complex Indicators
  - Complex Communication
  - Complex Interpretation
  - Complex Presentation

- Decision Making
  - Priorities
  - Interests
  - Context
  - Powers
  - Decision Makers Needs
I started coding the data by reading the ready transcripts and adding the appropriate codes to the data. However, as my research progressed and after I had worked with the data of a few participants, I realized that my initial list was too broad and I needed to have a more compact list, which is represented in Figure 3 above. Nevertheless, my initial list helped me to understand my data and to focus my attention on the more important perspectives of this data.

After coding the data of all of the participants, I used a function in QDA Miner that gives the frequencies of the codes in the data. By looking at the frequencies I was able to understand the most important meanings in the data. I consolidated those meanings into themes. I then recoded the data using those themes. The next step was to retrieve the data that is relevant to each theme, and I used another function in QDA Miner that enables the user to sort and retrieve the data based on selected codes/themes. The data of each theme was saved in a separate file and it was used later to write this report.

4.2.5 Research Quality

Since the start of this research, I have been very attentive to research quality. In my study, I used Lincoln and Guba’s (1985) trustworthiness criteria. These criteria contain credibility, transferability, dependability, and confirmability. However, some of the practices to achieve trustworthiness could not be followed, including member checking, and triangulation.

Credibility refers to the rigor of the study, and it can be achieved by using several strategies such as using a rigorous research methodology that is “well established” in the
study domain (Shenton, 2004). Other strategies include “prolonged involvement, persistent observation, triangulation, peer debriefing, negative case analysis, and member checks” (Ballinger, 2006, p. 239). Credibility could also be achieved by using reflexivity (Morrow, 2005). Reflexivity is a “thoughtful, conscious self-awareness” of researcher’s position, perspective, and presence (Finlay, 2002).

In my thesis, I was careful to select an appropriate research methodology, and I have documented the rationales behind this decision. I also consulted with my supervisory committee in almost all of the stages where I had had to make pivotal decisions. I had several debriefing sessions with two of my peers who were doing their Ph.D. degrees. In these sessions, I presented my work and answered the questions of my peers regarding my research design and research findings. I have written about my role as a researcher (Chapter 4), and I have written reflexive notes about my assumptions and beliefs (Chapter 6).

**Transferability** refers to the applicability of the research findings to other contexts, and it can be achieved through thick description, which refers to the detailed description of research context, participants, and processes (Morrow, 2005; Ballinger, 2006). In my thesis, I have provided a detailed description of my research participants and my research processes. The thick description also requires a detailed description of the research context. However, the absence of an organizational research context prevented me from providing a complete description of the research context at an organizational level. Nevertheless, I provided a partial description of the context of health policymaking.

**Dependability** refers to the reliability of the research process, and it can be achieved by providing a detailed description of the research process so that other researchers can fully understand and repeat it. It can be strengthened by auditing the research process by external researchers or peers (Morrow, 2005). I have described my research methodology and methods in this chapter. My description covers the tool design, demonstration, and exploration. It also covers how I conducted the interviews. I also had a web conference with my supervisor via Skype just before I started writing this report. During that meeting, I used the “screen sharing” feature to present to him how I organized my
research process files and the different tools that I have used, including the qualitative data analysis tool—QDA Miner—and Microsoft Visio. I also showed him the data-analysis files, the codes used, and the highlighted data.

**Confirmability** represents what Lincoln and Guba (1985) the “qualitative objectivity”, which is concerned not with the objectivity of the researcher, but rather it is concerned with the objectivity of data:

> [It] removes the emphasis from the investigator and places it where, as it seems to the naturalist, it out more logically to be: on the data themselves. The issue is no longer the investigator’s characteristics but the characteristics of the data: Are they or are they not confirmable? (p. 300)

Confirmability can be achieved by the audit trail, which refers to showing verifiable evidence for the evolution of the researcher’s understanding of the research problem, and the research process. In my thesis, I documented the evolution of the design of the tool. My interview guide also evolved, and I created four versions of that guide to be able to explore other aspects of the phenomenon that emerged throughout the interviews. I also created several charts and mind maps to represent certain concepts and to facilitate my thinking and decision-making. Confirmability can also be achieved through reflexivity, and the reader may review my reflexive notes in Chapter 6.

### 4.2.6 Ethics

The Western University Non-Medical Research Ethics Board (protocol #106967) approved this study.

Confidentiality of information and anonymity and privacy of my research participants were respected. All of my participants received a letter of information and consent form. Each participant received a copy of the transcript of his/her interview, and participants were invited to express any concern they might have had regarding the content of the transcripts. Although my research poster included an honorarium—a $25 gift card—, some participants did not accept it.
4.3 The Visualization Tool

The tool is a major component of my research. It is a website that includes several pages, and it presents the CSDH framework, which provides access to a set of visualizations. The tool’s website address is: http://www.healthvisualization.ca/, and the following figure represents the sitemap of this website:

![Figure 4: a Site Map for www.healthvisualization.ca](image)

Figure 5 represents the visualized framework:

![Figure 5: The Visualized CSDH Framework](image)
By clicking on any of the determinants of health, the user can see the corresponding visualization. For example, Figure 6 represents the cause-specific mortality by education in Canada:

![Figure 6: Cause-Specific Mortality by Education in Canada](image)

There are many interaction techniques in each visualization. For example, the following visualization (Figure 7) represents a choropleth map for a set of health indicators. These indicators represent access to healthcare services along the rural-urban continuum in Canada. The user can select the indicator from a list of indicators. The user can also select the types of rural and urban areas to see. The user can also zoom in and out. Figure 7 also shows a tooltip provided when the user hovers over a specific area (Toronto for example).
Figure 7: A Choropleth Map Representing Access to Healthcare Services along the Rural-Urban Continuum in Canada

I have used different encoding marks in the visualizations. For example, in Figure 8, which represents the influence of neighborhood deprivation, gender and ethno-racial origin on smoking behavior of Canadian youth, colors and shapes have been used to represent different variables in the visualization.
Figure 8: Encoding Techniques

The encoding and representation techniques used in all of the visualizations reflect my judgment of the effective way to represent the indicators and tell the story of health equity (or inequity) in Canada.

More screenshots are provided in Chapter 5 (the results chapter), where I discuss the different aspects of the tool and the user experience. The reader can also visit the tool website on www.healthvisualization.ca.

4.3.1 Designing the Visualization Tool

As is the case in many software prototypes developed by university students, the design of a prototype and the technology used to develop it are influenced by the experience of the student, the available time, the available financial resources, and the research questions that the prototype is created to address.
As for myself, I have been a computer programmer since 1989, and I have earned a many professional Java programming certificates from industry leaders, including Oracle and Sun Microsystems. Therefore, my initial plan was to create a software product rather than just a prototype, and my supervisor encouraged me to do so. My supervisor suggested two options for developing the tool. The first one, which is more time and effort consuming, was to use a specific programming platform called D3, which is a JavaScript library used to create computer visualizations for the Web, and he showed me some computer programs developed by some of his Ph.D. students using D3. The second option was to use the Tableau platform, which is a software product for designing interactive visualizations, and it offers many features for different levels of users, and it can also be programmed to achieve certain functions. I decided to use D3, and I started learning D3 at the beginning of June 2015. However, after two months of learning, I realized that I could not reach a stage where I could confidently develop a sophisticated tool. Therefore, I decided to go with the second option, which is to use Tableau.

I started working with Tableau in August 2015, and I started developing my tool in October 2015. While Tableau gave me the capability to create the visualizations, it could not help me to visualize an important and major component in my tool, which is the CSDH framework for the social determinants of health, and I had to use HTML and Javascript to create that framework. I also used Google Blogger as a web content management platform to design and host my tool. I used Net Beans IDE, which is a development environment from Oracle to create Java and JavaScript applications. I also used Microsoft Expression Web to design the web pages for my tool.

The following table shows the technology used for developing the tool:

<table>
<thead>
<tr>
<th>Component</th>
<th>Technology Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The web site (<a href="http://www.healthvisualization.ca">www.healthvisualization.ca</a>)</td>
<td>Google Blogger</td>
</tr>
<tr>
<td>2. CSDH Framework</td>
<td>HTML, JavaScript</td>
</tr>
<tr>
<td>3. Indicator Visualizations</td>
<td>Tableau</td>
</tr>
<tr>
<td>4. Integrated Development Environment</td>
<td>NetBeans</td>
</tr>
<tr>
<td>5. HTML Design</td>
<td>Microsoft Expression Web</td>
</tr>
<tr>
<td>6. Data Management</td>
<td>Microsoft Excel</td>
</tr>
</tbody>
</table>
4.3.2 Health Indicator Data Sources

As a researcher and healthcare professional, working with health indicator data sources is very important to me. When I started planning for my thesis in February 2015, I had thought of using raw data from Statistics Canada, and mainly from the Canadian Community Health Survey. Therefore, I contacted the Research Data Centre (RDC) at Western and attended a presentation about the available data sources. In February 2015, I also met with one of the officers at RDC, who explained to me how to access the available data sources through ODESI data delivery system (http://odesi.ca) provided by the Ontario Council of University Libraries. I also explored more summarized versions of the data sources, through Statistics Canada website. After that, I started exploring the available data sources, and I soon realized that extracting meaningful and statistically significant data from the raw data is a research endeavor by itself. I also found that the summaries provided by Statistics Canada, for example, the summaries on http://www.statcan.gc.ca/eng/health/index are incomplete, and they only present one type of health indicators, such as mortality rates and smoking rates, but they do not present the relationships among the different indicators of health—the health disparities. Therefore, I decided; after consulting with my supervisor and my committee member; that I was better off if I worked on secondary data taken directly from published studies. I looked for studies that show a relation between any social determinants of health and a health outcome. My first source for relevant studies was a journal published by Statistics Canada, and it is called Health Reports. It is a peer-reviewed journal of population health and health services research, and it is indexed by PubMed. The journal is an online journal, and it provides different tools to browse the articles by subject, and to do a full-text search in the articles. I was only able to get three articles from this journal, and I had to use other sources, including Google Scholar, and BioMed Central to find other articles. I used keywords, such as inequity, social determinants, gender, ethnicity, health behavior, and neighborhood. I also used two keywords in every search I did, and these were health and Canada. While I was able to find several articles, my challenge was to find articles that provide their underlying data sources. All of the studies selected are quantitative research studies because the visualization platform that I used to develop the
visualizations works with numerical data only. This selection doesn’t reflect any bias towards certain research approaches.

The following table shows the articles that were used to create the visualizations:

**Table 5: The Articles Used for Creating the Visualizations**

<table>
<thead>
<tr>
<th></th>
<th>Article</th>
<th>Journal</th>
<th>Publisher</th>
<th>Publishing Year</th>
<th>Social Determinates</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Cause-Specific Mortality by Income Adequacy in Canada</td>
<td>Health Reports</td>
<td>Statistics Canada</td>
<td>2013</td>
<td>Income</td>
</tr>
<tr>
<td>2</td>
<td>Social Determinants of Lung Cancer Incidence in Canada</td>
<td>Health Reports</td>
<td>Statistics Canada</td>
<td>2015</td>
<td>Occupation</td>
</tr>
<tr>
<td>3</td>
<td>Cause-Specific Mortality by Education in Canada</td>
<td>Health Reports</td>
<td>Statistics Canada</td>
<td>2012</td>
<td>Education</td>
</tr>
<tr>
<td>4</td>
<td>Influence of Neighborhood Deprivation, Gender and Ethno-Racial Origin on Smoking Behavior of Canadian Youth</td>
<td>Preventive Medicine</td>
<td>Elsevier</td>
<td>2011</td>
<td>Gender Ethnicity</td>
</tr>
</tbody>
</table>

**4.3.3 Visualizing the Health Indicators**

All of the selected articles provided different perspectives for the determinants of health in Canada. These perspectives represent the different variables examined in each article. For example, the article titled “Cause-Specific Mortality by Education in Canada”
provided many perspectives, including the mortality rates for different educational levels, age groups, and gender. Therefore, I have created several visualizations for each article. However, when I started publishing the articles on the tool website, I reduced the number of visualizations per article to reduce the effort and time required by my research participants to explore the tool. I also provided visualizations for some of the determinants only to reduce the time required to examine the tool by research participants. However, I believe that I have provided enough visualizations to demonstrate the tool and collect sufficient data.

In my tool, I wanted to test the utility of visualizing frameworks, which is my main research question. I also wanted to evaluate different visualization constructs, including different interaction techniques, visualization techniques, and data encoding techniques to develop the next version of the tool. Interaction techniques that I have provided in my tool included zooming, hand scrolling, filtering, hovering and tooltips, and sorting. I have created several kinds of representation techniques, such as scatter plots, heat maps, bar charts, and choropleth maps. I have used two visual encoding marks: color and shape. These marks have different attributes, including color saturation, and shape size.

Developing the visualizations started at the beginning of September 2015 and ended by the end of December 2015. The development stage resulted in three versions of the visualizations. The third version was the one used in the final tool. Except for a few minor changes in some visualizations, research participants saw and explored the same version of visualizations.
Chapter 5

5 Results

The purpose of my thesis is to explore the use of information visualization to represent the social determinants of health and health equity indicators, and to understand the benefits of such use in knowledge translation and health policymaking. While the focus of my thesis is to examine the perceived utility of visualizing a conceptual framework for the social determinants of health, my thesis reveals many aspects of health policymaking and knowledge translation.

In this chapter, I present my research findings. In my presentation I use the following terms to represent specific meanings:

1. The tool or the visualization tool: These terms refer to the tool (www.healthvisualization.ca) that I have developed for my thesis.

2. The framework or the visualized framework: These terms always refer to CSDH framework, which was developed by the World Health Organization’s Commission on the social determinant of health.

3. Visualizations: Although the word visualization is a non-count noun, a plural form of it has been used in information technology literature to refer to a group of visualized charts, and I have used it here for the same purpose.

4. The expert: This term is defined in Chapter 2 (the literature review), and it refers to expert policy actor, who has the technical expertise or policy area expertise that enable him/her to analyze policy problems and suggest solutions. Experts might be professionals working in healthcare or public health organizations in Canada, including epidemiologists, data analysts, or researchers in research centers. The experts could also be researchers in academia who participate directly in decision support activities either in hospitals or in not for profit organizations. Expert policy actors are knowledge producers, who produce the knowledge required for health policymaking.
Quotations from my participants’ talk were put in quotation marks. In some quotations, I have put my words in square brackets. Whenever put, my words always refer to a meaning that was explicitly or implicitly mentioned in the conversation. For example, if I had asked a participant a question about a specific concept, then this participant might have used the pronoun “it” to refer to that concept, and I might find it more useful to clarify certain sentences, without changing the overall meaning that the participant wanted to convey. I have also underlined some sentences for emphasis.

The themes presented represent the stories told by my participants, and I have tried to explicate these stories by objectively interpreting the content of the interviews that I conducted with my research participants. I have also tried to use a relevant coding system to analyze my data and to facilitate an objective interpretation of it. However, given the semi-structured nature of the interview guide, some themes could be the direct result of specific questions. For example, themes related to the usability of the tool were expected to appear because I have asked about it, albeit using open-ended questions. On the other hand, some themes reflect my participants’ priorities and concerns and were not prompted directly by interview questions. For example, the misinterpretation of information by laypeople theme, and the complexity of health policymaking were brought up by some participants.

The following themes emerged from my analysis:

1. Expert's Perceived Usefulness of the Framework.
   
   a. The Framework as a knowledge construct.
   
   b. The Framework as a visualization construct.

2. Expert's Perceived Usefulness of the Tool.


5. Expert's Concerns about Users' Misinterpretation of Knowledge.

7. Expert's Evaluation of the Features of the Tool
   a. Ease of Use.
   b. Representation Techniques and Encoding Marks.

5.1 Theme 1: Expert's Perceived Usefulness of the Framework

Participants talked about the use of the framework as a gateway to explore the social determinants of health. All of the participants valued the use of the framework. However, participants talked about two different concepts: The framework as a knowledge construct and the framework as a visualization construct.

5.1.1 The Framework as A Knowledge Construct

5.1.1.1 Main Finding

All participants agreed that conceptual frameworks, in general, are useful in presenting the theoretical perspectives of the research and the theoretical lenses of researchers. Some participants believed that the CSDH framework was necessary and useful for representing the social determinants of health. However, because it is a knowledge construct, some participants believed that the CSDH framework was difficult to understand, or was incomplete.

5.1.1.2 Participants’ Voice

Participant#5, an assistant professor, believed that the CSDH framework illustrated the complexity of the SDoH very well:

“It is a good framework. Obviously, I have seen lots of different frameworks trying to capture the concepts of the social determinants of health. I think this is a good one, and it captures the complexity of the factors. Some of the other frameworks are more generic, and they look like lists of factors than a framework, and they don't
capture some of the interactional components, so I like that the interactions [among
the determinants] are captured in this one.”

Participant#2, who is a registered nurse and researcher, had a similar view about CSDH
framework:

“The way the framework is prepared is very helpful in understanding the levels that
SDoH contribute to the equity of healthcare.”

Participant#3, who is a registered nurse and a Ph.D. student, thought that conceptual
frameworks are necessary for research studies, and she believed that CSDH framework
used in the tool was helpful, but it was incomplete:

“A conceptual framework increases the quality of the study, so I think we should
always use a framework that directs us… So while the framework has the reliability
that is based on evidence, this evidence changes for Northern Ontario, especially
when talking about rural and urban areas, so a research gap here is how to adjust
this framework for Northern Ontario… I thought that we need more on culture
because I think culture does have an impact on access to healthcare services,
especially when you have a multi-culture community like Northern Ontario and
some other parts of Canada.”

Participant#4, who is an epidemiologist and a program manager at a health unit, believed
that frameworks are useful and should be used whenever possible. However, CSDH
framework was new to her, and she needed to review the provided background
information before she was able to understand it, and, therefore she seemed to have found
it less intuitive:

“This framework didn't resonate with me, and I really had a hard time to understand
what material circumstances are. … So what I did is that I went into the description
you had on your website, and that really did help me to understand, …So it is useful
to use the framework, and it allows the users to see the different components, but I
did need clarification on the [CSDH] framework you are using. I actually had not
seen that before, despite my work in the social determinants of health, so it was really good for me to see it and to read about it.”

Participant#7, who is an assistant professor and epidemiologist, thought that CSDH framework presents the SDoH phenomenon in a logical way:

“I actually would use a framework to organize the material that I will present because that would create a very useful logical structural context and construct, so in that sense, a report could be organized using this framework. So I don't question the usefulness of CSDH framework for me to present information to others. Also, if you are trying to present information to me, it still useful for me to have indicators organized by a framework.”

5.1.2 The Framework as A Visualization Construct

Almost all researchers use frameworks in their research. However, a framework might be presented explicitly—visually—in the study, or it might be described in a narrative way. In electronically published studies, frameworks might be provided as attached files. Therefore, in my discussion with my research participants, I asked them about the value of visualizing frameworks and using them to present complex healthcare problems. I was very careful to explain to my research participants that visualization implies the use of information technology and interactive visualization to present the framework.

5.1.2.1 Main Finding

Most of the participants believed that visualizing CSDH framework (Figure 9) helps to present the social determinants of health more effectively, and it makes the phenomenon more understandable. However, one participant believed that providing topical access to the visualizations might be more effective than accessing them through the framework.
5.1.2.2 Participants’ Voice

Participant#5, an assistant professor, believed that visualizing the framework helps people to understand the complex problem of the social determinants of health. He showed me a recent study that he had done with his colleagues, where they created a framework for that study. That study was printed on paper, but Participant#5 had hoped that his study had been published electronically, and its framework was represented using interactive visualization:

“I don't really love the print version, and what I would love is that my study framework is put online; where I can zoom into different pieces and interact with them and then zoom out. I think that would be much better; because I know that the framework is complex, and people who read it will not engage if it is too much, but if it was visualized, then the interactivity lets you simplify the framework by focusing on different pieces.”
Participant#5 also stated that he “fundamentally disagrees” with the idea [suggested by another participant] of replacing a framework with a list of topics, because a visualized framework facilitates theoretical understanding of SDoH.

Participant#6, a health records specialist, also found some value in visualizing the CSDH framework:

You can understand things a little better, and it is easier to interpret the framework by visualizing the relevant studies, but it is important that the studies be in the same context.

Participant#1, who is a data analyst and epidemiologist, believed that the visualized CSDH framework is useful:

“It gives us a clear and big picture, and then once you get into those determinants, you will know more detail.”

However, Participant#4, who is an epidemiologist and a program manager at a health unit, felt uncomfortable with the visualized framework and preferred to see, instead, a list of topics or indicators—a topical access. Nevertheless, she remained open for the idea of framework visualization:

I am not saying that what you have done is bad by any means. I am just saying what I am comfortable with. Maybe it is good that you are challenging my comfort and that you are turning the tables around, and you are making me navigate the determinants of health rather than the topic areas. I think it is good, but I wanted to tell you where my comfort area is.

Participant#7, who is an assistant professor and epidemiologist, believed that visualizing a framework might be more useful for presenting health indicators to laypeople than just showing indicators using tables and lists:

There are a lot of benefits if your target audience is lay individuals; because they lack a conceptual framework in which to interpret and assign a value to the indicator information. This [visualization] is providing laypeople with an analytic
[visualized] way to understand how things are connected, and so that they are able then to consume the information in a more assimilable way. As opposed to just being overwhelmed by a huge number of indicators, they can now organize them into a logical structure that has a meaning in terms of causality, so this is a very useful approach I think for a lay audience as a target.

5.2 Theme 2: Expert's Perceived Usefulness of the Tool

The tool refers to the visualization tool that I have created for this research. It is a website that includes the visualized framework, and the visualized studies. The visualized CSDH framework is only one part of the tool, and, therefore, I wanted to evaluate the utility of the tool and identify potential future enhancements. I also believe that the distinction between the tool and the visualized framework was clear to my research participants, and it was reflected in their comments, which are presented here.

5.2.1 Main Finding

My participants were satisfied with the tool. The tool’s interaction capabilities were the main reason for participants’ interest and satisfaction. Participants believed that the tool can be used for different purposes. Researchers could use it to present and communicate research findings and to have a quick review of the studies about the social determinants of health. Professors can use it for teaching purposes. Data analysts and decision supporters can use it to prepare reports for decision makers. Finally, laypeople could use it to learn about the social determinants of health. Some participants also suggested that ease of use and the cost of the tool could be key factors for adopting this tool in organizations. My participants also expressed their opinions on using the tool by policymakers; however, I have discussed that in theme 6.

As an example for interaction capabilities, Figures 10 and 11 represent the access to healthcare services along the rural-urban continuum in Canada. In Figure 10, the user sees five indicators in all the rural and urban areas (the census subdivisions). However, in Figure 11, the user uses the filter to see only two indicators, which are the unmet health needs and the visiting of a specialist physician in two census subdivisions, which are the most urbanized and the most rural areas in Canada.
Figure 10: Interaction Capabilities- Before Using the Filters

After applying the filters, the user sees that those who live in the most urbanized areas have a higher rate of specialist visits than those living in the most rural areas. However, the user can also see that those living in the most urbanized areas believe that they have unmet healthcare needs more than those living in the most rural areas do.
5.2.2 Participants’ Voice

Participant#5, an assistant professor, believed that the tool is useful because it helps in presenting complex issues such as the social determinants of health:

“I think trying to make a more interactive dynamic way to explain very complex health and social phenomena is a worthy endeavor.”

Participant#6, a health records specialist, believed that interaction makes the tool suitable for data analysts. However, she was not sure that decision makers in her organization would find the tool easy to use or whether they will have the time to use it:

“I think it is valuable; especially the ability to interact with the visualization and filter the information. I think it is good for data analysts, but when you give it to people who don’t know how to use it, they don’t want to spend the time learning it or have the time to do that… But I don't know if the managers would have time to play around with the [tool] and look for a kind of patterns.”
She also mentioned that the cost is an important factor that is taken into consideration when adopting this tool or similar tools:

“[using such tool] costs money and, as you know, in healthcare, understandably the system doesn't want to spend money unnecessarily. So it has to show a really good value before some organizations are going to take it on, I think it can show values, but it takes time and a lot of effort.”

Participant#3, who is a registered nurse and a Ph.D. student, believed that she will use the tool because she can “control the visuals” by interacting with the tool. She said that she would use the tool for presentation and teaching purposes:

“I really think that I will be excited about it because you need to present your findings in a succinct manner, and the tool would be fairly easy to learn. It can also help you in your presentation by putting all these visuals and then controlling them. I would use this tool in my teaching and my class, and it would be informative for the students because they are computer savvy, and they will love it. It can help them to learn about the social determinants of health.”

Participant#4, who is an epidemiologist and a program manager at a health unit, who felt uncomfortable with the CSDH framework, believed that the tool is “very good, easy to use, and intuitive”, and she also described her experience with the tool:

“I could look at different variables and turn things on and off. It was neat to see some of the patterns…, and being able to see different diseases broken down was very interesting, and looking at things like the differences in equity between diabetes and ischemic heart disease. So it was very useful.”

For her, it is all about the interaction with data:

“I actually think that this interactivity is what is so special; because if you allow people to interact with the data; they will start to understand it just by playing with it, and turning things on and off, they are going to get [it], they will see that there are patterns to be seen.”
She also believed that manpower and cost are key factors in adopting it her health unit:

“I don't have the [staff] to do it right now. I have to wait for the right time and the right product to make this [transition] simple and easy, and this will take a fair amount of time. So, I think I will have to wait until others have done it, and then jump on board, I need to see other health units, I need to see people like yourself, and that is why I was interested in participating [in your research].”

Participant#1, who is a data analyst and epidemiologist, felt that the tool was useful, and believed that interaction capabilities such as those provided by the tool are very important, and compared the passive reader of a traditional paper with the capable reader of the articles published in the visualization tool:

“In a paper, you can passively get the information about the factors and the outcomes. But with the visualization tool, you can just play with it, and you can freely pick some certain factors you are interested in, and then you can choose your reference groups and compare. But in a paper, you are forced to accept this information and you can't play with it. Let's say I want other information, and I want specific information on a specific cause of death, you can't pick that from the paper, but in the visualization you can easily just play with it, and I think that this is something really creative and novel.”

She also believed that cost and ease of use are major factors in adopting such tool:

“If you really think you have the energy, the time, and the money to train those people [in organizations], and you think the cost is small compared to the benefit they will gain then go for it. “

Participant#7, who is an assistant professor and epidemiologist, said that he can use the tool to do a quick review of the relevant studies, but he would still review the source research papers to get more details:

“I may use this kind of a tool as a first quick view, what indicators are available, what other data and studies are available, and from there I would probably go to
read the actual study. So once this tool is completed, and if there were enough studies in it, I would use it to get a very quick overview then follow up with the details in the studies that interest me. So I think in that sense it could be quite useful.”

Participant#2, who is a registered nurse and researcher, believed that interactive visualization allows readers to understand complex graphs:

“When a graph or a chart is so big, your eyes go back and forth, and you ask yourself which part I should look at, or which part I am interested in. But with the filters that you have put on the side of the visualization, you can select which data you want to see at this time…, so you have the overall view of the findings of the study, and then you can be selective to what section of the data you want to see.”

5.3 Theme 3: Expert's Perceived Complexity of Knowledge Communication

5.3.1 Main Finding

All of the participants talked about the complexity of knowledge communication, and how they can reduce this complexity through interactive visualization. Participants agreed on the importance and necessity to reduce the complexity of healthcare reports by using understandable indicators to enable policymakers to understand it and use it. One participant suggested that knowledge producers—the experts—be trained on knowledge communication so that they can convey their knowledge products to their target audience. However, one participant believed that it was also important to train decision makers on the basics of healthcare indicators and epidemiological methods.

In my presentation for the complexity of knowledge communication theme, I have not talked about the potential utility of information visualization in reducing this complexity because I have covered that in my presentation for Theme 2—the perceived utility of the tool. Instead, I have focused on the complexity of knowledge communication as described by these participants.
5.3.2 Participants’ Voice

Participant#5, an assistant professor, reflected on his recent experience in designing a physiotherapy funding policy for people with low income, and expressed his thoughts about the complexity of physiotherapy for low-income people, and the complexity of communicating this issue to policymakers:

“To try to get, for example, city planners or bylaw officers working together with healthcare professionals to understand the complexity of that kind of issue, you are trying to get them to understand the determinants of health and how to have a good impact on physiotherapy funding for someone with low income. You need to be attuned to particular components and how they interact. However, trying to describe that is often challenging, and trying to show it with just a static picture is challenging as well.”

Participant#6, a health records specialist, asserted on the necessity to create health reports that are understandable by their intended users. However, she acknowledged that this might not be an easy work when the reports include some complex healthcare indicators:

“When we create reports they have to be [presented] in a certain way so that people [decision makers] can understand them or else it has no effect, it doesn't do anything for anyone. So if someone has an issue in some wordings or statistical terms we may change it. But the indicators used [in the tool] are standard ones, like the age-standardized mortality rate. This [indicator] and other indicators are needed in the background of our reports and our visualizations, and we can't change them, maybe we can add more explanation, but we are mandated to use them.”

Participant#4, who is an epidemiologist and a program manager at a health unit, identified three challenges that she had been facing, as an expert and a knowledge producer, in knowledge communication. These are the diversity in audience types and needs, the complexity of information, and the insufficient communication skills of knowledge producers—researchers and data analysts. These challenges could cause
disconnection between knowledge producers and knowledge users and could make knowledge users less interested in the new information:

“I think your challenge is your audiences and what you need to provide them with, and that is something we are challenged every day in our health unit because as we roll out health status reports, we are constantly saying who the users for these reports are? And we end up creating three or four different kinds of reports for three or four different kinds of users… When I first took, our health and income inequalities report I focused on the differences between PYLL (potential years of life lost) and mortality rates among income groups. I realized that no one understood what I was saying, I tried to explain what PYLL was, and people stared without a blink, and I knew I lost them. They would ask me what mortality rates are, and I would have to explain to them age standardization and ratios, and I was losing them, so I switched instead to look at life expectancy instead… and they understood it… I think what is happening is that people who publish these studies and work with the data are not necessary the best technology and communication experts. Their skills are very strong in analysis and in working with data, but they are not necessary trained for presentation and communication. There is a gap between their skills and the people’s needs to use the data and understand it… So you are building the bridges with this data visualization.”

Participant#1, who is a data analyst and epidemiologist, agreed that audience diversity and information complexity are challenges faced by researchers. Additionally, she also thought that visualization could help researchers to communicate knowledge:

“When you see a very professional medical paper that is full of statistical terms, like p-value or the confidence interval, the general people are probably not interested in it. But with visualization, you provide them with a vivid picture that shows how the factors are linked to the outcomes, and people will get the idea much more clearly.”

Participant#7, who is an assistant professor and epidemiologist, believed that the challenges in knowledge communication lie not only on the visualization tools we use to present information but also on the complexity of this information. Although he
acknowledged that he had to produce simple reports for the decision makers in his health unit, he asserted that reducing the complexity of information, by using simple indicators such as percentages, might not be helpful for decision-making. Because the validity of research findings should be evaluated correctly before making decisions based on these findings. Therefore, he believed that public health decision makers need to be familiar with the underpinnings of some of the healthcare indicators and measurements:

“The way that information is presented will have an impact on how the decision maker can assimilate it … So to me, the problem is not just the visual tools, but it is presenting the information in a way that is understandable to the person consuming it. I am not sure how one deals with that, but I can tell you that just coming up with a different graphics is not going to be sufficient from my point of view, so the impact of this [problem] is quite large within public health. If you look at the kind of reports that are typically done they are often very simple reports involving very little statistical analysis, and I think that that is problematic, because often there are confounding factors that should be taken into consideration in the comparisons that are made… I think to communicate that kind of information effectively; the consumers [the decision makers] need to have some familiarity with what standardization is. I think that the education piece is what we need to elevate their level of understanding for good epidemiologic analysis rather than simply accepting the results produced by epidemiologists.”

Participant#2, who is a registered nurse and researcher, didn’t seem to be too concerned about communicating knowledge to health decision makers:

“If I have the time and qualification to use interactive visualization [in my organization] then definitely I will use it [to prepare my reports for decision makers], and I will send some side notes and simple instructions on how to use these visualizations.”

Additionally, she believed that researchers could benefit from interactive visualization to perform effective presentation at conferences:
“People [researchers] are looking for non-traditional ways for presentations, and I think that everyone is finding it more interesting to find some new ways for presentation, and if we just use traditional ways then this is just because these are the accessible ways, not the best ways ... I find it little challenging to present the findings. Because when you are in a conference, you can't present all the findings in one graph so that you will be very selective to the most significant findings of your research. But people attending the conference may ask you questions about different parts of your research, but if you don't have the findings in the chart, you will have to rely on your memory to remember the relevant information. But I found the way you used to present the studies in your tool easier. So you can have all of your data and select which data to present, and if any question came up, then you can present the relevant part of the visualization to answer that question so that you can make the most out of your findings and you can really communicate them in a reader-friendly way.”

5.4 Theme 4: Expert's Needs for Quality Information

According to Stvilia, Twidale, Smith, and Gasser (2008), Juran’s definition of quality as “the fitness for use” has also been used to define information quality. However, they argue that a “context-specific understanding” of information quality is more useful than a general one. Such understanding could be reached by defining context specific quality criteria. For example, there could be financial information quality, health information quality, and online information quality.

Although I discuss health information quality criteria; neither it was in the scope of this research; nor did I intend to discuss it with my research participants. However, I found that information quality was a concern for my research participants.

5.4.1 Main Finding

There were three quality concerns brought up by my research participants regarding the information presented in the visualizations. These concerns were about the validity of information, the credibility of information, and the context of information.
The validity of information refers to “the extent to which claims for the findings truly reflect the nature of the phenomena under study” (Ballinger, 2006, p. 238). The credibility of information refers to its believability, and it results from the credibility of its source (Rich & Danielson, 2007). My research participants used this concept to refer to the credibility of research studies presented in my tool. This concept denotes the “trustworthiness, verisimilitude, and plausibility of the research findings” (Tracy, 2010). The context of information refers to “where it came from, why it is important and to whom it is important, and how it should be used” (Eppler, 2001, p. 335).

Participants wanted to see more information about the research studies included in the tool. This information should include research questions, the context of the studies, the conclusions and the limitations of these studies. Participants also wanted to see information about the statistical significance of the research findings. They also suggested establishing quality criteria to select the studies that will be included and visualized in the tool.

5.4.2 Participants’ Voice

Participant#5, an assistant professor, believed that the important issue is how to select the studies to be visualized. He asserted that, for each visualized study, I need to provide information about the research and its conclusions and limitations as stated by the authors of the study:

“For me, the challenge here is going to be what data gets into the tool, what data can become the best illustration of these concepts [the social determinants of health], and how do you find the best datasets that are going to have the best impact for illustration?... You need to put the conclusions of each study,… [and] be explicit about your criteria for selecting the studies that will be shown in the framework.”

Participant#6, a health records specialist, believed that providing more information about the context of the visualized indicators would make these indicators and the framework itself more understandable:
“A lot of time these frameworks are very complex, so I think if you can make this framework clear, understandable and helpful [by giving] the context for those indicators and the research behind them, then they are very valuable.”

Participant#3, who is a registered nurse and a Ph.D. student, believed that it is necessary to provide the context of the studies. She also argued that CSDH framework itself cannot be generalized:

“The CSDH framework is not incomplete, but it is not context-specific. So the while the framework has the reliability that is based on evidence, this evidence changes for Northern Ontario, especially when talking about rural and urban areas, so a research gap here is how to adjust this framework for Northern Ontario.”

Participant#4, who is an epidemiologist and a program manager at a health unit, was satisfied by seeing statistical details provided in some of the visualizations because that gave her a clearer picture about the validity of the visualized information:

“When I floated over with my mouse I could see the confidence interval; I could see the rates and that was excellent; because I like seeing the confidence intervals, and it also gave me, as an epidemiologist, some degree of understanding about the statistical differences.”

Participant#1, who is a data analyst and epidemiologist, expressed her concern about the validity of aggregating different studies under one framework, and asserted the importance of providing enough information about research process of each study:

“The one thing that I was really curious about is that you provided those specific numbers from all different sources, or from different reference papers, but once you put them in the same framework they are showing the same outcome. I mean that you get the factors from different studies but the outcome is the same. And I think that their measurement could be different, and the control groups could be different, and also, they might be done on different populations, so I think that if you collect this information from the same study and same population, it would be more attractive… You need to give people more information about the framework,
introduction or background information, study background, research questions of specific studies, and outcome definitions. Research questions and objectives will help people to understand the CSDH framework.”

Participant#7, who is an assistant professor and epidemiologist, believed that it is important to attend to the credibility of the studies before visualizing them, and to show proof of this credibility to the user of the tool:

“\textbf{It is not only seeing the information but also knowing how it was created. I think it is useful to have some metadata associated with the [visualized] information so that I can find out how it was extracted and how it was manipulated. In our business when you use something you own it, so before I present or adopt something, I want to have a degree of confidence about how information was produced, and any quality issues that exist in the data. For example, missing data is valuable to know.}”

Participant#2, who is a registered nurse and researcher, thought that the tool should have provided information about the statistical significance of the research findings of the visualized studies:

“\textbf{[What was missing is] probably showing the significance of the statistical findings, so I would probably like to see how significant the difference in outcome among different groups is. So as a researcher, I am interested in whether statistically significant differences were found.}”

5.5 Theme 5: Expert's Concerns about Users' Misinterpretation of Knowledge

According to Eppler (2001), information misinterpretation occurs when information “is not seen in context”; and, therefore, high quality information includes details about its context:

High-quality information is always presented with its context of origination and its context of use (where did it come from, why is it important and to whom is it important, how should it be used). Through this, the information should become
clearer for the target group because it can understand the information’s background. The target group can also better assess whether the information holds true for the new context and if it is correct even under different circumstances. (p. 335)

5.5.1 Main Finding

Some of my research participants expressed their concerns about misinterpreting some of the visualized information about the social determinants of health by laypeople. Such misinterpretation may happen as a result of not providing enough details about the context, conclusions, and limitations of the research studies as stated by their authors. It could also happen when readers do not have background information about the problems presented in these studies. However, all of these participants rejected the idea of not showing the information and asserted that even with the probability of misinterpretation, presenting the available information is always better and helps in sensitizing people about the social determinants of health and creating public pressure, which could lead to policy action.

5.5.2 Participants' Voice

Participant#5, an assistant professor, stated that he was more for exchanging knowledge in academia channels such as journals and conferences than in other public channels such as websites and newspaper because research quality criteria are presumably used in producing research papers in academia:

“When you read a research paper it has the kind of the thought and the process behind that data, so that the reader can understand how exactly the researchers have gotten this data, what are they saying and what are the conclusions that they can functionally make. For example, in our research papers we always write our limitations, and in the limitations, we will caution people, by saying that here are the conclusions that you can make from this particular data, and here are the conclusions that you shouldn't be jumping into with this data… So one of the challenges when you just have the data, and you don't have the context around how this data was collected and what the researcher is warning you about with that data; is that people might start jumping to conclusions. And this is the problem with Code
Red, [a web-based tool that presents data and interactive visualization about the social determinants of health in Hamilton in Ontario] because it led to a stigmatization of particular neighborhoods because people were able to see that there are obvious health differentials. People started avoiding to live in these neighborhoods if they could because these neighborhoods are not safe. So it didn't lead people to this complex understanding [of health inequity causes] but instead, it led them to conclude that these were crappy neighborhoods… I think that this is the challenge of visualization because people may start asking different questions from what the data was meant for.”

However, Participant#5 did not reject the idea of using non-academic publishing channels to present information about the social determinants of health. Rather, he asserted that I, as a developer for this tool, understand the lessons learned from Code Red, which is a web-based tool that presents data and interactive visualization about the social determinants of health in Hamilton in Ontario:

“The lesson that people learned from Code Red is that if you just give people the data without pushing them back to the theoretical understanding, there is a risk that they make their own conclusion… With each visualization, you need to put the conclusions and the limitations of each study; so that we can see what the researchers are telling us to see in the data. You also need to make it explicit that each of these visualizations is part of the CSDH framework… those results need always to point back to the framework so that people understand the complexity of the [health equity] problem.”

Participant#6, a health records specialist, asserted that although misinterpretation could occur, it does not mean that information should not be published:

“I think that you are going to have that problem [of misinterpretation]. People will jump to conclusions, and they might have issues with it. But we are supposed to have a transparent system. We are supposed to have everything available to the public. And if people are not happy with something they should be able to do something about it. So if there is more violence in an area then there will be issues,
and people might not want to live in that area, and that could lead to discrimination.  
But once people are aware of it and once people are talking about it, then something will be done about it. So I think it is definitely important to the public to be aware of these things.”

Participant#4, who is an epidemiologist and a program manager at a health unit, thought that the possibility of misinterpretation does not mean that data should not be published:

“[The health indicator map] was interesting because one of the questions was “do you think you have the healthcare services you need or something like that “, and the map actually showed that rural people thought they have better or more services than urban people, and it is very confusing. So you see that and wonder how someone, without the background knowledge, can interpret it. So it does make you think: do you have to lead them there, I mean; is the visualization just one step and then you have to lead them to that kind of conclusion because maybe they just don't know what they don't know. So I will be a little worried that someone may misinterpret that, but this shouldn't stop you from putting the data out there.”

Participant#7, who is an assistant professor and epidemiologist, had a similar view, and he believed that Canadian public health could learn from the US public health regarding information disclosure:

“When you share information in a form that allows people to interact with it and organize it and make a comparison, it doesn't always mean that they are going to make correct or legitimate comparisons or arrive at conclusions, which are supportable based on the evidence, so that is always a danger. For me, that is not a reason not to share information. If you look at where the United States' public health system has gone in terms of its disclosure of information on health, there are open portals where individuals have access to information about their neighborhoods in terms of disease rates and potential environmental exposures. And there is no guidance in terms of how they might consume or interpret that. So yes that is going to lead to a great deal of turbulence, but I think that is not necessarily a bad thing because at least now you have got bases for engagement. The important
question is does public health have the capacity to participate in that engagement? so that individuals can actually profit and learn from access to the information.”

5.6 Theme 6: Expert’s Perceived Complexity of Policymaking, and Policymakers’ Needs

According to Oliver (2006), “Science can identify solutions to pressing public health problems, but only politics can turn most of those solutions into reality” (p. 195). Some of my research participants shared the same view when I discussed with them the social determinants of health and how to present relevant indicators. They brought up issues related to health policy and policymaker’s needs and expressed their views with regards to presenting the indicators and using the tool to support policymaking.

5.6.1 Main Finding

Policymakers do not have time to learn how to use visualization tools, or to understand reports that include complex analysis. They prefer simple graphics, which can deliver information in a clear way. They also prefer information that reflects their community problems more than the provincial or national problems. Information visualization and presentation might be of secondary importance for policymakers. Public awareness, public pressure, and media pressure could have a higher impact on policymaking. Additionally, there was no definitive evidence for the possibility of using the tool by policymakers.

5.6.2 Participants’ Voice

Participant#5, an assistant professor, believed that information presentation is of secondary importance and that policymakers will respond to healthcare issues only when there is enough pressure from the media:

“I don't think that the problem is in the presentation..., yes it has to be a convincing story so that policymakers can understand why this is a change that is required and how it is going to work, but to me; creating action is more about creating the desire for a change. The way that data is presented is less important than, for example, a couple of newspaper articles that come out and make the government look really
bad about the issue, or some real community concern, which leads to sending letters to the government about the issue... To me, they have lots of convincing things to work with…, they need to put your issue somehow on the top of their pile… and I am not sure that the visualization is the main component; it is probably a secondary component. They just don’t want the people to get mad at them. So I think the number one issue is that they have a sense that this is a priority issue, probably the secondary thing is that they can understand what the best way to approach the issue is, and that is when they would get into how the data is being presented.”

Participant#6, a health records specialist, described her work as a data analyst. She did not comment on the political aspects of decision-making in healthcare. However, she did describe decision makers’ time constraint and their needs for understandable graphs and quick answers to their questions, and how they do not have time to learn new tools:

“People [decision makers] wanted to see graphs; they wanted to see visualizations, and they needed to be able to interpret the data, or see the data in a certain way that they can understand. If they just see numbers, it is [the data] irrelevant to them or it is not important unless the numbers were so big or so small, but usually most people want to see graphs. As for visualization tools, people in the management don't have time to learn anything; they want an answer quickly. They want to know what is going on by just looking at what they have to look at. They don't have time probably to learn this whole thing [visualization tools] if it was easy maybe, but if it gets too complex for some people they just don't want to have anything to do with it. Managers want answers to specific questions; they want to see the direction of things, but they don't want to spend the time exploring what is going on. However, [Information visualization] is fun and interesting to data analysts or decision support managers, who might have the time to explore all of that.”

Participant#4, who is an epidemiologist and a program manager at a health unit, described the information needs of the decision makers in her health unit. Decision makers want to see healthcare indicators that are relevant to the geographic area of their
health unit rather than the provincial or national indicators. This participant believed that this might even impede the use of my tool because it shows Canadian level data:

“Will it help decision makers, at my regional level where I work, see the impact? I would say no, because in [our] region we are a very affluent community, and it is very easy for them to say well this is Canadian data, and It doesn't apply to [our region]. I have been challenged many times, and I have had to do our own local data reporting on health inequities to convince the decision makers at my end because they say the Canadian and the provincial data doesn't apply to us, we are a special case. In fact, we are not, and I needed to show them that.”

Participant#7, who is an assistant professor and epidemiologist, believed that decision makers do not prefer very analytical information such as the information presented in the tool:

“I found your presentation very understandable, but I don't think that it is easily transferable to decision makers without a lot more background for them. However, my personal experience is that many decision makers don't really want to spend the time to understand these things. So from their point of view it should be obvious, the moment that they read it, it should not require any time of additional training to interpret what they are being told.”

5.7 Theme 7: Expert's Evaluation of the Features of the Tool

One of my research goals was to get the subjective feedback from participants about the different features of the tool to develop a new and enhanced version of it. Although all the themes that I have identified do provide me with ideas about the future modification to the tool, this theme reflects my participants’ opinions about the features of the tool as an IT artifact.
5.7.1 Subtheme: Ease of Use

5.7.1.1 Main Finding

While the tool was easy to use, some participants found that the visualizations were crowded with information and suggested simpler visualizations to start with while still enabling the user to add more layers of information to any visualization. All participants favored simple visualizations over complex visualizations. Figure 12, which represents cause-specific mortality by education in Canada, is, in many participants’ opinions, a crowded visualization because it shows many variables, including gender, age groups, causes of death, and education levels.

![Figure 12: a Crowded Visualization](image)

5.7.1.2 Participants’ Voice

Participant#5, an assistant professor, hoped that the tool will be simple to use. He believed that the studies presented in the tool should have simpler start up visualizations
that give the first time user a clear message about the content of each study. He compared
the tool to Code Red, which is a web-based tool that presents data and interactive
visualization about the social determinants of health in Hamilton in Ontario, and believed
that Code Red is simpler than the tool:

“That website [Code Red] has a very simple default, so I think that that makes it
welcoming. You just get in, and you find just a few things that you can switch
around, and it engages you. It is not overwhelming, and you can get what is being
said immediately, then you can add layers on top of that, layers of complexity. You
can add more pieces of data, more tools, and more options, but it doesn't scare you
away because you don't see tons of options, different checks, and sliders.”

Participant#6, a health records specialist, believed that the more crowded the
visualization is, the less clear it is. She pointed out that some of the visualizations in my
tool had too many categories and data points. Even though the provided filters were
useful according to all participants, Participant#6 believed that for these crowded
visualizations, a user will have to do lots of work to filter the data and simplify the
presented chart:

“I found certain things were little overwhelming; I checked the education
visualization, and it was very clear but overwhelming in certain spots. When there
is a large number of things to work with, it takes more time to look at the indicators
and to get your head around it. It is not that you can't do it, but you need to go back
and forth to understand the legends, but things were much easier with the visualized
bar chart used in one of the studies. I know, from my experience, that the simpler
the graphics, the easier it is. But for people looking at the data, they need the
graphics to indicate clearly or show what is going on. But if you have too much that
is going on then it will just get confusing for the person who is looking at it. So, it
can be clear, and it doesn't have to be too complex for you to get what you need out
of it.”

Participant#3, who is a registered nurse and a Ph.D. student, found the tool to be “fairly
easy to learn”, but she said that she might need some training to use it:
“I found it helpful, but I would need some training on how to use it, because you know I have grown up in an age of baby boomers where we were not that technological but that is no excuse because a lot of baby boomers have learned the technology.”

Participant#4, who is an epidemiologist and a program manager at a health unit, found the tool to be “easy to use and intuitive”:

“It is very easy; I had no problem with it. I am not that tech-savvy, but I had no issues and no problem with navigating with it and play with it, so I felt it was quite good.”

Participant#1, who is a data analyst and epidemiologist, found the tool to be “a nice tool”, and believed that the simple the visualizations the better they are for the users:

“Compared to the traditional format, data visualization is trying to help people make things easier, and facilitating conceptualizing the data. But if you make it more complex and more difficult, then in some sense it loses the initial idea of visualizing the data to help people to accept it, and people need to be trained, or it will be too overwhelming, and they are better off reading the whole [published] papers… If you are presenting it to people like healthcare professionals to help them better understanding the relationships between the factors and the outcomes, I would say the simpler, the better.”

Participant#7, who is an assistant professor and epidemiologist, also believed that the initial screens of the visualizations in the tool were full of information and “very busy to start off”, but he was able to adapt these screens using the provided data filters:

“It might be problematic when I am faced with a screen full of colors and shapes, and it might take me some time to figure that out, but I think they [the colors and shapes] can be effective although the way they are presented in the initial screen provides too much information. So for them to be valuable, I have to start turning off certain things. I find the graphs very busy to start off.”
Participant#2, who is a registered nurse and researcher, found the tools to be easy to use, and the visualizations were easy to understand, and she asserted that it is important to keep the visualizations simple:

“I didn't find any challenges, and I think it is very friendly. I can tell you also that the visualizations used in this tool were very simple, and I think that it is much easy to read the findings if you had simple visualization, and I think that if the visualizations were too complex they will distract you [as a reader] from seeing the findings.”

5.7.2 Subtheme: Representation Techniques and Encoding Marks

This subtheme refers to the research participants’ subjective evaluation of the visualization’s representation techniques and encoding marks. Representation techniques are the diagrams used to present the information. Encoding marks are the symbols used to represent the data points in a diagram, and they could have different sizes and colors. My participants did not use these terms in their comments, rather, they used words like colors, sizes, and shapes, in addition to using the familiar names of the diagrams, including bar charts and maps.

5.7.2.1 Main Finding

Using too many symbols—encoding marks—could be overwhelming for the users. Colors were effective in representing the data. However using the size dimension as an encoding mark was less successful. All of my research participants preferred visualizing traditional charts such as the bar charts, over creating complex visualizations. Showing tooltips when the user hover over data points was an effective way to show more details about each data point. Some participants believed that the choropleth map of health indicators was useful; however, other participants believed that map visualization, in general, could lead to misinterpretation of information. Filters were effective to control the visualizations. However, sliders were less effective.

Figure 13, which represents the influence of neighborhood deprivation, gender and ethnoracial origin on smoking behavior of Canadian youth, is an interactive bar chart. The user
sees a tooltip that contains the 95% confidence intervals of the odds ratio of smoking for any particular bar.

![Interactive Bar Chart with Tooltips](www.healthvisualization.ca/p/ethnicity-and-gender-indicators.html)

**Figure 13: Interactive Bar Chart with Tooltips**

### 5.7.2.2 Participants’ Voice

Participant#5, an assistant professor, said that while he was able to figure out the different encoding marks, he suggested simplifying the visualization by not using a big number of symbols, and by visualizing traditional charts like bar charts. However, he was also for using color and size. He liked the health indicator map presented in the tool, but warned that maps could be misinterpreted:

“I found that it is a little cumbersome figuring out some of the different symbols, but once I got it I like it… Once there were too many symbols it might be difficult to understand them all; but; color is very effective particularly in the map where you see the health gradients. I think the size could probably be used well, although in one
of the visualizations the size didn't reflect the different values well; maybe the scale used could have been different… What is most successful is always what you are most familiar with so I think a bar chart is just good, and I also liked the choropleth map of indicators. However, maps come with a high risk of people making their own conclusions.”

Participant#6, a health records specialist, found some visualizations overwhelming, and she liked the choropleth map:

“Once you get into too many factors in [a visualization] and too many different types of visualization and colors and so on, it can be overwhelming and confusing for the individual who is interpreting it. I found certain things to be interesting [such as the map of indicators]. I think representing the census areas, the metropolitans, and the rural areas is interesting, and I think that maps are really good to represent certain things.”

Participant#3, who is a registered nurse and a Ph.D. student, liked the colors and the choropleth map, but she found the visualizations to be small:

“I found that the visualizations were small; I know that I could zoom in, but I found them small maybe because of my eyesight problem. One thing that I liked is the use of colors; I found them interesting. I also liked the map, although I found it small, it was interesting. I think that the color shading was also useful, and it captures a lot in a small area.”

Participant#4, who is an epidemiologist and a program manager at a health unit, found the symbols and the colors to be effective. However, she said that using the size of the shapes to present different data points was not successful. She liked the tooltips shown when a user hover the mouse over any data point. She was also for visualizing traditional charts because they are easier to use by decision makers:

“I liked the symbols and the colors, and they worked for me quite well. There was one issue with the sizes of the squares that I struggled with, and what I did is that I floated over them, and what I loved is when I floated over with my mouse I could
see the confidence interval, I could see the rates, and that was excellent… So being able to put the mouse over was a perfect solution… I think you have done the right job by sticking with the more traditional charts for the people that are interacting… but to have someone be doing that [use non-traditional visualizations], who may be a decision maker but without a lot of data background, I think it is better sticking with the traditional ones or with what people are used to seeing.”

Participant#1, who is a data analyst and epidemiologist, liked the tooltips shown for data points, but she felt that having to scroll to see the full visualization might be distracting. She was for visualizing the traditional charts and keeping visualizations simple:

“The important feature, which I really like, is that when you move the cursor over a data point, the exact number in the Y-axis shows up [a tooltip], but in static images, you have to try to guess based on the points before and after your point in the chart… In one of the visualization, I had to scroll the screen to the right to see the full visualization, and I think that scrolling might cause the disappearance of some part of the visualization… If you visualize the traditional charts you will give your audience a clear picture. I think that it depends on the audience, but the simple the visualization the better it is.”

Participant#7, who is an assistant professor and epidemiologist, thought that the visualizations in the tools were busy, and he believed that the sliders were not helpful. He also believed that visualizing traditional charts would be more effective than creating complex visualizations. He shared with me his personal experience with interactive maps, and he said that he had become less convinced about the effectiveness of using interactive maps to present health indicators and that he preferred using static maps instead. However, he believed that the interactive choropleth map used in the tool was consistent with what he saw elsewhere:

“I find in general your dashboard is very busy. Initially, when I first went on I found it overwhelming, but after spending some time, I became more familiar and comfortable. I think the idea of your dashboards is excellent. I think the implementation can be improved somewhat by not making it quite so busy to begin
with, maybe start off with a single indicator and allowing individuals to add to it. We already have a great deal of knowledge about graphical presentation, including bar graphs, lines and even pie charts. What I think is that, with the new emerging technology, we can make those graphs simpler and interactive. So I think using bar charts is very effective and even more effective when you combine it with a level of interactivity that it can be customized… I don't really like the idea of interactive maps, where people can control; for example; indicators and create different cutoffs. I am very careful now in my use of maps; particularly related to small areas because I think those maps are very subject to technical decisions about how to display the indicator, how to create the cutoffs for the categories. So I think they can be quite potentially misleading. I think that there are some technical issues that are best addressed with static maps that are produced and interpreted [by researchers] rather than allowing individuals to construct their own particular view. But your implementation [for the choropleth map] is very consistent with what I have seen presented elsewhere… In your visualizations, I found some of the sliders to be particularly not helpful, and difficult to control.”

5.8 Summary

Seven main themes and four subthemes emerged through my data analysis. These themes represented five core concepts in this thesis, including the tool, the CSDH framework, the knowledge, health policymaking and policymakers’ needs, and information visualization.

Theme 1 represents the participants’ perceived usefulness of the framework as a knowledge construct and as a visualization construct. The usability of the tool was represented by Theme 2 (expert’s perceived usefulness of the tool) and Theme 7 (expert’s evaluation of the features of the tool: Ease of use). Three themes represented different perspectives of knowledge and information, including Theme 3, which represented participants’ perceived complexity of knowledge communication, Theme 4, which represented participants’ needs for quality information, Theme 5, which represented participants’ concerns about users' misinterpretation of knowledge. Theme 6 represented participants’ perceived complexity of policymaking, and policymakers’ needs. Finally,
different information visualization features were represented by Theme 7 (expert’s evaluation of the features of the tool: Representation techniques and encoding marks).

The following figure represents these themes:

![Figure 14: Themes and Subthemes](image)

**Figure 14: Themes and Subthemes**
Chapter 6

6 Discussion and Conclusion

6.1 Introduction

The purpose of my thesis was to examine the use of information visualization to represent the social determinants of health and health equity indicators, and to evaluate the benefits of this representation for health policymaking. However, during the planning phase of my thesis, I realized that this was a broad purpose. Therefore, I decided to create a computer program or a web based tool that I could use as a research instrument to explore the complex system of health policymaking. The tool that I created had two major components:

1. A visualization for the CSDH conceptual framework. This framework was developed in 2010 by the World Health Organization’s Commission on the social determinant of health, and it is called The Conceptual Framework for Action on the Social Determinants of Health (CSDH).

2. A set of interactive visualizations that represent some indicators of health inequity and the social determinants of health. These indicators were obtained from published research studies.

This tool became the focus of my research, and I have had a single research question: What is the perceived utility of visualizing a conceptual framework for the social determinants of health in performing complex cognitive activities such as analyzing health equity problems?

In searching for an answer to this question, I was able to explore different aspects of health policymaking. Most of these aspects were identified by my research’s conceptual framework. However, some other aspects, including those related to knowledge communication and misinterpretation, were highlighted by my research participants. Additionally, the research methodology that I used, which is the informal user experience...
evaluation, enabled me to evaluate the usefulness and usability of my tool as an IT artifact and as an information visualization tool.

The following discussion represents my interpretation of the research findings, and I have used section headings to organize my argument. I have also underlined key points in quotations taken from references.

6.2 Information Presentation Is of Secondary Importance, but Policymakers Cannot Make Decisions without Evidence

The study findings (theme 6 and theme 3) show that policymakers do not have the time to learn new software tools, and they have specific information needs regarding the content, the amount, and the complexity of information. Information presentation might be of secondary importance for policymakers, and the information is only one factor, among other factors, in policymaking. Other factors include context factors and stakeholders’ powers and interests. However, none of the participants believed that information is of limited value. These findings are consistent with the views that already exist in health policy and knowledge translation literature, including Graham et al. (2006) and Lavis (2006).

Additionally, researchers who have critical views about the value of evidence in policymaking, such as Trisha Greenhalgh and Thomas R. Oliver, don’t deny the value of information, knowledge, and evidence in policymaking. Rather, they call for a holistic understanding of policymaking as a product of a large number of contextual factors, such as health system factors, political factors, social factors, economic factors, and technological factors. Here are some examples of the work of these researchers:

Scientific evidence is often ambiguous, incomplete, partisan and open to multiple interpretations; tacit and local knowledge may be relevant to policy decisions; it may be practically impossible to change policy in a particular ‘evidence-based’ direction; and research findings may serve to challenge general ideologies and assumptions as much as to inform specific decisions. Research evidence may be
used instrumentally and rhetorically to back up particular value-based positions. (Greenhalgh & Wieringa, 2011, p. 507).

I believe that Greenhalgh and Wieringa assert that the process of knowledge to action—the know-do process—is not value-free and that the same evidence could be used by policymakers either to solve an issue or to deny it. In fact, these researchers call for a new “mode” of knowledge, which “emerges from active, two-way partnerships between researchers, decision-makers, funders, industry and other stakeholders” (p. 507). This new mode of knowledge has a higher chance of use and uptake by policymakers.

Another example from Oliver (2006):

Science can identify solutions to pressing public health problems, but only politics can turn most of those solutions into reality. The primary influence of health services research on public policy may be through its role in problem documentation—statistical reporting and estimation of healthcare use, costs, and quality. Yet numbers alone are insufficient to push an issue higher on the governmental agenda (Oliver, 2006, pp. 195-198).

I believe that if research findings can be used to challenge ideologies of all stakeholders, inform decision-making, or document health system issues; then producing knowledge and creating evidence are probably important for health policymaking.

6.3 If Information Is Probably Important, How Can We Present It to Support Policymaking?

All of my research participants said that information communication is a challenging task. Challenges include the complexity of health indicators, time constraints of policymakers, inefficient presentation tools, and ineffective communication skills of knowledge producers. These challenges make it important to create short and summarized reports for policymakers.

In my literature review, I have presented evidence on the necessity of communicating research findings in an understandable language (Tugwell, Robinson, Grimshaw, &
Santesso, 2006; Santesso et al., 2006; Bosch-Capblanch, 2011; Rader et al., 2014; AHRQ, 2014). Different KT products have been developed to communicate research findings, including health systems guidance, summary guides, policy briefs, and the friendly front ends. The developers of these products are expected to attend to the content of the products and the representation of information.

Additionally, there is another rarely told story in knowledge translation literature, which, however, was told by my research participants, and it is about the complexity of producing those easy to consume knowledge products, such as summary guides, policy briefs, and the friendly front ends. As I have presented in Theme 3, some participants believed that this complexity is unavoidable in certain cases because they must use certain indicators that are considered complex to understand by non-experts. Otherwise, these participants will not be able to deliver the information properly. One participant also believed that policymakers should get some education on public health statistics. These findings are consistent with Carroll et al.’s (2014) systematic review, which I have presented in the literature review chapter:

   The desire for a system [a visualization tool] that allows users to query the data and receive results in plain language may undermine the very nature of complex data. Future research should endeavor to help users strike a balance between the in-depth understanding of data and system usability. [In our review], a few of the studies addressed the growing need for enhanced statistical education to enable users to better understand their data in more depth. (Carroll et al., 2014, p. 295).

Some of my research participants clearly stated that they feel more comfortable in communicating knowledge in academia, because they can use a scientific language to present their research, and they can also use statistical concepts to report their findings and reduce the possibility of misinterpreting these findings.

Research participants emphasized that complexity of knowledge communication could be reduced by using information visualization. However, health indicator communication and representation do not receive high attention from organizations that produce health indicators. For example, this year (2016) the National Center for Health Statistics in the
USA produced the “Health, United States, 2015” report, which represents the health status in the USA. This report is produced in PDF format, and it can be downloaded from (http://www.cdc.gov/nchs/hus/index.htm). The report includes 114 indicators on primary healthcare, health expenditure, and health disparities in the USA. These indicators were represented using 114 tables of numerical data and 27 static charts (National Center for Health Statistics, 2016). Another example is the Primary Health Care in Canada report produced this year (2016) by Canadian Institute for Health Information. This report is also produced in PDF format, and it can be downloaded from (https://secure.cihi.ca/estore/productFamily.htm?locale=en&pf=PFC3137&lang=en), and it relies on static charts to represent the indicators. I believe that producing these reports using information visualization could have some benefits to their prospective users.

Therefore, despite the capabilities and the possible usefulness of information visualization, more research is required to examine its use in different domains and analyze the factors that could impede or support this use.

6.4 Information Quality Is Important for All Types of Users

My research participants emphasized the importance of information quality for knowledge producers and knowledge users. Participants wanted to see more information about research studies that are included in the tool, including research questions, the context of the studies, their conclusions, and their limitations. They also wanted information about the statistical significance of the research findings. They suggested establishing quality criteria to select the studies that will be visualized. Certain criteria for information quality were underscored by my research participants. These criteria include validity, credibility, and the context of information. Information quality is important because it helps the users to use information and interpret it correctly. My participants were concerned about potential misinterpretation of data not only by experts but also by non-expert users, including laypeople and policymakers. Such misinterpretation, according to my research findings, could happen because of non-adherence to quality criteria discussed above, which could lead to seeing information out of its context of origination and context of use. This out of context view could lead to misinterpretation (Eppler, 2001).
These findings are consistent with Carroll et al.’s (2014) study. However, that study added other reasons for misinterpretation of information, including, misrepresentation of information, cognitive overload, and the lack of proper analytical skills by users. On the other hand, my study findings suggest that visualizing the framework would also help in preventing the misinterpretation of information, but this will be discussed in the next section.

Additionally, while the literature is full of research on the topic of misinterpretation of medical and health information by laypeople, including misinterpreting online health information, food labels, and drug labels, there is a scarcity of research on misinterpreting health indicator information. Therefore, the significance of the current research findings about information misinterpretation by laypeople cannot be validated with existing literature. However, it is noteworthy that my research participants who showed their concern about the possible misinterpretation of information by laypeople asserted that such possible misinterpretation should not be a reason for not publishing information. Making information available helps people to become sensitized about healthcare issues and could lead to public pressure that could lead to policy action.

Lastly, I believe that while making information about the social determinants of health available to laypeople is important, action to address health inequity is to a great extent a political action, and it is subject to different contextual factors including policymakers’ priorities and stakeholders’ powers and interests. This view is consistent not only with my research findings but also with health promotion and health equity literature, including Marmot et al. (2008) and WHO (2009). The latter reference clearly mentioned that while educating people and making information available are important objectives for health promotion, information alone is not enough:

Information and education provide the informed basis for making choices. They are necessary and core components of health promotion, which aims at increasing knowledge and disseminating information related to health (WHO, 2009, p. 30). Health promotion programs may be inappropriately directed at individuals at the expense of tackling economic and social problems... Information alone is
inadequate; raising awareness without increasing control or prospects for change may only succeed in generating anxieties and feelings of powerlessness. (WHO, 2009, p. 31).

6.5 Does Visualizing the CSDH Framework Have Any Value for Knowledge Communication? What Kind of Value, and to Whom?

The value of visualizing the CSDH framework is my main question in this thesis, and my research participants’ answer to this question was “yes”, except one participant. Research participants believed that the framework was a good knowledge construct and a good visualization construct. The visualized CSDH framework could help in representing and communicating complex healthcare issues such as the social determinants of health to policymakers and laypeople. It might prevent people from jumping to wrong conclusions about the problem and the solutions. The framework could remind the users that the outcomes on health are not the result of a single determinant of health alone and that there are multiple pathways to poor health, in which multiple determinants interact and affect population health. Therefore, one of the participants suggested that the visualized framework should always be presented with every visualization to remind the users about the complexity of health inequity and the social determinants of health.

However, my research findings of the overall value of knowledge in policymaking, presented earlier, show that we cannot predict whether the visualized framework will have a direct impact on policymaking beyond what knowledge translation literature tells us. I believe that it will probably help some people to see and realize the social determinates of health. I also believe that other frameworks that are related to other healthcare issues, including healthcare quality or public health, could also be visualized for the same potential value.

Finally, there is a scarcity of research in framework representation, and only three studies were found and presented in the literature review, including Pega, Valentine, Matheson, and Rasanathan’s (2014) study; Bruno, Burke, and Ulmer’s (2010) study; and Quay and Hutanuwar’s (2009) study. These studies recommend representing frameworks of
indicators to support policymakers. Therefore, no comprehensive studies analyze this topic, and the significance of the current research findings of the value of framework visualization cannot be validated with existing literature.

6.6 Usability of the Tool

In section 3.2.1, I have explained the different usability measures that are used in HCI field. In my thesis, I have used three subjective usability measures: Ease of use, usefulness, and user satisfaction.

My research findings show that participants were satisfied with the tool. Interaction capabilities—interactivity of the tool—were the main reason for this satisfaction. This view is consistent with Fekete, Van Wijk, Stasko, North (2008) and Sedig, Parsons, Dittmer, Haworth (2014) as presented in the literature review chapter. Interaction capabilities support the user’s performance for some complex cognitive activities such as problem-solving, sensemaking and learning.

However, there were certain interactive features that caused dissatisfaction for some participants. For example, some visualizations included sliders to adjust specific variables and to show or hide some data points. These sliders were ineffective for some participants. Other participants stated that some visualizations were overloaded with information and that they had to use the filters to hide some data points.

Therefore, I would like to emphasize that satisfaction is a subjective usability criterion and that an accurate judgment of the interactivity of the tool requires further research and task-oriented user testing. It also requires, according to Sedig, Parsons, Dittmer, Haworth (2014), a conceptualization for the tool’s interactivity. This conceptualization should create a well-defined set of criteria for interactivity evaluation.

Secondly, according to my research participants, the tool is probably useful, and it could be used for different purposes, as illustrated in the following table:
Table 6: Possible Usefulness of the Tool

<table>
<thead>
<tr>
<th>User Group</th>
<th>Possible Usefulness of the Tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laypeople</td>
<td>Learning about the social determinates of health.</td>
</tr>
<tr>
<td>Teachers</td>
<td>Teaching aid at universities.</td>
</tr>
<tr>
<td>Experts: Researchers</td>
<td>Knowledge Communication and Translation.</td>
</tr>
<tr>
<td>Experts: Data analysts and epidemiologist.</td>
<td>Knowledge Communication.</td>
</tr>
<tr>
<td>Health Policymakers</td>
<td>Indirect benefits for policymaking.</td>
</tr>
</tbody>
</table>

The tool could be used by experts and by laypeople. However, my research findings did not yield a definitive answer with regards to using the tool by policymakers. In the previous sections, I have argued that, from knowledge translation and public policy perspectives, it is hard to predict whether policymakers will use the tool, how they will use it, and for what purpose. My research findings reinforce the notion, prevalent in the literature, that policymakers (at least according to study participants) do not have the time to learn new tools, and they prefer summaries and quick answers. Additionally, none of my research participants was a policymaker, and I have explained that in the research methodology chapter. Therefore, the voice of policymakers was absent in my collected data. However, I argue that if, as suggested by my research findings, the tool could be used by data analysts and decision support staff to create policy briefs and reports for policymakers, then policymakers may benefit indirectly from the tool.

Thirdly, the tool was easy to use for most participants, although some participants needed more time to learn how to use it. However, some visualizations were crowded with data points, axial categories, symbols, colors, and interaction elements such as filters. This crowdedness impacted the ease of use of the tool. Additionally, my research findings show the importance of using simple and traditional charts. Participants preferred the visualization of the “familiar” charts such as the bar chart over more complex visualizations. These findings are consistent with Carroll et al.’s (2014) study presented
in the literature review chapter, which shows that complex visualizations are difficult to use and could lead to misinterpretation. However, the complexity and simplicity of visualizations are subjective attributes, which are not clearly defined in the literature. Therefore, these attributes were not clearly defined to my research participants, and I had had to explain to them my understanding of these two concepts and show them some third-party visualizations, which, in my opinion, were complex. Thus, I believe that further research is needed in information visualization field to develop a framework or specific criteria for simplicity and complexity of visualizations, and all that I can say with regards to my study, is that my research participants preferred easy to use and familiar charts.

Fourthly, I believe that the features of the tool might have impacted my participants’ satisfaction and how they feel about the ease of use of the tool and its usefulness. My research findings show that using colors and shapes in my visualization was effective, but using the size of shapes to encode data differences was less effective. However, my research findings show that using too much encoding marks could be overwhelming for the users, which parallels Carroll et al.’s (2014) study. Additionally, the data point tooltips, and the filters were useful. The choropleth map of health indicators was useful. However, some participants believed that the visualized maps could lead to misinterpretation of information, which is also consistent with Carroll et al.’s (2014) study.

6.7 A Conceptual Framework for Using Information Visualization to Represent the Social Determinants of Health

I would like to end my discussion by presenting a conceptual framework (Figure 15) that summarizes my research findings and reflects my understanding of the core concepts in my thesis. This framework represents the use of information visualization to represent the social determinants of health. The framework shows the users of the tool, the context, the information, and the artifact—the tool. It also shows that policymakers are probably not going to use the tool; but rather, they would rely on the experts who are also the knowledge producers, including researchers, epidemiologists, and data analysts to get
the knowledge. However, this knowledge will only reach policymakers through knowledge translation processes and products.

![Figure 15: A Conceptual Framework for Representing the Social Determinants of Health Using Information Visualization](image)

6.8 The Future of the Tool

I have stated in the first chapter of this thesis that this research study informs the design of a new version of the tool. Therefore, I want to talk about how I see this tool evolving and my plan for the future.

Based on my research findings, I believe that the tool is useful and that there will always be a need for presenting healthcare indicators in an easy to understand form. I know that the tool has some usability issues and that my visualizations need to be enhanced and less crowded. I also need to add relevant studies for every determinant in the CSDH
framework and provide more details about the studies included in the tool, including their context, limitations, and conclusions.

Once I complete my work, I will open the tool for the public, and I expect that the tool will be part of my future research in healthcare performance management.

6.9 Contribution to Knowledge Translation

Based on my discussion in this chapter, I believe that this tool could represent a new form of the ‘friendly front ends’ of knowledge translation.

In section 2.7.3.1 in the literature review chapter and in section 6.3, I have presented that the knowledge translation’s friendly front ends are used to provide summaries of evidence to different user groups, including patients, physicians, and policymakers. These KT products can help these users in decision-making (Lavis, 2006; Santesso et al., 2006; Rader et al., 2014). These products could help a patient to understand more about his/her conditions and the available treatment options. The physician would use these products to know more about the best available evidence for treatment and to communicate this information to patients. Policymakers would use these products to inform policymaking (Rader et al., 2014, p. 208). Tugwell, Robinson, Grimshaw, and Santesso (2006) suggest the development of friendly front ends for health equity indicators, which could help for disseminating and sharing knowledge about health equity. These friendly front ends include graphics, audio, video, and text; and some of them are web based.

Additionally, my research findings suggest that these KT products could benefit from information visualization.

While my research findings suggest that policymakers would benefit only indirectly from information visualization tools, these findings also suggest that decision support staff, including data analysts and epidemiologists, could use these tools to support policymakers. Therefore, these tools could represent a new form of the ‘friendly front ends’ of knowledge translation. However, further research is required to explore this hypothesis.
6.10 Contribution to Health Communication

My research findings suggest that visualizing a conceptual framework and using it as a means to access health indicators might be useful and effective. Public health organizations, research centers, and governmental agencies working in health promotion, health service research, or community development would benefit from this thesis because it sheds light on different aspects of health indicator communication. However, further research is required to explore how these organizations manage and publish their knowledge bases of indicators and the usability and utility of these knowledge bases for different user groups.

6.11 Implication for Research in Knowledge Translation and Health Promotion Fields

Firstly, knowledge translation has focused on the needs of knowledge consumers—the physicians, policymakers, healthcare providers, and patients. The findings of this study suggest that knowledge producers have their needs too and that producing different KT products is a complex job. My research participants talked about how difficult it is to communicate health reports to different groups of audience, and how they had to produce multiple versions of reports with simplified indicators and graphics. My research findings also suggest that using visualization tools could have a positive impact on reducing this complexity and making health indicator communication more effective and less difficult. In this chapter, I have also suggested that information visualization tools could be developed as a new form of KT’s friendly front ends. However, I believe that further research is required to explore these suggestions.

Secondly, my research findings suggest that health indicator communication could be enhanced by using different information visualization constructs including visualizing conceptual frameworks. I believe that further research is required to explore this suggestion and to explore how organizations that develop health indicator knowledge bases manage and publish these knowledge bases of indicators and the usability and utility of these knowledge bases for different user groups, including laypeople, healthcare professionals, and policymakers.
6.12 Implication for Future Research in Information Visualization Field

My study findings suggest that employees in decision support positions, such as data analysts and epidemiologists, feel more comfortable with using simple and more familiar visualizations.

I believe that further research is required to define different usability measures including simplicity of the visualizations, ease of use, and user satisfaction, and to explore their meanings to different groups of users and users from different domains.

6.13 Limitations

This thesis used a qualitative research methodology to evaluate the utility of a visualized framework and the usability of a visualization tool. The study also aims to understand the potential usefulness of this tool for all the people who participate in policymaking. I wanted to recruit participants who are in different positions in policymaking. However, I was only able to recruit experts who were professionals in decision-support positions or researchers. These participants provided the technical expertise and made decisions regarding technical aspects of health policy in their organizations. They were all highly educated in fields related to healthcare, including four participants having P.h.D degrees, one P.h.D student, and two participants having Master degrees. Therefore, they all recognized the value of knowledge in decision making. However, I was unable to recruit decision makers in political positions or top management positions. Initially, I thought of recruiting these participants. However, during the planning stage, a committee member advised me to change my target sample because policymakers will not have the time to engage in a study that requires training on using the tool, using the tool, and interviewing. Therefore, the voice of policymakers was absent in my thesis.

Secondly, although usability measures used in this study, such as ease of use, usefulness and user satisfaction, are important measures, they do not give any information about the effectiveness and efficiency of the tool in performing specific tasks. Conducting task-oriented tests requires longer time from the users and the use of different research methodology.
Thirdly, the tool itself might have had an impact on the findings. All of my participants were satisfied with the tool and believed that it is useful, and they also said that they prefer simple and familiar charts to be visualized, and this is what they saw in the tool. However, to eliminate any instrumentation bias, I should have created a complex visualization that is unfamiliar to my participants, and then asked them to compare it with other visualizations. However, creating such complex visualization requires using a different visualization platform and more time and efforts, and, therefore, it would not have been a feasible choice for my master’s degree.

Fourthly, as I have stated in section 4.2.5 (research quality), I have used Lincoln and Guba’s (1985) trustworthiness criteria. These criteria contain credibility, transferability, dependability, and confirmability. However, some of the practices to achieve trustworthiness could not be followed, including member checking, and triangulation.

Member checking method requires that I keep an open channel with my research participants and that I share with them not only the transcript of the interviews but also my analysis and conclusions. The aim of member checking method is to show that my research participants saw and understood my claims and analysis and that they had a voice in all of my work. Member checking method in my study included sharing the transcripts of interviews with research participants. However, sharing my data analysis and research findings was not feasible because my participants did not belong to one organization or cultural context, despite the fact that they all work in health data analysis and use data to generate knowledge. Because they do not belong to one shared organizational context; they might have different thoughts about my research findings, and to accommodate for their different views in my thesis, I will need a longer time and more efforts, and I am not sure how cooperative my participants will be.

Triangulation requires the use of different data collection methods to ensure that different perspectives of the phenomenon are explored. Because I did not have direct access to the field, I was unable to do triangulation.
6.14 Applicability and Transferability of the Research Findings

Transferability refers to the applicability of the research findings to other contexts, and it can be achieved through thick description, which refers to the detailed description of research context, participants, and processes (Morrow, 2005; Ballinger, 2006). However, qualitative research studies can only claim “tentative application” of their findings because these findings are context-bound—context specific (Lincoln & Guba, 1985).

In my thesis, I have provided a detailed description of my research participants and my research processes. I have also described the contexts of healthcare indicator production, knowledge translation and use as they were described by my research participants. However, it is the responsibility of other researchers, wishing to use these findings, to verify the applicability of the findings in similar or different contexts (Lincoln & Guba, 1985).

6.15 Reflexive Notes

I believe that health equity and the social determinants of health are value-laden concepts, but discussing them with my research participants was out of the scope of my thesis. I also didn’t ask my research participants about their positions from health equity and the social determinants of health. However, I know that five of my seven participants were interested in the social determinants of health and had worked on projects and research linked to health equity. Nevertheless, I do not know how far their answers and views were affected by their ideological positions from the social determinants of health.

An important lesson that I learned out of my recruitment process is that the value or the importance of the research, as claimed in the research poster, are not the main factors that will attract participants. I believe that the main motivation for participation is the direct benefit that the participants expect to get out of their participation. The expected benefits were, in my case, not the honoraria. Instead, all of my participants were interested in learning about new ways to present health indicators. Therefore, in my future research, I need to think about how to market my work and propose the value of my research to prospective participants.
6.16 Conclusion

Representing healthcare indicators to provoke policy action is a major challenge. This study was conducted to examine the problem of indicator representation and to evaluate the use of interactive visualization as a possible solution for this problem.

Knowledge translation and health policy literature shed light on some aspects of this problem and suggest some solutions. Evidence uptake is impacted by several factors, including the complexity of information, information needs, policymakers’ priorities, interests, and time constraints, governments’ financial and human resources, and stakeholders’ powers. There are different KT products and methods that have been developed to communicate the best available evidence to different audiences. These products include health system guidance, policy briefs, and the so-called ‘friendly front ends.’

However, there are factors that affect the representation of healthcare indicators. These factors are the complexity of knowledge communication, which represents knowledge producers’ dilemma to produce sophisticated and quality knowledge products that effectively convey healthcare indicators, while still being consumable by their intended audiences, including policymakers, healthcare providers, and laypeople. Another factor that impact indicator representation is the possibility of misinterpreting the represented knowledge by laypeople, regardless of how complex it is. This misinterpretation may happen as a result of not providing enough details about the context, conclusions, and limitations of the knowledge. It could also happen when the audience does not have enough background about the problems addressed by this knowledge.

The study proposed a possible solution that uses an information visualization tool to represent the social determinants of health and health equity indicators. This tool is a web-based tool that has two major components: a visualized conceptual framework and a set of interactive visualizations that are used to represent each of the determinants of health. The visual framework represents a conceptual framework for the social determinants of health, called the CSDH framework, and was developed in 2010 by the World Health Organization’s Commission on the social determinant of health.
The study findings show that visualizing the CSDH conceptual framework is useful and could help in reducing the complexity of the presented information and the possibility of misinterpreting the presented information. The study shows that the tool’s interactivity is the main reason for user satisfaction, and that the usability of the tool could be enhanced by using simple and familiar graphics.

The study findings suggest that the tool could be used by experts and by laypeople. The study shows that researchers could use the tool to present and communicate research findings and to have a quick review of the available studies about the social determinants of health. Professors can use it for teaching purposes. Data analysts and decision supporters can use it to prepare reports for decision makers. Finally, laypeople could use it to learn about the social determinants of health. However, the study findings did not yield definitive evidence on using the tool by policymakers, and these findings suggest that policymakers do not have the time to learn how to use the tool.

While the actual contribution of knowledge and information visualization/representation to health policymaking could only be understood by taking into consideration the different factors that impact health policymaking and evidence uptake, knowledge production and dissemination remain noble objectives, especially, if they aim to reduce health inequity.
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Appendices

Appendix A: Interview Guide

This guide evolved into four versions.

<table>
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<tr>
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<tr>
<td>Blue: Version 3</td>
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<tr>
<td>Orange: Version 4</td>
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</tbody>
</table>

The Tool Evaluation Interview Script

After using the visualization tool developed as part of this research, participants should answer the following survey questions:

**Background Questions**

1. Q1 - Tell me about your work, previous work ...
2. Q2 - How do you present your research?

**CSDH Framework**

3. Q3 - Did you have any information about the SDOH before using the tool?
4. Q4 - Did the framework and the visualizations help you to understand the social determinates of health in Canada and the process of impacting people’s health? If yes, How? If no, why?
5. Q5 - Do you think you could have understood the SDOH and health equity by just viewing either the framework or the visualizations?
6. Q6 – There is a study conducted by the Institute of Medicine in the USA in 2010, and it aimed to evaluate and enhance the effectiveness of major national reports about healthcare quality and health equity. The study argued that while the significance of health indicators and findings is high, those indicators were not presented effectively enough to provoke action. How can we present health indicators to provoke action?
7. Q21- Did the framework give you a better idea about the Health equity problems and the SDOH?
8. Q22 – Addressing the SDOH is a core objective of the health units if you want to advise someone to use this tool, will you go by just presenting the visualizations...
alone, the framework alone, or you will present them both as we have done in this tool?

9. Q 23 – Have you ever seen any visualization provided by other organizations, including Statistics Canada and CIHI? It is very rare that you see a framework visualized, and usually, those who own the data provide either tabular version of the data or some static images, but they don’t provide you or show you a framework behind the data. So in your work, will you advise your organization to start showing or presenting their data using the framework that governs the data, just as we did in this tool?

10. Q 24 - There are specific terms used in visualization terminology. For example, we use the word interact. while most people use “play”, and we use the word “filter” and people use words like “select”. Do you think we need to explain more about the technical terminology used in visualizations so that our prospective users start to use them?

11. Q 28 - How do you explain that while most of the publishing channels are online, you can only find static images in most of the research papers published in these channels, although the capability to show visualized images is already there?

Information Visualization related

12. Q8 - Does this tool help in decision making? How? Will it help people with a certain background or all the people?

13. Q9 - If we were to enhance this tool and develop a new version, what should we focus on? OR: “What’s missing from this tool?”

14. Q10 - How do you compare interactive visualizations to static charts—those that you see in printed magazine, for example?
15. Q11 - Let’s assume that you have been tasked to prepare a report for your top level managers, which they need to make a decision. You have been given the option to use your organization’s intranet website to create an e-report that enables you to embed interactive visualizations. Will you use it or do you prefer to use the traditional paper-based report and static charts?

16. Q12 - What are the tool features that you find important? Why? What wasn’t important? Why not?

17. Q15 - Do you think it is more useful to visualize the traditional charts, such as the bar chart, and the pie chart or you think more complex visualizations might also be acceptable to their intended users? Knowing that those who create complex visualizations believe that they can visualize complex problems and that they are giving the users more capabilities to interact with information.

18. Q16 - For the cause-specific mortality by education, when you select Suicide you can see that certain age groups disappear because there have been no suicide incidents in these groups, do you think that you could have noticed if you were reading the original study, which doesn’t use any interactive visualization?

19. Q 25 - What do you think we need to do to make visualization popular and to change the culture of data presentation?

20. Q 26 - What about the GIS visualization, was it helpful to present the indicators?

21. Q 27 - In visualization there is this concept of multiple encoding, where we use different encoding techniques, including colors, shapes, and size. We also use interaction capabilities, so how did you find that in the visualization presented in the tool, do you think this has been straightforward or what do you think about it?
Usability

22. Q17 - How likely are you going to use this tool? Why?
23. Q18 - Describe how easy or difficult is to learn using this tool?
24. Q19 - What do you think the obstacles for using this tool are?
25. Q13 - What features did you find most difficult. Why?
26. Q14 - What features did you find easy to use. Why?
27. Q29 - How do you feel about different interaction features in the tool, e.g., filtering, and zooming?
28. Q7 - Describe your experience in using this tool. Did you find it simple, easy to use, or complex, please use your terms?

Strategic Questions

29. Q20 - In your opinion, in research, what is more important: data analysis or data presentation? Why?
Appendix B: Research Ethics Board Approval

Western University Non-Medical Research Ethics Board
NMREB Delegated Initial Approval Notice

Principal Investigator: Kamran Sedig
Department & Institution: Science/Computer Science, Western University

NMREB File Number: 106967
Study Title: Using Information Visualization to Represent the Social Determinants of Health

NMREB Initial Approval Date: August 31, 2015
NMREB Expiry Date: August 31, 2016

Documents Approved and/or Received for Information:

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<th>Comments</th>
<th>Version Date</th>
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<tr>
<td>Revised Western University Protocol</td>
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<td>Revised Letter of Information &amp; Consent</td>
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<td>2015/08/09</td>
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</table>

The Western University Non-Medical Research Ethics Board (NMREB) has reviewed and approved the above named study, as of the NMREB Initial Approval Date noted above.

NMREB approval for this study remains valid until the NMREB Expiry Date noted above, conditional to timely submission and acceptance of NMREB Continuing Ethics Review.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario.

Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00060941.

This is an official document. Please retain the original in your files.
Appendix C: Letter of Information and Consent Form

Western

Letter of Information and Consent to Participate in a Research Study

**Study Title:** Using Information Visualization to represent the Social Determinants of Health

**Principal Investigator**
Dr. Kamran Sedig, PhD Department of Computer Science
The University of Western Ontario
Phone: [Redacted]

**Co-Investigator**
Moutasem Zakkar
Health Information Science Program
The University of Western Ontario
1. **Conflict of Interest**

The principal investigator and the co-investigator declare no conflict of interest.

2. **Introduction**

You are being invited to participate in this research study about examining the use of information visualization to represent the social determinants of health and health equity indicators because your professional experience and responsibilities include health policy analysis or healthcare data analysis.

3. **Background/Purpose**

Health equity is the absence of health disparities among population groups defined socially, economically, demographically or geographically. It results from several factors known as the social determinants of health (SDoH). Addressing health equity problems is a major policy objective. However, there are many factors that hinder planning and designing of policy interventions for solving health equity problems. These factors are health system complexity, decision makers' bounded rationality and cognitive needs, knowledge translation barriers, decision makers' information needs, and the complexity of health indicators.

Visual representation of SDoH can help policy makers by facilitating problem analysis, communication, knowledge sharing, and decision making. Information visualization is “the use of computer supported, interactive, visual representations of abstract data to amplify cognition”. Information Visualization has been used to facilitate decision making in many domains; including business and urban planning. However, there is a scarce literature on using visualization in healthcare.

3.1. **Purpose of the study**

The purpose of the study is to examine the use information visualization to represent the social determinants of health and health equity indicators and perform complex cognitive activities such as analyzing health equity problems.

3.2. **The reason for participation**
You are being asked to participate because your professional experience and responsibilities include health policy decision making, health data analysis, or healthcare service management. Your experience can help us to understand the utility of the information visualization tool that will be created and used to represent the social determinants of health.

3.3. The number of people to participate.

Up to 10 people will participate in this study, and it will take three months to complete.

3.4. The length of the study.

It is expected that you will be in the study for a maximum of one month.

4. Study Design

The study includes the development of a prototype for a visualization tool—a computer program—, which will represent health indicators through representing the conceptual framework for the social determinants of health that was developed by the World Health Organization’s commission in 2010. This tool will be used by the study participants whose feedback will be collected in an interview in order to evaluate the utility of the tool in health policy making.

5. Procedures

Participation in this study includes three steps that can take place at the participant workplace or at Western university; based on the participant preference:

1- A demonstration session, in which a co-investigator will present the tool to the participant.

2- Exploring the tool and test its different functions by the participant.

3- Giving feedback about the tool through an interview with a co-investigator. This interview will be audio recorded; however it can be recorded on paper if a participant requests to do so.
These steps are summarized in the following table.

<table>
<thead>
<tr>
<th>Step</th>
<th>Name</th>
<th>Description</th>
<th>Actors</th>
<th>Location</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Demonstration</td>
<td>A co-investigator will present the tool to the participant.</td>
<td>A co-investigator, A participant.</td>
<td>Participant workplace or Western</td>
<td>One Hour.</td>
</tr>
<tr>
<td>2</td>
<td>Exploration</td>
<td>A participant explores the tool and performs any tasks on it freely and without attendance of a co-investigator.</td>
<td>A participant.</td>
<td>Participant workplace or Western</td>
<td>A minimum of one hour but can be extended upon participant request.</td>
</tr>
<tr>
<td>3</td>
<td>Feedback Interview</td>
<td>A co-investigator will interview the participant and ask him/her a set of open-ended questions in order to evaluate the perceived utility of the visualization tool.</td>
<td>A co-investigator, A participant.</td>
<td>Participant workplace or Western</td>
<td>One or two sessions. Expected duration is two hours per session.</td>
</tr>
</tbody>
</table>

6. **Voluntary Participation**

6.1. Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your professional status. We will give you new information that is learned during the study that might affect your decision to stay in the study.

6.2. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”.

7. **Withdrawal from Study**

7.1. The Researchers can take you off the study for reasons such as:

- Your incapability to allocate the required time to complete all the steps of the study.
7.2. If you request to be withdrawn from the study, you have the right to request withdrawal of information collected about you.

8. **Risks**

This study has no known implicit or explicit harms to study participants.

9. **Benefits**

There are no known benefits to you associated with your participation in this research study. However, this study will shed light on the utility of information visualization in health equity policy making, and it will inform the development of a decision support tool, which could help decision makers in addressing healthcare problems.

10. **Reminders and Responsibilities**

10.1. While we highly appreciate your participation, we appreciate your punctuality and cooperation.

11. **Confidentiality**

11.1. Information gathered in this research study may be published or presented in public forums; however your name and other identifying information will not be used or revealed.

11.2. Participants will not be named in any reports, publications, or presentations that may come from this study.

11.3. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

11.4. Unless required by law, no people/groups/organizations outside the study team will have access to information collected except what will be publicly published by the research team.

11.5. The study researchers will keep any personal information about you in a secure and confidential location for a maximum of 5 years. A list linking your study number with
your name will be kept by the study researchers in a secure place, separate from your study file.

12. Costs

12.1. You will not have to pay for any of the steps involved with this study.

12.2. You will receive no payment or reimbursement for any expenses related to taking part in this study.

12.3. As explained in section 5 of this letter, this study has three steps, including a demonstration, an exploration, and an interview. These steps can be completed in any location convenient to you. However, you can also complete any of these steps in an office at Western University, and in this case your parking expenses will be paid for you.

12.4. At the end of the study; or upon withdrawal from the study, participants will receive an honorarium of a $25 gift card.

13. Rights as a Participant (in the event of a study related injury)

13.1 You do not waive any legal right by signing this consent form.

14. Commercialization

Research team intends to claim sole ownership of any research results consistent with this consent. By signing this consent, you agree that you will not receive any financial benefit that might come from the research.

15. Questions About the Study

You are free to ask any questions that you may have about your participation and your rights as a research participant. If any questions come up during or after the study, please contact:

Dr. Kamran Sedig, Phone: [Redacted]

Mr. Moutasem Zakkar, [Redacted]

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics (519) 661-3036, email: ethics@uwo.ca.

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16. Consent

Study Title: Using Information Visualization to Represent the Social Determinants of Health

Principal Investigator: Dr. Kamran Sedig

Co-Investigator: Mr. Moutasem Zakkar

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

I agree to be audio recorded in this research

☐ YES ☐ NO

I consent to the use of unidentified quotes obtained during the study in the dissemination of this research

☐ YES ☐ NO

Participant signature________________________

Date __________

(dd/mm/yyyy)

Participant printed name: ___________________
PARTICIPANTS NEEDED FOR RESEARCH in Information Visualization and Health Policy Making

We are looking for volunteers who work in health policy analysis, data analysis, and program planning, to take part in a study of *Using Information Visualization to Represent the Social Determinants of Health.*

If you are interested and agree to participate you would be asked to:

1. Attend a presentation about a computer program (a visualization tool).
2. Evaluate the visualization tool.
3. Give your feedback through an interview with the researcher.

All of these activities might take place at your convenient time and place, and they can also be done online via Skype.

Your participation would take two to three hours, including a demonstration session, and one or two interview sessions;

In appreciation for your time, you will receive an honorarium of a $25 gift card.

For more information about this study, or to volunteer for this study, please contact:

Moutasem Zakkar
Health Information Science Program
Email: [redacted]

Page 1 of 1    Version Date: 25/January/2016
Curriculum Vitae

Name: Moutasem Zakkar

Post-secondary Education and Degrees:

- Damascus University
  Damascus, Syria
  1989-1994 DDS.

- New York Institute of Technology
  Abu Dhabi, United Arab Emirates
  2005-2006 MBA.

- The University of Western Ontario
  London, Ontario, Canada
  2014-2016 MHIS.

Related Work Experience:

- Teaching Assistant
  The University of Western Ontario
  2014-2016

- Managing Director
  RELEMIT IT Solutions
  India and United Arab Emirates
  2010-2012

- E-Service Development Advisor
  Ministry of Culture, Youth and Community Development
  United Arab Emirates
  2008-2010

- Computer Programmer
  The World Health Organization
  2005

- Dentist
  Syria
  1994-1999