

Inclusive Knowledge Translation

by

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Abstract

This three-phased qualitative study examined the extent to which VP-Net succeeded in conducting Inclusive Knowledge Translation (IKT). Three phases of data collection: documentation of VP-Net knowledge translation activities, semi-structures interviews, and a focus group/critical reflection, were conducted with a total of fourteen participants. Key findings indicate that before a researcher can work to include people with disabilities in their research, they need to ensure inclusion in their own lives. Only then can a researcher move onto the Elements of Inclusive Knowledge Translation and incorporate them in their work. This research is important as Inclusive Knowledge Translation, a new and innovative concept, has never been studied before therefore there is a lack of evaluation conducted regarding the effectiveness of knowledge put into action. Embedded assumptions regarding characteristics and qualities of researchers and research users leave people with disabilities out of the research process.

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“It takes a village to raise a child” –African Proverb

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Together we can make a change.

Chapter 1

Introduction

Over one billion people in the world today, or approximately 17% of the world's population, live with a disability (WHO, 2011). Many of the norms and social constructs that shape our society have a “nondisabled” bias and are “based on the experiences of nondisabled people” (Peat, 1997). These constructs result in the marginalization of individuals with disabilities, pushing them out and leaving little space for equal opportunities in health care, education, employment and recreation (Peat, 1997).

In this thesis, I define what it means to conduct Inclusive Knowledge Translation. This study creates the Elements of Inclusive Knowledge Translation and it examines whether the Vulnerable Persons and End of Life New Emerging Team (VP-Net) was successful at achieving Inclusive Knowledge Translation, using the elements as indicators of success.

From 2004 to 2012 an interdisciplinary group of researchers --The Vulnerable Persons and End of Life New Emerging Team (VP-Net) -- strove to understand experiences in end-of-life care by individuals who face barriers to access to care, services, information and supports (VP-Net Brochure, n.d.). During the final year of the VP-Net project, knowledge translation events were held in Calgary, Winnipeg, Toronto and Halifax.

My thesis is guided by the central research question: Using the indicators of Inclusive Knowledge Translation (IKT), to what extent does VP-Net succeed in conducting Inclusive Knowledge Translation?

What does it mean to be inclusive? “Inclusion is about all of us, inclusion is about our abilities, inclusion is about living full lives, inclusion treasures diversity and builds community, inclusion is about change and inclusion is not just about disabilities” (Pearpoint, Kahn, & Hollands, n.d).

What is knowledge translation? Knowledge translation refers to the process used by researchers and research users, to share information and research findings, and to then put this knowledge into action (CIHR, 2000; NIDDR, 2005, NCDDR, 2007). As the following study outlines, knowledge translation goes beyond the sharing of information; it’s about the knowledge that is produced and “addressing important problems facing clinicians, managers, and decision-makers” (Bowen & Graham, 2013).

There are numerous definitions of the term *knowledge translation*. Different disciplines describe the process in a variety of ways. Due to the inconsistent usage of the term *knowledge translation*, there is often a great deal of confusion around its meaning and application. For the purpose of this study, the literature on knowledge translation was reviewed to identify a consistent meaning of knowledge translation. Although there has been extensive literature regarding knowledge translation, its methods, theories and framework, there is a lack of conclusive evaluation of the effectiveness of having knowledge actually put into action. In addition, the embedded assumptions regarding the characteristics and qualities of researchers and research users leave people with disabilities out of the research process.

The combination of the lack of evaluation of knowledge translation and the marginalization of people with disabilities in the literature creates a gap in the literature with regards to people with disabilities being “othered”, being treated not like “us” but as

“them” (Wolfensberger, 2000). In addition, there is a gap in the process of the evaluation of efforts to put knowledge into action.

The Elements of Inclusive Knowledge Translation (IKT) (Appendix F) were initially developed based on the current literature and the guiding theoretical perspectives of this project (described below). The Elements of Inclusive Knowledge Translation were amended and finalized to represent the perspectives of the three communities of interest -- people with disabilities, healthcare providers and policy-makers.

In order to achieve a comprehensive understanding of what participants believed the Elements of Inclusive Knowledge Translation are, and their perspectives on whether VP-Net achieved these elements I conducted a three-phase qualitative study.

The first phase was a narrative/ document analysis with a VP-Net former project manager and a co-investigator to understand the knowledge translation process VP-Net undertook. For the second phase, the perspectives and experiences of eight (8) individuals in total from the three communities of interest whom attended the final VP-NET knowledge translation events were explored through semi-structured interviews to understand if the Elements of Inclusive Knowledge Translation were achieved. The final phase was a focus group of the VP-Net co-investigators (three individuals) and a semi-structured interview with one VP-Net co-investigator to allow them to critically reflect on the VP-Net process.

The purpose of this three-phased qualitative study is to explore:

- a. The assumptions that are currently embedded in knowledge translation;
- b. The Elements of Inclusive Knowledge Translation;

- c. Current knowledge translation strategies such as VP-Net and evaluate if it was inclusive;
- d. Additional recommendations Canadian people with disabilities, policy-makers and healthcare providers have regarding how to conduct Inclusive Knowledge Translation.

Using multiple sources of data collection for this project ensured the perspectives of the three communities of interest were accurately portrayed (Mactavish, Lutfiyya & Mahon, 2000).

Following the data collection, thematic analysis was used to generate themes and identify the participants' perspectives of the Elements of Inclusive Knowledge Translation and their experiences of the VP-Net knowledge translation events.

Knowledge translation is a term and definition that is ever evolving and forever changing. It is important to note, that although this thesis has created a list of the Elements of Inclusive Knowledge Translation (Appendix F), these elements will constantly be adapting, and changing to align with the most current research and the needs and desires of people with disabilities.

This research is important because not only does it fill a gap in knowledge translation literature by evaluating if the VP-Net final knowledge translation events were successful, but this research has created an innovative, ground-breaking term "Inclusive Knowledge Translation".

By conducting this study I am adding to the current research on knowledge translation and I am creating literature to fill the gap regarding including people with disabilities in the research process. Above and beyond these two research initiatives, I

have outlined in this project various themes (e.g., establishing relationships, trust, flexibility, engagement) that researchers wanting to conduct research *with* individuals with disabilities can explore, and how future researchers can dig deep within themselves to create space within their hearts before they create space in their minds regarding inclusive research techniques.

The desired outcomes of this study are to: draw awareness of researchers to these gaps in the current literature *on* people with disabilities rather than *with* people with disabilities; draw awareness of funding bodies regarding the elements that are required before and after Inclusive Knowledge Translation; creating a standard within these national agencies regarding what it truly means to conduct research *with* people with disabilities. I also hope this project creates space in the hearts of researchers and allows them to recognize the importance of humility and humanity within research. This study will provide insight into the real-life experiences of people with disabilities and the “research-world”.

My conclusions suggest it is essential that we, as researchers recognize our place in the research process and accept that a study must be flexible, continuously adapting and acknowledge that research needs to meet those of the participants.

Theoretical Perspectives

Two theoretical perspectives -- Emancipatory research and the social model of disability -- are used to inform this research project. These theoretical perspectives help to understand what people with disabilities, policy-makers and healthcare providers believe it means to conduct inclusive and accessible research as well as identify markers of Inclusive Knowledge Translation.

Emancipatory research.

Much of the disability-related research has been criticized because non-disabled researchers conduct research on disabled participants and disabled researchers are not included. Some authors suggest that the vast majority of disability research has been conducted with “an oppressive theoretical paradigm and within an oppressive set of social relations” (Stone & Priestley, 1996, p. 1). The developments from overcoming these challenges have led to the creation of emancipatory research (Stone & Priestley, 1996, p. 1). Emancipatory research is “research that seeks to empower the subjects of social inquiry” (Letherby, 2006). The principles of emancipatory research provide the framework for identifying inclusive research.

Emancipatory research is grounded in the development of the disabled people’s movement and the advancement of the social model of disability (French & Swain, 2004). Emancipatory research and the social model, the second theoretical perspective, are intertwined, as the foundation of emancipatory research is based on the physical, cultural, societal and environmental barriers that exclude people labeled disabled from participating in ‘mainstream society’ (Barnes, 2001; Oliver, 1990).

There are a number of embedded assumptions by past researchers that portray researchers and research users as having certain characteristics. Currently in the literature, there are implicit power relationships in the status quo of knowledge translation that do not recognize people with disabilities in research or as researchers. Barnes and Mercer (1997) explained that much of the disability research to date, especially research conducted by non-disabled researchers, has led to the exploitation of people with disabilities, rather than their liberation and integration.

Given these embedded power relationships, the theoretical perspective of emancipatory research is used to explain how individuals without disabilities can contribute to the research process as allies (Stone & Priestley, 1996). It is the job of an ally, in this particular project, to explore these assumptions and explain how to breakdown these barriers and facilitate Inclusive Knowledge Translation.

Emancipatory research gives the control of the research process (which includes funding and the research agenda) to people with disabilities and their organizations rather than researchers and academics (Barnes, 2001). Barnes (1992) explains,

Emancipatory research is about the systematic demystification of the structures and processes which create disability and the establishment of a workable 'dialogue' between the research community and disabled people in order to facilitate the latter's empowerment. To do this researchers must learn how to put their knowledge and skills at the disposal of disabled people (p. 122).

There must be a fundamental shift in the 'researcher-researched' relationship (Stone & Priestley, 1996). According to both Barnes (2001) and Stone and Priestley (1996), there are six key principles of the emancipatory research model that works towards this shift:

- Accountability to people with disabilities; commitment in actions and words (Stone & Priestley, 1996; Barnes, 2001)
- Must abide by the epistemological framework of the social model of disability; disability is socially constructed by the environment, social attitudes and barriers, structures and oppression rather than an individualized bodily impairment in need of correction.
- Objectivity. The researcher's position and commitment must be clear from the onset of the project by stating ontological and epistemological positions (Barnes, 2001).
- Data collection strategies can be qualitative, quantitative or a combination of both.
- The role of experience. Space needs to be made in disability research to advance the individual experiences of people with disabilities (Morris, 1991).
- Emancipatory research is a continuous project, not a single project or group of projects and must have some meaningful practical relevance in the lives of their participants and themselves, not simply the academy (Stone & Priestley, 1996; Barnes, 2001).

When conducting emancipatory research, researchers can learn from disabled people and *vice versa*. This collaboration aims to reduce the power relations and allows researchers to make themselves 'available' to disabled people" (Zarb, 1992, p. 128). It is important to note, "simply increasing participation and involvement will never by itself constitute emancipatory research unless and until it is disabled people themselves who are controlling the research and deciding who should be involved and how" (Zarb, 1992, p.

128). Current research is influenced by the power, privilege and assumptions of non-disabled people, rendering an oppressive environment for people with disabilities. In order to develop markers of Inclusive Knowledge Translation, the principles and practices of emancipatory research suggest several key elements:

- Meaningful involvement of and decision-making by people with disabilities in all aspects of the project;
- Accountability for research to the communities of people with disabilities;
- Recognizing and removing socially constructed barriers for people with disabilities in and through research.
- Breaking down relationships of power between the researcher and the researched

Social model of disability.

The second theoretical perspective used in this project is the social model of disability. Within this framework, disability, defined by the WHO (2012) as a component of health, rather than a consequence of disease, a determinant of health or a risk factor, is recognized as socially constructed. Further, Oliver (2009) defines disability, not as a medical matter, but as “all of the things that impose a restriction on a disabled person; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on” (p. 21). These constructs result in the marginalization of individuals with disabilities, leaving them out of the research and leaving little space for equal opportunities in health care, education, employment and recreation (Peat, 1997). The perspective of the social model of disability is that individuals are disabled by

societal, attitudinal, systemic, physical and education barriers (McColl et al., 2008) rather than by their physical or mental impairments or conditions.

Using the social model of disability enables us to critically analyze and reflect on the social, physical and societal environments in which our actions and practices occur and what is required to ensure they are accessible and available to all individuals. It recognizes that any human being can experience disability and acknowledges the impact that social constructs and the environment have on disabling individuals.

There is resistance within our society to accommodate people with disabilities or create spaces that are universally accessible. The Principles of Universal Design (which are explored below) require an environment that is: equitable, flexible, intuitive, perceptible, safe, easy and accommodating (The Principles of Universal Design, 1997). Designing a space under these principles fosters an inclusive environment and a universal way to eliminate environmental barriers that render individuals *disabled*.

The social model lens offers an opportunity to uncover underlying assumptions that may exist in the ‘researcher-researched’ relationship. In addition, the social model reminds us to ask how to make knowledge translation inclusive and accessible.

From this perspective, we can identify several additional Elements of Inclusive Knowledge Translation:

- Evaluate and identify barriers for knowledge users and producers;
- Identify those missing or invisible in the research and research process;
- Remove barriers to participation and ensure access for all by flexibility, multiple entry and access points, and development of tools for a variety of audiences.

The combination of the Social Model of Disability and Emancipatory Research creates a unique point of view and offers an inclusive perspective to this research. The seven (7) indicators listed above will be used to evaluate if the process VP-Net undertook was truly Inclusive Knowledge Translation. In summary, the theoretical perspectives illustrate three key aspects of Inclusive Knowledge Translation:

- Uncovering barriers between knowledge users and producers to create empowerment of people with disabilities;
- The need to break down physical, environmental, cultural and societal barriers that create disability;
- Creating space and involvement in the entire research process for people with disabilities.

As a non-disabled researcher and ally, it is my intention to disrupt dominant discourses related to these power imbalances in medicine and healthcare and promote a more diverse and inclusive way to produce research and conduct future practices. My goal is to look at the entire research process and work to bring people with disabilities into the center.

In this project, people with disabilities, healthcare providers and policy-makers are included in the research by evaluating if they believe Inclusive Knowledge Translation was reached by VP-Net based on the formal list of indicators further in this report.

The collaboration of these two theoretical perspectives along with my personal location, as the researcher will create a unique foundation for the research project.

Personal Location

It is important to recognize my place within the lives and communities of people with disabilities as I identify as an able-bodied woman. My path to disability studies began many years ago.

My involvement with people with disabilities began early on in my childhood with a dear friend. My friend has many complex impairments and he lives with a great deal of pain. From the time we met, he and I developed an immediate connection. He and his family educated me about the complexities of his life and the battles they all continuously fight to ensure he lives a life with the human rights and dignity entitled to all Canadian citizens. This friendship taught me how to be an ally and encouraged me to increase my capacity and knowledge of the challenges people with disabilities face on a daily basis. It empowered me to want to work to influence change in Canadian health policy and disability rights.

My goal is to incrementally shift the perspectives of Canadians and breakdown the barriers and embedded assumptions regarding people with disabilities in the healthcare system. This led me to the program in Disability Studies.

Throughout my master's program, it became evident to me that my personal perspective, values and vision for the future, support the social model, bringing knowledge-to-action and involving people with disabilities as participants in the research process. My vision of inclusive research involves collaborative interdisciplinary work that aims to reduce environmental, systemic, attitudinal, physical and educational barriers and increase knowledge and awareness of disabilities.

My personal goals and ongoing role as an ally, in conjunction with my professional desire to ensure change occurs at the policy and system levels, bridge my interests in disabilities and putting research into action. This vision directly aligns with my hope to establish what it means to have an inclusive and accessible knowledge translation strategy.

As I work to further understand what changes need to be made to establish an inclusive and accessible method to facilitate knowledge translation, it is essential that I include, engage with and listen to the perspectives of people with disabilities from the onset of my research. I am not able to declare what changes need to be made for individuals with disabilities or suggest how they should be implemented without clear input and understanding of the key issues.

As a non-disabled researcher, working to place disabled people at the center of the research, I believe I have an active and critical role to play as an ally. The first and what I believe is the most important step to becoming an ally is to include people with disabilities from the very beginning of the research process.

I believe I have a critical role to play as an ally in the construction of an Inclusive Knowledge Translation strategy that will then impact policies and the way research is disseminated and applied. I do not have the ability to describe any situation first hand as a disabled individual; I can however, act as a voice and conduit to create awareness for those who do.

In order to understand how people with disabilities are portrayed in the current literature, I conducted an in-depth literature review describing current knowledge translation research and research conducted on or with people with disabilities. Together

with the theoretical perspectives, the current literature and the findings from this project the Elements of Inclusive Knowledge Translation will be created.

Chapter 2

Literature Review

For this project, I will review the literature on knowledge translation in Canada. The literature will include the methods, theories and frameworks of knowledge translation and an evaluation of the strategies used in knowledge translation. There is no simple definition for knowledge translation; this review explores the evolving definitions and reflects upon this complexity, noting the strengths and criticisms of various usages and definitions.

Many themes in the literature on knowledge translation recur. Currently, there are numerous studies that have identified various knowledge translation and exchange models and frameworks. However, the uptake and use of these interventions have rarely been evaluated and it remains unclear which model should be used in what context (Tugwell, Robinson, Grimshaw, & Santesso, 2006; Mitton, Adair, McKenzie, Patten, & Wayne Perry, 2007). One reason for the lack of evaluation is the inconsistency in the terminology and the misconceptions and misunderstandings between researchers and health policy decision-makers (Mitton et al., 2007). Particularly, there is a gap in the research conducted on successful knowledge translation strategies for and with people with disabilities. Current literature on knowledge translation and exchange strategies is evaluated and successful interventions or strategies for people with disabilities are clearly identified.

One goal, many names.

Organizations, researchers, health care providers and the general public indicate that we as a society need to move research evidence into practice and policies. However, there is considerable misunderstanding and misconception about the various concepts used to describe the process of moving knowledge into action. The confusion is understandable given the array of terms used to explain all or elements of knowledge translation (Graham, Logan, Harrison, Straus, Tetroe, Caswell, & Robinson, 2006). One study reviewed thirty-three applied research-funding agencies in nine countries and found twenty-nine different terms used to define the concept of knowledge to action (Graham, Robinson, Grimshaw, & The International Funders Study Research Group, 2005). In addition, terms are often used interchangeably, which can lead to confusion and misinterpretation (Graham et al., 2006). In this section, I will consider four terms most widely used in Canada. These are: knowledge translation, knowledge transfer, knowledge exchange and knowledge mobilization. Only these four terms will be defined in detail as they are the most relevant to this thesis and the most widely used within the context of this thesis and the literature review. Appendix A outlines seven terms identified in the literature, where they are most used, and their key components.

Knowledge translation.

Knowledge translation (KT) is often used in Canadian healthcare fields to explain the process of moving research findings into practice settings. (Sudsawad, 2007). The term knowledge translation was created in 2000 by the Canadian Institutes of Health Research (CIHR) and was originally defined as “the exchange, synthesis and ethically-sound application of knowledge -- within a complex system of interactions among

researchers and users-- to accelerate the capture of the benefits of research for Canadians through improved health, more effective health services and products, and strengthen the health care system” (para. 2). The original definition created by CIHR emphasizes the interplay and reciprocal action between research creators and knowledge users. Other institutions have since used this inaugural definition as the foundation for developing their own definitions of knowledge translation.

The University of Toronto, Faculty of Medicine, Knowledge Translation Program defined Knowledge Translation in 2004 as, “the effective and timely incorporation of evidence-based information into the practices of health professionals in such a way as to effect optimal health care outcomes and maximize the potential of the health system” (para. 14). This definition emphasizes the importance of integrating evidence-based information into clinical health care practices, but does not address integrated collaboration between knowledge creators and knowledge users.

The World Health Organization (2005) modified CIHR’s definition and defined Knowledge Translation as “the synthesis, exchange, and application of knowledge by relevant stakeholders to accelerate the benefits of global and local innovation in strengthening health systems and improving people’s health” (p. 2). The World Health Organization added the specificity that the translation of knowledge is to be “by relevant stakeholders,” whereas CIHR simply stated “researchers and users”. This specification is important because the complex process of Knowledge Translation will vary depending on the research topic, the research creators and the research users. The WHO however, eliminated the piece about “interactions” which is crucial achieving successful to Knowledge Translation.

The National Institute on Disability and Rehabilitation Research (NIDRR) established a working definition of knowledge translation as well in 2005. NIDRR defines Knowledge Translation as “the multidimensional, active process of ensuring that new knowledge gained through the course of research ultimately improves the lives of people with disabilities, and furthers their participation in society” (p. 8195).

Following the NIDRR, the National Center of the Dissemination of Disability Research (NCDDR) (2007) devised a working definition for Knowledge Translation as, “The collaborative and systematic review, assessment, identification, aggregation and practical application of high-quality disability and rehabilitation research by key stakeholders (i.e., consumers, researchers, practitioners, policy makers) for the purpose of improving the lives of individuals with disabilities” (p. 4). Both of these definitions rely upon the emergent definition of Knowledge Translation while specifying the users and stakeholders as people with disabilities.

Sudsawad (2007) elaborated on the vision of CIHR, by identifying the importance of using Knowledge Translation throughout the research process to “help define research questions and hypotheses, select appropriate research methods, conduct the research itself, interpret and contextualize the research findings, and apply the findings to resolve practical issues and problems” (p. 2). In addition, according to CIHR (2004), interactions and partnerships within and between different groups of knowledge creators and users for all stages of the research process are crucial aspects of knowledge translation.

As CIHR continued to develop their knowledge translation process, the Institute explained that Knowledge Translation is a greater concept that describes terms relating to “moving knowledge to use”(Sudsawad, 2007, p. 2). In 2008 Ian Graham, CIHR Vice

President of Knowledge Translation, created a revised working definition of knowledge translation as “a dynamic and interactive process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the healthcare system” (p. 1). Tetoe of CIHR (2007) argues that by explicitly stating “synthesis” and “ethically sound application of knowledge” this redefined definition of Knowledge Translation suggests that thought should be given to the information that is translated and to the audience it is being shared with. This suggests that while all researchers are encouraged to translate the results of their studies, they must be thoughtful in the way they convey their message and ensure it is directed to the appropriate audience. This is one critical theme of knowledge translation: while Knowledge Translation may be universally applicable, the process of Knowledge Translation varies with the context and audience.

Graham et al. (2006) identify a second critical theme of Knowledge Translation: it is interactive and requires a two-way collaboration. They emphasize that what is important about both CIHR and NCDDR’s definitions is that “the primary purpose of Knowledge Translation is to address the gap between what is known from research and knowledge synthesis and implementation of this knowledge by key stakeholders with the intention of improving health outcomes and efficiencies of the health care system” (p. 14). In addition, Graham et al. (2006) explain that the CIHR definition acknowledges that the process of knowledge translation occurs “in a complex social system of interactions among stakeholders” (p. 16). Whereas the CIHR definition does not explicitly discuss

what is meant by *interactions*, the NCDDR definition clearly states that the interaction is *collaborative and two-way*.

For the purposes of this paper, the term knowledge translation will be used and defined by three key elements:

1. Knowledge Translation is a dynamic process of moving research into use and action;
2. Different Knowledge Translation strategies are required for different audiences and;
3. Knowledge Translation requires two-way collaboration throughout the research process.

Knowledge transfer.

Outside the healthcare field, knowledge transfer is the most commonly used term. Knowledge transfer is used to describe the process of transmitting knowledge to stakeholders (Graham et al., 2006). This term includes knowledge from research as well as all other forms of gaining knowledge such as the media, networking, and education. Knowledge transfer is defined by the Government of Alberta (2007) as “a systematic approach to capture, collect and share tacit knowledge in order for it to become explicit knowledge. By doing so, this process allows for individuals and/or organizations to access and utilize essential information, which previously was known intrinsically to only one or a small group of people” (p. 15).

Knowledge transfer has been criticized as a unidirectional process of knowledge flowing from producers to stakeholders, even though many people who use the term see it as a two-way transfer of knowledge (Graham et al., 2006). Another criticism of this term

is that *transfer* may be interpreted as the first step of disseminating knowledge to stakeholders but does not imply putting it into action (Graham et al., 2006).

Knowledge exchange .

The Canadian Health Services Research Foundation (CHSRF) adapted the term knowledge transfer and redefined it as “knowledge exchange” so as to acknowledge researchers and decision-makers collaborating in terms of culture and perspectives on research and knowledge. CHSRF defines knowledge exchange as “collaborative problem-solving between researchers and decision-makers that happens through linkage and exchange. Effective knowledge exchange involves interaction between decision-makers and researchers and results in mutual learning through the process of planning, producing, disseminating, and applying existing or new research in decision-making” (para. 2). This definition has also been termed the “two-communities theory” (Wingens, 1990, p. 28), which is an attempt to explain the relationship between researchers and policy-makers and why policy-makers are not consistently using research. Two-communities theorists argue, “social scientists and policy makers live in separate worlds with different and often conflicting values, different reward systems, and different languages” (Caplan, 1979, p. 459). The differences between these two groups have created a significant gap that some authors believe can be bridged through personal relationships (Caplan, 1979). This approach extends knowledge translation’s recognition of possible different audiences and suggests that there may be communities of interest that interact.

According to CHSRF, knowledge exchange also emphasizes interaction between researchers and decision-makers during the entire knowledge-to-action process (Graham et al., 2006). The collaboration between researchers and decision-makers begins with the

research question and does not end until the knowledge is applied. During each phase of the research project appropriate stakeholders were engaged to ensure the ideas generated were relevant and suitable for the given community (Graham et al., 2006). This element is similar to that identified in knowledge translation. But by underlining the importance of communities of interest, this approach to knowledge exchange encourages the development of relationships throughout the research process. This shifts attention from individual users to groups of people with common interests.

Knowledge mobilization.

Knowledge mobilization is the term largely used within the social sciences and humanities community in Canada. The Social Science and Humanities Research Council of Canada (SSHRC) established a two-year Knowledge Mobilization Strategy in 2009. SSHRC defined knowledge mobilization as, "...moving knowledge into active service for the broadest possible common good." Here knowledge is understood to mean any or all of the following:

1. Findings from specific social sciences and humanities research;
2. The accumulated knowledge and experience of social sciences and humanities researchers and
3. The accumulated knowledge and experience of stakeholders concerned with social, cultural, economic and related issues" (Social Science and Humanities Research Council of Canada, 2009).

The goals of knowledge mobilization extend beyond the scope of knowledge translation. Much like knowledge translation, knowledge mobilization aims to increase and enhance the research shared amongst researchers, and between researchers and knowledge users

(Social Science and Humanities Research Council of Canada, 2009). However, knowledge mobilization extends further with the goal to create and facilitate connections and reciprocal relationships between researchers and knowledge users to “co-create” and use research knowledge (Social Science and Humanities Research Council of Canada, 2009).

In turn, knowledge mobilization strives to facilitate the development of lasting and ongoing relationships and networks of researchers and knowledge users from any field of practice and to have the networks create tools and best practices (Social Science and Humanities Research Council of Canada, 2009).

Knowledge mobilization is similar to knowledge exchange in terms of collaboration between stakeholders and researchers, however the scope of knowledge mobilization extends beyond the researchers and decision-makers to encompass their continued and long lasting collaboration (Social Science and Humanities Research Council of Canada, 2012).

Other terms.

A variety of other terms are used to discuss the area of moving knowledge into action. However, they have much less currency and presence in the literature and in some cases predate the discussions in this area. They do not identify any additional key criteria for this area of research. For the purposes of a thorough literature review, I will briefly discuss the six remaining terms.

The term knowledge utilization has been used since the early 1970's for the most part in the nursing profession (Tetroe, 2007). Knowledge utilization, also known as, research utilization, was first used to describe the integration of research evidence into

clinical practice (Tetroe, 2007). *Research utilization* was defined by Backer in 1993 as “including a variety of interventions aimed at increasing the use of knowledge to solve human problems” (p. 217). While Backer believed that knowledge utilization encompassed many topics such as technology transfer, information dissemination and utilization, research utilization, innovation diffusion, sociology of knowledge, organizational change, policy research, and interpersonal and mass communication, the core of research utilization is focused on “solving human problems,” whereas the other terms outlined in this literature review are focused on putting the desires of the public, people with disabilities, healthcare providers and policy makers into practice in order for change to be made on a daily basis in the healthcare system.

Since Backer’s definition, the term has been redefined and become more specific over time. More recent definitions of research utilization have focused on the sole aspect of putting research findings into practice (Titler, Mentes, Rakel, Abbott, & Baumler, 1999; Brown, 1999; Estabrooks, 1998). Definitions of research utilization do not specify the professions or field of practice, but simply state the importance of putting knowledge learned from research into practice. Research utilization is often used as a noun to describe the knowledge-to-action process and is sometimes used as a verb to describe putting knowledge into action (Graham et al., 2006).

A final term, implementation research is used in the United Kingdom and Europe (Graham et al., 2006). Implementation research is defined as “the scientific study of methods to promote the systematic uptake of clinic research findings and other evidence-based practices into routine practice and, hence, to improve the quality and effectiveness of health care” (Foy, Eccles, & Grimshaw, 2001, p. 353).

The words dissemination and diffusion both relate to putting knowledge into action. However, they refer only to the transmission of knowledge to “increase stakeholders’ awareness” (Graham et al., 2006, p. 17) and thereby lack attention to uptake and implementation of knowledge as well as the two-way exchange or mobilization identified in earlier terms.

Before departing from this ongoing discourse surrounding terminology of the knowledge exchange process, the terms translational research and continuing education must be clarified because they are often misinterpreted as knowledge translation.

Translational research refers to “the transfer of science discoveries into clinical applications,” while continuing education focuses on “enhancing health care professionals’ clinical competence” (Graham et al., 2006, p. 18). Both of these terms suggest the sharing of information, however the implementation and two-way interaction is missing, rendering them incomplete of knowledge-to-action. Continuing education however is an essential component of knowledge translation; health care professionals must learn about action-implementation theories and frameworks to be able to effect and influence change in their health care fields (Graham et al., 2006).

Putting knowledge into practice/action.

Through an analysis of the many definitions and interpretations of what it means to *put knowledge into practice*, three predominant themes emerge. The first theme prominent in many of the above definitions is that knowledge translation, or whatever it may be termed, is a complex process that involves interactions between knowledge creators and knowledge users. Knowledge translation is used to enable knowledge users to identify what needs to be researched and researchers to share and facilitate the use of

their information. The second theme is that knowledge translation is used to identify and close the gap between what information is known, and how that knowledge is used (Graham, 2010). The third consistent theme is the importance of turning information into action through a collaborative process of knowledge creation and application of the known information.

In order to successfully implement knowledge translation, these three themes must be present. In order to achieve this goal of *integrated knowledge translation*, Ian Graham of CIHR (2010) identified three key principles that need to be followed. The first is that researchers need to do the right research (Graham, 2010). To that end, reviews of the research determine what information is already known, while collaboration with knowledge users identifies what they would like to know more about. The research is solution-based, targeted to fill the existing gaps.

The second principle is that knowledge translation needs to involve the right people from the beginning (Graham, 2010). Including knowledge users in the process from the outset will ensure relevance and facilitate greater adoption of the results. Identifying the right knowledge users requires an analysis of who the intended audience is and what the research is investigating. Different people have different needs and therefore the *right* knowledge users vary depending on who the stakeholders are. As a result there is no one-size-fits all approach to knowledge translation. Healthcare providers, policy-makers and the public (the consumer) are all interested in different aspects; therefore the stakeholder-specific goal of knowledge translation is to get “the right knowledge to the right people and the right time” (Sampson, 2002, p. 14).

The final principle for achieving integrated knowledge translation is for researchers to adapt their knowledge translation strategy in order to meet the context being studied. This requires flexibility and the understanding that one size does not fit all. In addition, knowledge producers have a responsibility to ensure the knowledge users have a firm understanding of the information to allow them to accurately apply it to a specific context.

The principles identified by Ian Graham (2010), according to a recent study, Bowen & Graham (2013) suggest,

We need to reconsider the assumptions on which the knowledge transfer paradigm are based: (1) research questions are typically driven solely by researcher curiosity; (2) there is knowledge that is ready to use; (3) scientific knowledge (research) is sufficient to inform decisions; (4) the movement of knowledge is unidirectional (ie, from the researcher to the user); and (5) the major challenges relate to appropriate communication and user readiness or capacity to take up the new knowledge (p. S4).

According to recent literature, one of the factors that contribute to the gap in knowledge-to-action is a problem of knowledge production (Bowen & Graham, 2013). In other words, research findings are unused and not shared because the imperative problems and challenges clinicians, managers, and decision-makers are facing are not being addressed in the research; it is not because of a failure in dissemination, as previously believed (Bowen & Graham, 2013). Given this finding, Engaged Scholarship is a critical component to successful knowledge translation (Bowen & Graham, 2013).

Engaged Scholarship is defined as “a collaborative form of inquiry in which academics and practitioners leverage their different perspectives and competencies to co-produce knowledge about a complex problem or phenomenon that exists under conditions of uncertainty found in the world” (Van de Ven & Johnson, 2006, p. 803). In alignment with the definition by Van de Ven & Johnson (2006), Bowen & Graham (2013) explain, “Engaged Scholarship is based on the belief that higher-quality, more relevant research results from true collaboration and from integrating the diverse perspectives of multiple stakeholders” (p. S5).

According to supporters of Engaged Scholarship, dissemination is too late if the questions that have been asked are not of interest to users (Bowen & Graham, 2013; Van de Ven & Johnson, 2006; Shapiro, Kirkman, Courtney, 2007). In addition, Bowen & Graham (2013) indicate, “while the principles of engagement are commonly accepted and practiced by researchers in some fields and for some problems (e.g., community-based participatory research), the potential of engagement in health services research is only now being explored” (Bowen & Graham, 2013, S5). Engaged Scholarship highlights “the importance of collaboration and meaningful interaction as a critical factor in predicting research use” (Bowen & Graham, 2013, S5).

The principles identified by Ian Graham (2010), along with the key indicators from the theoretical perspectives helped shape the initial list of Elements of Inclusive Knowledge Translation. Using the theory of collaboration and coproduction of knowledge of different perspectives from the definition of Engaged Scholarship, the three communities of interest -- people with disabilities, healthcare providers and policy-

makers -- contributed to the final list of Elements of Inclusive Knowledge Translation.

The list is included later in this chapter.

Models, theories and frameworks to put research into action.

While there are multiple terms and definitions related to putting knowledge into practice, each definition leads to the same argument. All of the terms described above (and in Appendix A) indicate that research needs to move beyond words on paper, into practice and policies. Each definition and theory has a different approach to accomplishing the goal of identifying different knowledge users. However, the bottom line remains the same, that is, to share and exchange research knowledge and put it into everyday practice.

Three main categories of knowledge translation models are used to interpret and exchange knowledge. First, there are models in which knowledge creation and action are fluid (Graham, 2006; Lavis, Robertson, Woodside, McLeod, Abelson, & Knowledge Transfer Research Group, 2003). The second type of knowledge translation framework includes models that involve a specific process knowledge users go through to create and implement change (Rogers, 2003; Lomas, 1993). The final model commonly used involves many concrete steps that individuals go through as they work through a strategy to put research into practice (Green & Kreuter, 1999; Kotler, 1983; Berwick, 2003; Kitson, Harvey, & McCormack, 1998; Graham & Logan, 2004). This section further examines these most commonly used models. While additional models are present, they are less prominent in the literature and outlining them all is beyond the scope of this thesis.

Knowledge creation and action are fluid.

In models where the knowledge creation and action or implementation stages are fluid, all phases in the process influence each other. Graham et al. (2006) explain that when the entire process occurs and knowledge producers (researchers) work collaboratively with knowledge implementers (users), this model demonstrates the CHSRF definition of knowledge exchange.

One concrete model of this approach is called knowledge-to-action (KTA). KTA is a dynamic and multifaceted process where the two phases, knowledge creation and knowledge action, overlap. It is based on relationships and an exchange of knowledge between relevant stakeholders that results in action. The theory behind KTA is that knowledge is created much like a funnel and the action phase is a cycle surrounding the funnel signifying all of the activities and methods of knowledge use or application.

The first step in this process is to identify the relevant stakeholders and to establish a common understanding of KTA (Graham et al., 2006). The knowledge funnel begins with “knowledge inquiry”. As knowledge moves through the funnel, it becomes more specific with the aim of being more useful to stakeholders (Graham et al., 2006). The second stage, “knowledge synthesis,” uses systematic reviews to make the information more reproducible and precise in order to guide a specific research question (Graham et al., 2006, p. 19). In the third stage, tools and products such as guidelines, decision aids and rules, and care pathways are created to present knowledge in plain-language and to ideally influence stakeholders’ decisions (Graham et al., 2006). These three stages are part of the knowledge creation phase.

At any point in the knowledge creation phase, ‘knowledge producers’ can shape their efforts to address the needs of their stakeholders and potential ‘knowledge users’ (Graham et al., 2006). In addition, ‘knowledge producers’ can modify the message they disseminate once the results are available to suit a given audience (Graham et al., 2006). Lavis, Robertson et al. (2003) and the Canadian Health Services Research Foundation (2004) indicate knowledge producers can facilitate the uptake of research by addressing five questions: What should be disseminated? To whom should it be disseminated? By whom should it be disseminated? How should it be disseminated? And with what effect should it be disseminated? (Lavis Robertson et al., 2003, p. 244; Canadian Health Services Research Foundation, 2004, p. 1)

The action phase involves implementing or applying the attained knowledge. This is done through the use of activities that are dynamic, can influence each other, and can be influenced by the knowledge creation phases (Graham et al., 2006).

Creating and implementing change.

A second set of models attempt to understand and explain how change occurs within individuals, organizations and environments and the ways in which knowledge translation can be used to initiate or support such change.

One of the most common theories, Rogers’ Diffusion of Innovations Theory, has been used to explain how research is implemented in clinical practice and health organizations (Rogers, 2003; Dobbins, 2002). Lomas (1993, 1994) created another model, titled Coordinated Implementation Model that pertains explicitly to the medical context. Rogers (2003) proposed that potential knowledge users go through five stages as they decide if they will adopt the innovation: knowledge, persuasion, decision,

implementation, and confirmation. Rogers (2003) observed that innovations are more readily adopted if they align with current values, beliefs and practices, are seen to be more beneficial than current practice, are easy to implement, appear to be used by others and can be tested before adopted in a simple manner. Both Lomas' Model and Rogers' Model are primarily descriptive and identify a process that individuals go through to create and implement change particularly in health-related environments.

Others have focused on change that happens in policy environments and how knowledge transfer can be used to support that change. Hanney and colleagues (2003) reviewed how policy makers used health research and found that research should contribute to the policy process in at least three stages: agenda setting, policy formulation and implementation. They emphasized the importance of interactions between the research producers and the users during various stages of the process (Hanney, Gonzalez-Block, Buxton, & Kogan, 2003).

Concrete steps to put research into practice.

A third group of models attempt to document the steps or actions necessary to put research into practice and implicitly argue that replicating these steps will ensure a successful outcome of moving research into action. Each of these models suggest different steps, but all are focused on achieving one step before moving onto the next in order to allow research to be put into action successfully.

The Precede-Proceed model describes specific steps that should precede a strategy for putting research into practice and recommends ways to proceed (Graham & Logan, 2004). The preceding stages, identified by the implementer, are characterized by factors

such as predisposing, enabling, or reinforcing, whereas the proceeding stages are defined by implementation and evaluation of the strategy (Graham & Logan, 2004).

A sequential model is The Social Marketing Planning Model (Kotler, 1983). This model consists of many stages: planning and strategy; selecting the relevant channels and materials for intervention; developing and piloting materials with the target audience; and implementation, evaluation, and feedback. The Social Marketing Planning Model is used to effectively implement research knowledge into action in health related behavior at the community level and for quality-improvement strategies (Graham & Logan, 2004).

Berwick (2003) developed seven rules regarding how an implementer should successfully transfer research into practice. Likewise, Kitson et al. (1998) established a Research into Practice Framework to ensure three elements were addressed prior to moving research into action.

The Ottawa Model of Research Use is used to plan knowledge transfer initiatives and to evaluate or facilitate organizational changes in research innovations (Graham & Logan, 2004). A significant benefit of this model is that it can be applied at any level in the delivery of care (individual, team, organization, system) (Graham & Logan, 2004). The Ottawa Model of Research Use provides direction to what issues should be addressed and the mechanism that they should undergo to create change based on the model of assessing, monitoring, and evaluating (AME) each aspect before, during and after a decision is made (Graham & Logan, 2004). The AME process before, during and after each decision allows barriers to be tailored and implementation to be enhanced (Graham & Logan, 2004).

Ebener, Khan, Shademani, Compernelle, Beltran, Lansang, & Lippmana, (2006) explored how integrating a knowledge map into a conceptual framework may help explain the complex process and identify gaps in the knowledge translation process. Ebener and colleagues (2006) believe that knowledge mapping will allow individuals to increase their awareness of the complexities of the knowledge translation process and in turn enable them to be more informed actors within the health care system. This proposition by Ebener et al. (2006), similarly to the framework proposed by Lavis, Robertson et al. (2003), recommends five pieces for consideration when organizing Knowledge Transfer and Exchange: message, target audience, messenger, knowledge transfer process and support system, and evaluation strategy.

From the studies outlined above, it appears that following concrete steps can lead to successful implementation of research knowledge into practice. It is critical to identify the knowledge users and work in collaboration with them to ensure the knowledge translation and exchange method is appropriate for the population at hand because different methods work for different users and audiences.

The Ottawa Model of Research Use is the most convincing and useful method. While the Precede-Proceed and Social Marketing Planning Models also outline various stages, the assessing, monitoring and evaluating aspect of the Ottawa Model of Research Use provides an effective strategy to ensure each step of the process is analyzed correctly and evaluated to ensure it is heading towards implementation. A knowledge map is a critical tool that visually depicts the various steps of the knowledge translation process. A knowledge map enables individuals to see the dynamics of a health care system and allows people to see where resources are located and where they need to go (Ebener et al.,

2006). A knowledge map can be an effective tool for visual learners; however, having a knowledge map alone might not be clear. That being said, supplementing the Ottawa Model of Research Use with a knowledge map would be an effective method, enabling individuals with different learning styles to best understand the process.

Evaluating knowledge translation.

From literature, it is clear that the goal of knowledge translation is the use or application of research knowledge (Sudsawad, 2007). In addition to moving research into practice and policies, many researchers, policy-makers and organizations recognize the need to evaluate the extent to which these models are implemented and their effectiveness in putting knowledge into clinical and policy action (Tugwell et al., 2006; Mitton et al., 2007; Eager, Cromwell, Owen, Senior, Gordon, & Green, 2003; Lavis, Roberston et al., 2003; Curran, Grimshaw, Hayden, & Campbell, 2011). But, as Mitton et al. (2007) document in their review, only 20% of the studies they examined reported a “real-world” application of a Knowledge Transfer and Exchange strategy and even less had been evaluated. This, they argue, leads to an inadequate basis from which to do evidence-based knowledge translation for health policy decision-making.

The literature illustrates several measures that can be used to evaluate knowledge translation including impact, learning by knowledge users or evidence of change.

Researchers, organizations and funders alike recognize the importance of measuring the impact of health research on policies and clinical practices (Mitton et al., 2007). Lomas and NCDDR argue that a successful and effective model or framework for knowledge translation results in the production of knowledge with a practical influence on the healthcare system and results in a “positive impact on the health and well-being of

the intended beneficiaries” (Lomas, 1997; National Center for the Dissemination of Disability Research, 2005). Evaluation of the impact of knowledge translation strategies is subject to the purpose of the evaluation and the resources available to conduct the evaluation (Tugwell et al., 2006).

Further, Lavis et al. wanted to identify the impact of the knowledge on policies if resources were available, as opposed to simply disseminating the research evidence to policy makers (Lavis, Ross et al., 2003). To that end, Lavis et al. created an assessment tool for funders and research organizations to measure the practical impact of the research (Lavis, Ross et al., 2003). The assessment tool consisted of four stages: (1) identify target audiences for research knowledge, (2) select appropriate categories of measures, (3) select measures given resources and constraints, and (4) identify the data sources and/or collect new data, analyzing whether and, if so, how research knowledge was used in decision making (Lavis, Ross et al., 2003b). Mitton and colleagues (2007) note that the fourth stage regarding the *how* knowledge is used, goes beyond *if* it is used.

Knowledge translation has been evaluated by asking knowledge users what has been learned, changed or accomplished using a range of quantitative and qualitative tools (Tugwell et al., 2006; MacDonald, Archibald, Stodel, Chambers, & Hall, 2008; Jacobson, Butterill, & Goering, 2003; Curran et al., 2011). Knowledge users are most commonly perceived as academics, policy and decision-makers, and clinicians, but rarely include groups directly affected by the gained knowledge, such as people with disabilities.

Mitton et al. (2007) reviewed six studies in regards to the relationship between knowledge translation stakeholders and the effectiveness of knowledge translation strategies. An important finding is that different stakeholders from different backgrounds

expressed similar perspectives. Almost all of the stakeholders' observations were regarding the benefits of the decision maker's involvement in the research process, enhancement of the relationship between researcher and policymaker, and interactive sharing of knowledge (Ross et al., 2003; Goering et al., 2003; Trostle, Bronfman, & Langer, 1999; Sibbald & Kossuth, 1998).

MacDonald et al. (2008) asked health care professionals what they learned through knowledge translation using Lavis, Ross et al.'s (2003) framework discussed above. The participants reported that they learned new information and skills; they transferred knowledge to the workplace and reported that the information they learned had a positive impact on the residents they cared for (MacDonald et al., 2008). These results suggest that changes had been made as a result of knowledge translation and support using Lavis, Ross et al.'s (2003) knowledge transfer framework to assist in evaluation.

In an effort to identify the evidence of change, Landry, Amara, & Lamari, (2001) evaluated the extent to which Canadian university faculty members were sharing and exchanging research knowledge. The faculty members indicated research was used in a six-stage cumulative process: transmission, cognition, reference, adoption, influence and application (Landry et al., 2001). In this study, almost fifty percent of the respondents indicated that they had transmitted findings to practitioners, professionals and decision-makers, however researchers had rarely gone past the first stage of transmission (Landry et al., 2001). Landry et al. (2001) note that the most important elements in determining research utilization were mechanisms linking researchers and research users and the users' context.

Despite these measures to evaluate knowledge translation strategies, the literature is limited in defining user groups outside of researchers, clinicians or policy makers. In the literature reviewed here, only one of the studies included the general public and none of them included people with disabilities as knowledge users nor did it include them in evaluations of the knowledge translation strategies (Lavis, Ross et al., 2003). Knowledge translation with people with disabilities and the ways in which people with disabilities are treated in the research process are explored in the upcoming pages of this literature review.

Evaluating knowledge translation: Barriers and facilitators.

The literature clearly outlines barriers and facilitators to conducting knowledge translation (Mitton et al., 2007; Innvaer, Vist, Trommold, & Oxman, 2002; Granados, Jonsson, Banta, Bero, Bonair, Cochet, & Espinas, 1997; Grimshaw, Shirran, Thomas, Mowatt, Fraser, Bero, & O'Brien, 2001; Bowen, Martens, & The Manitoba Need to Know Team, 2005). In terms of health policy and decision-making, Mitton et al. (2007) concluded that barriers and facilitators can be classified on individual and organizational levels and involve relationships between researchers and decision-makers, communication styles, time and timing, and context. Personal contact between researchers and policymakers (face-to-face) and educational outreach visits or interactive meetings are reported to be more effective than printed reports and reviews (Jacobson et al., 2003; Lomas, 2000; Grimshaw et al., 2001; Granados et al., 1997; Grimshaw et al., 2004). This face-to-face contact helps to build trust. Furthermore it enables key individuals (such as decision-makers or opinion leaders) to be included in the planning and design stages of the research project; a significant facilitator of knowledge translation

(Bowen et al., 2005; DeRoeck, 2004; Lomas, 2000; Ross et al., 2003; Vingilis, Hartford, Schrecker, Mitchell, Lent, & Bishop, 2003; Whitehead, Petticrew, Graham, Macintyre, Bamba, & Egan, 2004). If personal contact cannot be achieved due to demographics or time, it is recommended that clear summaries be attached to policy recommendations and timely relevance is considered when selecting research topics (Innvaer et al., 2002). Wilson and Macleod (1999) indicate that researchers should produce shorter-term goals to meet the needs of policymakers.

The barriers of knowledge translation outlined in the literature include: lack of personal contact, lack of timeliness or relevance of research, mistrust, and power and budget struggles (Innvaer et al., 2002). Additionally, assumptions made by researchers, research users, funding bodies and other individuals who are carrying-out and contributing to the knowledge sharing process can be a significant barrier to the knowledge translation process.

While researchers and decision-makers believe knowledge translation is a beneficial process both groups feel they might not be able to commit to the demands required for the scope of successful knowledge translation (Mitton et al., 2007). The Canadian Health Services Research Foundation (1999) indicates that for researchers “challenges such as adapting the research cycle to fit real-world timelines, establishing relationships with decision-makers and justifying activities that fit poorly with traditional academic performance expectations” (p. 2).

The literature indicates that decision-makers identify that research is not always relevant to practice-based issues and the lack of timely results creates barriers to using evidence-based findings (Canadian Health Services Research Foundation, 1999).

Finally, both researchers and decision-makers feel they lack time and resources to engage and participate in knowledge translation (Canadian Health Services Research Foundation, 1999).

The Canadian Health Services Research Foundation has suggested some mechanisms to facilitate successful knowledge translation for policy/decision-making populations. These initiatives include researcher/decision-maker workshops, interdisciplinary teams involving decision-makers from the beginning of the research process, a collaborative effort to produce research questions, and using “knowledge brokers” - intermediaries whom understand both roles (Canadian Health Services Research Foundation, 1999). In addition, it is essential for researchers and decision-makers to establish a working relationship to foster successful knowledge translation initiatives (Thompson et al., 2006).

Funding bodies can play a significant role in increasing the evaluation of knowledge translation strategies (Mitton et al., 2007). Research suggests that funding bodies can provide monetary incentives for individuals to work in a placement for a research organization in order to evaluate knowledge translation projects that have occurred (Mitton et al., 2007). In addition, funding agencies, such as CIHR, SSHRC and CHSRF can and do fund projects that are solely about knowledge translation and exchange, rather than the knowledge translation piece being a sub-section of a larger project (Mitton et al., 2007). Bowen & Graham (2013) explain,

Research sponsors also need to change their approach to funding. While many funders are directing resources to issue- driven research questions and participatory research designs, this is still a small proportion of total research

funds, and not all review committee members have the personal experience or knowledge of engaged research methods that would equip them to review these sorts of project proposals (S6).

Bowen & Graham (2013) acknowledge that although there is ongoing evidence that knowledge translation on its own is rarely effective, “we have yet to change the way we fund, conduct research, or peer review it” (S7). As well, as academic researchers, “we have not allocated the resources needed to deal with the complexities involved in the implementation of actually moving knowledge into action” (Bowen & Graham, 2013, S7).

A silence in the literature rests around the inclusion of the individuals who partake in knowledge translation. The English language literature assumes that all individuals can read and write English or French print, failing to recognize the researchers or research users who use American Sign Language, Braille, or another text in a different language. There is the assumption that readers have a certain level of reading comprehension; it does not account for individuals who have low levels of literacy and may require information to be in plain language or through audio in order to understand it. Having materials available in a variety of formats such as print, electronic and audio will allow all individuals to use the format that they learn from best (Stienstra, 2012).

As well, there is a gap regarding the universal design of knowledge and information and the methods and implementation of knowledge translation. It is assumed in the research that all individuals are able-bodied and much like one-another. As Stienstra (2012) explains, “Canadians with disabilities face barriers to access in many parts of society as a result of environments - physical, natural and technological - that

have been built to accommodate able-bodied people” (p. 79). Stienstra (2012) continues to describe the resistance among our society to accommodate or create universally designed initiatives that would create a sense of inclusion for people with disabilities. This persistent gap is a significant space that remains empty and needs to be filled by future research and education. The Center for Universal Design at North Carolina State University developed the principles of universal design in 1997. The Principles of Universal Design require environments that are: equitable, flexible, intuitive, perceptible, safe, easy and accommodating; and are commonly used by: architects, engineers, urban planners and other professionals (The Principles of Universal Design, 1997).

There is by no means a one-size-fits all solution to any barrier, however removing environmental and systemic barriers creates space where more people feel included and fewer feel left out of the process. The use of these principles in the designing of buildings and physical environments has created spaces that are accessible for a greater number of people (Stienstra, 2012). In addition, Stienstra (2012) explains that the principles of universal design have been modified and used in the development of information and communications technologies, as well as, in education. Universal design in education is not about discussing the concepts of inclusivity and accessibility, but rather conducting education differently so that more people can benefit from education rather than facing barriers (Stienstra, 2012). To that end, learning materials and methods are created in a way that is accessible to all students regardless of their abilities (Stienstra, 2012). This in turn produces graduates that are educated in their desired field and work daily with an inclusive frame-of-mind. As Stienstra explains, “The use of these inclusive principles means that people with differing ways of using environments, learning and information

technologies are included rather than segregated through “special” measures” (p. 83).

This suggests there is a gap regarding the knowledge translation process and the existing barriers around universal design.

Evaluating knowledge translation: Implementation.

There are many frameworks that can be used to implement knowledge translation in different settings that range from sustained relationships, agreement on strategies, and inter-professional collaboration. Mitton et al. (2007) reviewed eighteen studies where a specific strategy was chosen and implemented to effectively disseminate and utilize research findings. Citizenship and Immigration Canada (CIC) and Social Sciences and Humanities Research Council (SSHRC) (2009) evaluated the success of transferring research knowledge to government policy-makers. The studies outlined above highlight the trend in the literature regarding successful implementation of research-based knowledge.

In order to achieve successful knowledge translation, sustained relationships are essential (Mitton et al., 2007; Canadian Institutes of Health Research, 2006). Sustained relationships mean long-term relationships that involve two-way communication and face-to-face interaction (Canadian Institutes of Health Research, 2006). Research users identified clear communication of research users’ needs as a definite priority (Citizenship and Immigration Canada & Social Sciences and Humanities Research Council, 2009). The need for strong trusting relationships is not a new phenomenon. In 1979, Caplan indicated, “[t]he need for reciprocal relations between knowledge producers and knowledge users in policy-making positions is clear” (p. 461).

Once firm networks are established, change cannot be made unless there is a collective agreement between all stakeholders regarding the need for change (Tetroe, 2007). This includes: the evidence being used for change, the evaluation of the impact of change and who is responsible for what parts of the change process (Tetroe, 2007). The findings indicate that collaboration between researchers and research users is important for effective knowledge translation.

Agreement from all players involved in the implementation process will allow for successful collaboration between the different professions. Establishing “executive-level buy-in” is considered a critical aspect when disseminating and mobilizing knowledge (Canadian Institutes of Health Research, 2006). In addition, policy-makers indicated that individuals who accessed research found it useful, however there was little time and support to access information (Citizenship and Immigration Canada & Social Sciences and Humanities Research Council, 2009).

The strategies listed above are helpful once the stage of implementing knowledge translation has been reached. Targeted messaging has been more effective than websites and knowledge brokering in promoting research-based evidence decision-making (Dobbins et al., 2007). However, the effectiveness of a strategy used by decision-makers varies depending on the decision-makers’ attitude toward research, increased contact with researchers, exposure to research-oriented events, and research experience (Birdsell, Thornley, Landry, Estabrooks, & Mayan, 2006).

Few studies formally evaluated their knowledge translation strategies and thus it is difficult to indicate which implementation strategies are the most effective. Out of eighteen studies investigated, only five of them formally evaluated their knowledge

translation strategies and only three studies identified outcome measures (Mitton et al., 2007). The majority of the studies highlighted the transfer and exchange of information rather than evaluate the success of the knowledge translation strategy (Mitton et al., 2007).

The evaluation of knowledge translation strategies is an essential element, but remains missing from most of the literature. Evaluation that involves knowledge users throughout the process is also critical but not well documented in the literature (Mitton et al., 2007). The impact of knowledge translation strategies is an important part of evaluation, and needs to include not only the process of engagement, but also the results. For example, research by the Citizenship and Immigration Canada & Social Sciences and Humanities Research Council (2009) has informed government policy-making, however there is little evidence suggesting that it has influenced policy-making. This evaluation was helpful in regards to what works when engaging with policy-makers. However, it does not appear that the findings of “what works” are implemented into everyday practice.

A recent study by Bowen & Graham (2013) explains a new theory of why there has not been substantial progress in addressing gaps within healthcare. This theory is that researchers continue to conceptualize all situations as simple and linear, when in actuality they are complicated or complex problems (Snowden & Boon, 2007). Bowen & Graham (2013) suggest, “while knowledge transfer activities may be effective in addressing simple, linear problems, they will be inadequate in addressing complex health issues” (p. S6). Complex problems are continually evolving and therefore do not have a clear cause and effect relationships and “cannot be solved by researchers working in discipline-

specific silos, or without the insight and expertise of those working within the system or the patients the system is attempting to help” (Bowen & Graham, 2013, p. S6; Tyrell & Palmer, 2009). This recent study aligns with “Engaged Scholarship” and the need to ensure all individuals whom the changes will impact are present and their voices are heard to collaboratively produce solutions to problems (Van de Ven & Johnson, 2006).

While Bowen & Graham in their most recent publication in 2013 have made insightful advances and explained the significance of researchers working together with the individuals for whom they are trying to find solutions, the strategies outlined above are not necessarily inclusive or accessible to all individuals. Recent publications allude to an increasing shift in terms of the academic community recognizing the need to include others in their work; however, rarely are people with disabilities included at the table.

Knowledge translation and people with disabilities.

One of the questions raised in this literature review is how do knowledge translation strategies address or include people with disabilities? The literature says very little about people with disabilities as researchers or knowledge users, and does not address how to develop and implement knowledge translation strategies effectively within this population. The few studies that address disability all focus on disability as a subject area, rather than including people with disabilities as part of the knowledge translation strategy.

Ouellette-Kuntz, Brown, Baur, Davis, Emerson, Kerr, Van Schroyenstien Lantman-de Valk, (2010) described the process used at the International Association for the Scientific Study of Intellectual Disabilities Health Issues Special Interest Research Group's Roundtable held in 2009 (Ouellette-Kuntz et al., 2010). The goal of the

Roundtable was “to increase awareness of the importance of, and opportunities for, knowledge translation to improve the health of individuals with intellectual disabilities (ID) through international collaboration” (Ouellette-Kuntz et al., 2010, p. 278). While this study seemed promising in its effort to address a method of knowledge translation for persons with disabilities, it was not the case. The focus of this report was ways in which researchers could translate information to health care providers to ameliorate the health of people with intellectual disabilities. This report brought people with disabilities into the process in a very limited way; they were not treated as knowledge users or producers but simply as subjects. This study focused on translating knowledge about people with disabilities but not exchanging knowledge with people with disabilities.

Rogers and Martin (2009) focused on the importance of knowledge dissemination and translation of innovative disability and rehabilitation research to policy makers and clinicians. They focused on the subject of impairment and disability rather than how to best conduct knowledge translation and develop relationships with people with disabilities (Rogers & Martin, 2009).

A study by Gross and Lowe (2009) evaluated a knowledge translation and exchange strategy that was designed to provide physical therapists with best practice information about disability prevention. This study focused on a medical and rehabilitation model geared towards preventing disability. Gross and Lowe (2009) indicated that in terms of disability prevention, interventions involving functional goals, effective communication and negotiation, and early reintegration of injured workers were more successful at facilitating return-to-work. Given that evidence, however, those interventions were not being conducted. Physical therapists continued to focus on

impairment-based goals and interventions. In addition, the results from the study indicate that the knowledge translation initiative did not impact clinical practice and the authors suggest that the culture of the setting in which the intervention is occurring be taken into account next time (Gross & Lowe, 2009). Not only was the setting of the physical therapists not taken into account during this study, people with disabilities were not part of the process.

It is important to note that the evaluation conducted was focused on the techniques of disability prevention not the transfer and exchange of knowledge with people with disabilities. The authors simply conducted an evaluation of a knowledge translation strategy involving *disability*. How to exchange and share knowledge with people with disabilities, decision-makers and researchers was not explored.

There is a common misconception “that if good research is available and well communicated, people will act on it. But most of our efforts to date, which have focused largely on research transfer, have had modest success. This has created a need to reexamine the evidence” (Backus & Jones, 2013, p. S1).

The literature is very limited in its attention to people with disabilities and knowledge translation. What little exists focuses on translating knowledge about disability and impairment as an object of study, rather than on translating knowledge with people with disabilities.

A study conducted in 2013 by Bowen & Graham highlights some factors of “what works” in knowledge translation. While this study does not explicitly discuss knowledge translation strategies with people with disabilities, it outlines a shift that is occurring within knowledge translation. Knowledge translation is shifting from traditional forms of

research that are academically driven, with the interests of academics in single-disciplinary silos to a multidisciplinary and “issue-driven” approach (Bowen & Graham, 2013). Issue-driven research is intended to “generate knowledge in response to societal needs [...] and recognizes and requires engagement with a diversity of stakeholders in the research process” (Bowen & Graham, 2013, p. S5).

It is thought that this shift within the academy regarding a multidisciplinary approach will both, change traditional views of how research topics are chosen and recognize the need to include people with disabilities in the knowledge translation process.

Including people with disabilities in the research process.

In order to include people with disabilities in the research process, it is important to first acknowledge how people with disabilities have been and continue to be treated in research and how research can be transformative by looking at the research subject through a different lens.

Many studies that attempt to improve the lives of people with disabilities often do not include individuals with disabilities in the research process (Rivera Drew & Short, 2010). Individuals with disabilities are not consulted when a research tool, such as a questionnaire, is constructed. They are simply left out of the process; they are not asked what they would like to change, what they would do differently or how they envision these changes being made.

People with disabilities have largely been left out of the process. They have not been asked about their experiences or expertise, portraying people with disabilities, their lives, knowledge and experiences as irrelevant to the research.

As Oliver (1992) outlines for disability researchers,

As disabled people have increasingly analyzed their segregation, inequality and poverty in terms of discrimination and oppression, research has been seen as part of the problem rather than part of the solution. Disabled people have come to see research as a violation of their experiences, as irrelevant to their needs and as failing to improve their material circumstances and quality of life (p. 106).

The research agenda is most often set by the researchers or funding bodies, which leaves research ‘subjects’ out of the equation, disregarding what they deem as relevant and in need of change. Within the research field, disability is commonly defined in a medical manner, as an internal condition of the individual who needs to be ‘fixed’ (Stone & Priestley, 1996). A disabled body is often defined by “the impaired body, tragedy and otherness” (Stone & Priestley, 1996, p. 670). To this end, traditional research pertaining to people with disabilities has led to their oppression and marginalization.

The research conducted on people with disabilities has created a great deal of concern for them and their organizations. Many disabled people feel that the primarily medically oriented research has had little or no direct impact on their lives (Abberley, 1992; Rioux & Bach, 1994). Some of the literature suggests that disability research needs to shift from doing research on people to doing research with people (French & Swain, 2004).

Mactavish, Lutfiyya & Mahon (2000) acknowledge the lack of research that includes the perspectives of individuals with intellectual disabilities, which reflects the broader gap around people with disabilities in general, and created a study that aimed “to enhance our understanding of social integration by examining the viewpoints of

individuals with intellectual disabilities” (p. 216). The study by Mactavish, Lutfiyya & Mahon (2000) is an illustration of how to conduct research in ways that enable people with disabilities to participate. During the course of their two-year qualitative study, the researchers, Mactavish, Lutfiyya & Mahon, outlined a specific strategy involving multiple sources of data collection and verification methods to ensure the findings reflected the feelings of the participants.

Mactavish, Lutfiyya & Mahon (2000) primarily used qualitative interviewing and focus groups to conduct their research. Each type of qualitative interview had a specific rationale and worked to “collect background information, build rapport, and explain the research and procedures” (p. 219). The intention of the focus groups was to “explore multiple perspectives on social integration” and the data collection concluded with two verification meetings “to verify accuracy of the researchers’ interpretations of the focus group data” (p. 219).

Mactavish, Lutfiyya & Mahon (2000) illustrated how using these multiple methods of data collection along with establishing a rapport with participants was effective in “facilitating the meaningful participation of these individuals [with intellectual disabilities]” (p. 226). This study used an array of different strategies that worked to include people with disabilities in each stage of the methodology.

As Mactavish, Lutfiyya & Mahon (2000) demonstrated, when specific strategies are utilized, people with disabilities can be included and listened to throughout the research process.

Conclusion.

In the literature to date, knowledge translation has been identified as a vehicle to close the gap between what we know and what we want to know. Knowledge translation is defined as a complex process of interactions between knowledge creators and knowledge users turning knowledge into action. The literature indicates that researchers need to ensure they are doing the right research and that knowledge translation needs to involve the right people from the onset of the research project (Graham, 2010; Bowen & Graham, 2013). Some of the reasons the literature to date suggests a lack of knowledge being put into action are: the lack of clarity in regards to the terms and concepts; the invisibility of people with disabilities and; researchers relying on simple knowledge transfer strategies that neither acknowledge nor reflect the complexity involved in changing clinical or management practice (Bowen & Graham, 2013).

In addition, there are significant gaps in the literature on knowledge translation when evaluating successful knowledge translation models, facilitators and implementation. As Bowen & Graham (2013) indicate “we must collectively find ways to provide incentives to both researchers and knowledge users to work together in identifying pressing research questions and conducting solutions-focused research to address these questions in a timely manner” (p. S7).

The literature review illustrates a number of substantive gaps related to the involvement of people with disabilities in research and knowledge translation:

- In general, people with disabilities are invisible in the research process and are not identified as contributing to the creation of knowledge or as users of knowledge;

- Knowledge translation research on disability portrays people with disabilities as objects of study;
- Knowledge translation has not been conducted with people with disabilities identified as active participants in the research and knowledge exchange process;
- Knowledge translation approaches assume that all people are non-disabled and as a result do not identify or address barriers to accessing knowledge, information and research that some people may face.

The Elements of Inclusive Knowledge Translation were created to address these gaps and reduce them in future research focused on knowledge translation and people with disabilities. Furthermore, the Elements of Inclusive Knowledge Translation were then used to evaluate VP-Net's knowledge translation strategy. These elements are drawn from the two theoretical perspectives (emancipatory research and the social model of disability), the critical components of knowledge translation identified in the literature, and feedback and suggestions from the three communities of interest interviewed for this project. They are:

1. Uncovering missing or invisible individuals in research
2. Engaging participants and researchers
3. Enabling flexibility
4. Providing accountability to communities involved
5. Involving communities from the beginning
6. Ensuring the right research is being done
7. Ensuring plain and clear language

8. Matching deliverables/ tools/ resources with communities' needs

The concept of Inclusive Knowledge Translation builds on the on-going development of the knowledge translation literature and is a new and innovative way to translate, share, exchange and disseminate research knowledge. There is no one-size-fits all approach to Inclusive Knowledge Translation. As the social model of disability explains, the model needs to adapt to meet the context. This includes continuous recognition and evaluation of barriers and creating space and involvement in the entire research process for all people, including those with disabilities.

The combination of knowledge translation with emancipatory research and the social model of disability, brings together areas of research that have never before come together. This synthesis creates a concept: Inclusive Knowledge Translation. Inclusive Knowledge Translation is lacking in both the literature on knowledge translation and the literature in relation to people with disabilities. The focus of the following study will be to use the indicators of Inclusive Knowledge Translation to evaluate the knowledge translation strategies of one research project, VP-Net.

Chapter 3

Methods

In this study, I used a qualitative three-phase evaluative case study approach guided by the research question: “Using the indicators of Inclusive Knowledge Translation, to what extent does VP-Net succeed in conducting Inclusive Knowledge Translation?” This project evaluates whether VP-Net was successful at conducting Inclusive Knowledge Translation events based on the list of Elements of Inclusive Knowledge Translation. The Elements of Inclusive Knowledge Translation were developed from the theoretical perspectives, current literature and the perspectives of the three communities of interest. In the methodological framework I outline the steps I undertook to critically analyze and reflect upon whether Inclusive Knowledge Translation was reached by the VP-Net.

The Vulnerable Persons and End of Life New Emerging Team (VP-Net) was a five-year research project that brought together a team of investigators to explore the availability and accessibility of end-of-life care for people who experience *socially constructed vulnerability*. The project was funded by the Canadian Institute for Health Research (CIHR) and examined four themes: clinical, policy, ethics and social/cultural issues in end of life care. VP-NET particularly targeted policy makers in health/palliative care and disability care providers, and the perspectives of people with disabilities in its final knowledge sharing activities using the theme: *Including: Good Palliative Care for All*.

In Halifax, Toronto, Winnipeg and Calgary from Nov 2011 to January 2012, knowledge translation sessions were held, focusing on rethinking vulnerability, inclusive palliative care, ethical decision making and meanings of words and pictures. At the knowledge translation sessions, disability-related accommodations were provided as requested and VP-Net attempted to address accessibility needs of participants.

The researchers involved with this project invited the participants from the knowledge translation sessions to discuss whether they believed Inclusive Knowledge Translation was reached. The process is outlined below.

Methodological framework.

Using a qualitative case study research approach with multiple sources of data, this study was conducted in three phases: a document analysis, semi-structured interviews and a focus group.

A case study is defined by Yin (1989) as “an empirical inquiry that investigates a contemporary phenomenon within its real-life context, when the boundaries between phenomenon and context are not clearly evident, and in which multiple sources of evidence are used” (p. 23). This method is appropriate for the intended research because Inclusive Knowledge Translation has never been investigated in the past, rendering it entirely contemporary. Bromley (1990) indicates that a case study is a “systematic inquiry into an event or set of related events which aims to describe and explain the phenomenon of interest” (p. 302). This research project does exactly that; it uses and assesses Elements of Inclusive Knowledge Translation in the context of one knowledge translation strategy.

The literature supports that “qualitative research methods are (e.g., case studies) particularly well-suited for translating a presumption of credibility into the collection of

meaningful data from individuals with intellectual disabilities” (Mactavish, Lutfiyya & Mahon, 2000 p. 217). While my study does not focus specifically on people with intellectual disabilities, Mactavish, Lutfiyya & Mahon, (2000) suggest, “when qualitative methods are used accurately they are conducive to building and maintaining rapport between the researcher and informant” (p. 217).

Within qualitative methodology, long-term participant observation is said to be “ideal” in terms of qualitative data-collection strategies and developing a relationship with the participant (Biklen & Moseley, 1988). As a participant in the Winnipeg VP-Net Knowledge Translation Event, I used participant observation by establishing a rapport with the VP-Net co-investigators, introducing myself to various other participants, listening and participating in the dialogue during the event and recording notes of my observations and experiences at the event. At the event in Winnipeg I met the VP-Net co-investigators for the first time.

In addition to participant observation, semi-structured interviews and focus groups are also considered beneficial data-collection strategies and were the methods of chosen for this study (Malik, Ashton-Shaeffer, & Kleiber, 1991; Sigelman, Schoenrock, Budd, Winer, Spanhel, Martin, Hromas, & Bensberg, 1983; Wyngaarden, 1981).

An interview is a conversation between two people, where an interviewer asks the interviewee questions. Interviews, which are designed to “get to know the interviewee better” (DiCicco-Blom & Crabtree, 2006, p. 314) are said to be the most widely used source of data in case study research (Merriam, 1998).

Interviews are categorized in different ways, many of which fit into three types: unstructured, semi-structured and structured (DiCicco-Blom & Crabtree, 2006).

In previous research with individuals with disabilities, *open-ended interviews* were commonly used (Mactavish, Lutfiyya & Mahon, 2000; Malik, Ashton-Shaeffer, & Kleiber, 1991; Sigelman et al., 1983). The interview process of this study incorporates *informal conversational interviews*, which “rely on questions that arise spontaneously from the natural interactions of the interviewer and the interviewee” (Mactavish, Lutfiyya & Mahon, 2000). In addition, an *interview guide approach*, which “involves out-lining, prior to the interviews, a series of issues and related questions to be explored” (Mactavish, Lutfiyya & Mahon, p. 219, 2000) is used to prepare the interviewer and create relaxed interactions between the researcher and the participant.

Semi-structured interviews are an appropriate methodology for this study because they are organized around a set of pre-determined questions relating to the research question and the conversation continues to flow with other questions that emerge from the dialogue during the interview session (DiCicco-Blom & Crabtree, 2006). DiCicco-Blom and Crabtree (2006) state semi-structured interviews are “a personal and intimate encounter in which open, direct, verbal questions are used to elicit detailed narratives and stories” (P. 317). The individual semi-structured interviews are an effective approach because they are intended to “reconstruct perceptions of events and experiences” of the interviewee which is the goal of this project (DiCicco-Blom & Crabtree, 2006, p. 316).

Based on the literature, semi-structured interviews are best suited for this project. However within the semi-structured interview, Malik, Ashton-Schaeffer, and Kleiber (1991) suggest there should be a variety of question formats, with an emphasis on open-ended questions, that can be posed in different ways and at different times during the interview. An interview guide was developed (Appendix E).

Research design.

The study was conducted in three phases to answer the research question and explore if: “Using the indicators of Inclusive Knowledge Translation, to what extent does VP-Net succeed in conducting Inclusive Knowledge Translation?”

VP-Net as a case study.

As previously explained, the VP-Net project was used as a case study. VP-Net worked “collectively to develop a common, interdisciplinary framework for understanding end of life care from the vantage point of those who face barriers to their access to care, services, information and supports” (Vulnerable Persons and End of Life New Emerging Team, n.d.). Over seven years, VP-NET implemented a series of knowledge translation activities, which included people with disabilities, healthy policy makers and end of life service providers in their target community.

The three communities of interest were explicitly selected for this study for multiple reasons. As a researcher I want to change current practices and implement innovative policies within healthcare that reflect the desires and perspectives of people with disabilities. Therefore, it is essential that people with disabilities were brought into the study from the onset. In addition,

If research is to be used, it must answer important questions of concern to knowledge users, and it must be integrated with contextual evidence in order to become actionable in a specific setting. This can only be accomplished if there is genuine participation of knowledge users managers, practitioners, and patients from the beginning of the research process (Bowen & Graham, 2013, p. S7).

Given the evidence in the literature regarding the need for relationships between researchers and research users and the importance of Engaged Scholarship, four participant groups are essential to this study (Biklen & Moseley, 1988; Mactavish, Lutfiyya & Mahon, 2000; Malik, Ashton-Shaeffer, & Kleiber, 1991; Taylor & Bogdan, 1998; Taylor, Bogdan, & Lutfiyya, 1995; Van de Ven & Johnson, 2006): the VP-Net co-investigator team; people with disabilities; healthcare providers and; policy-makers. Each provided a unique perspective about the relationships between researchers and research users.

Three Phases

Three phases of data collection were undertaken to evaluate the knowledge translation strategy of VP-Net and to accurately obtain how the VP-Net co-investigators and the three communities of interest perceive Inclusive Knowledge Translation. The three phases are:

1. Documenting VP-Net knowledge translation activities;
2. Semi-structured interviews with research participants (the three communities of interest);
3. A focus group/ critical reflection with the VP-NET team members.

All three phases of this project occurred in Winnipeg, Manitoba. Given the geographic location of some participants, interviews were conducted via e-mail and telephone in order to provide accessibility to all participants.

Ethics protocol.

The University of Manitoba Joint-Faculty Research Ethics Board approved the ethics protocol for study with human participants (Appendix G). In response to my primary ethics submission, the chair of the Joint-Faculty Research Ethics Board asked that I address several concerns, regarding clarity of my research instruments, participants and recruitment, a signed endorsement from all VP-Net co-investigators, an amendment to my “risks and benefits” section, and a revision to my consent letters. The Ethics Board granted a certificate of approval on October 30, 2012 (Appendix G).

The participants in each stage were given information to ensure they were well-informed of the study’s background, purpose, goals, and all expected outcomes, including those that will benefit them as participants. All participants were required to complete an informed consent (signed or oral agreement) before partaking in the study.

The consent form acknowledged that the participants’ rights were protected; it outlined the purpose and benefits of the research, any risks to the participant, confidentiality, and the right to withdraw from the study at any time. In addition, there was a statement requesting consent for the interview to be audio recorded and indicating that the recordings would be used strictly for transcription and analysis purposes. The participants were aware that I would share the transcripts with my supervisor if necessary. The interview questions and consent forms were written in simple English; they were clear and accessible. All participants completed the consent forms and agreed to have their interview audio recorded.

Risks and benefits.

There was minimal risk to the participants involved in all phases of this study. The topics discussed are not sensitive in nature, nor did they evoke an emotional response. There were processes in place, as Streubert and Carpenter (1999) suggest, to allocate some time at the end of the interview in case the interviewee felt distressed or wanted to discuss their feelings from the interview process. In addition, if the participant needed additional resources, I was able to provide information on how to access counseling services (Appendix E: Supports).

All of the participants were informed of the practical benefits of their contribution to this research project, including a way to identify what components of Inclusive Knowledge Translation may include. Participants did not receive monetary compensation for their participation. I hope to engage in reciprocity for their time, by volunteering my time to work with the VP-Net team after this project is complete to ensure these Elements of Inclusive Knowledge Translation are shared with researchers, community organizations, put on VP-Net's website and sent to the Knowledge Translation Branch at the Canadian Institute of Health Research (CIHR).

Anonymity and confidentiality.

Anonymity and confidentiality for this project required a different strategy for each phase of the research. For each phase the participants had the option to indicate if they wanted to remain anonymous (Appendix D).

In phase one, both individuals indicated they did not wish to be anonymous and are therefore referred to by their given names. In phase two, anonymity and confidentiality were maintained with each individual assigned a numerical identification.

The document indicating the participants' names and their number was saved in a different file from the database. For the purposes of this project, the individuals in phase two are all referred to by female personal pronouns, as they are all women.

In phase three, there could be no anonymity or confidentiality because the names of the co-investigators are public information. All co-investigators were aware of this and agreed to participate accordingly. I shared the transcripts and the final project with them and with my supervisor as necessary.

The transcripts were kept anonymous (for phase 2) and confidential (all phases) and will be destroyed one year after publication of this study.

Participant recruitment.

As previously outlined, the first phase of this study drew from VP-Net documentation and administrative information to develop a narrative account of the knowledge translation work of VP-Net between 2004 and 2012 (Appendix B). The participants the first phase were two members of the VP-Net team: the former VP-Net project manager, Janalee Morris-Wales and VP-Net co-principal investigator, Deborah Stienstra.

In the second phase, the recruitment goal was to have six research participants, two participants from each community of interest that participated in a VP-Net event: people with disabilities, policy makers and healthcare providers. Following the VP-Net events, an email was sent by the VP-Net project manager to all participants asking them to provide feedback and whether their email address could be shared with the other participants. All VP-Net participants agreed to have their email address distributed. I was a participant at the VP-Net event held in Winnipeg and therefore received the list of

participant email addresses. Using the email list, I enlisted the participants for this study using a recruitment email (Appendix C) signed by Dr. Stienstra and Dr. Chochinov and distributed by Dr. Chochinov. From the initial recruitment email I received a moderate amount of interest; a follow-up email was sent from Dr. Chochinov two weeks after the initial contact. The individuals in my study were self-selected from the recruitment e-mail and based on the first responders from each community of interest. The recruitment letter (Appendix C) provided background information on my project, my contact information for further questions or information and provided an endorsement from the VP-Net co-investigators to participate in my study.

The participant goal was surpassed and a total of eight individuals from the three communities of interest were interviewed. Each participant self-identified their community of interest. There were three individuals with disabilities, one individual who self-identified as a person with a disability and a healthcare provider, two healthcare providers, one policy-maker and one woman who self-identified as a healthcare provider and a policy-maker.

Geographic representation of the participants was reached as they reside across Canada in Alberta, Manitoba, Ontario and Nova Scotia. All of the participants in phase two were female.

The third phase of this study involved the VP-Net co-investigators. The members of the team approved this project and encouraged me to undertake it. At the onset of my work, I communicated with each VP-Net co-investigator who agreed to participate in a focus group to provide a critical reflection of the process their team undertook.

For phase three, the focus group, the intention was to have five participants, the VP-Net co-investigators and a disability community liaison. However, the focus group consisted of only three VP-Net co-investigators: Dr. Deborah Stienstra, Dr. Harvey Max Chochinov and Dr. Zana Lutfiyya. I conducted a one-on-one semi-structured interview with a fourth VP-Net co-investigator, Dr. Joseph Kaufert because he was unable to attend the focus group. Regretfully the fifth member, Dr. Jim Derksen, was unable to participate in the data collection stage. During this phase, the VP-Net co-investigators critically reflected on the Elements of Inclusive Knowledge Translation and evaluated how well they believed VP-Net did in developing and delivering the markers of Inclusive Knowledge Translation.

Participants.

There were a total of 14 participants in the three phases of research.

Table 1

Study participants

Phase	Number of Participants	Community of Interest
One	2	<ul style="list-style-type: none"> • VP-Net project manager • VP-Net co-investigator
Two	8	<ul style="list-style-type: none"> • 3 people with disabilities • 1 person with disabilities and healthcare provider • 2 healthcare providers • 1 healthcare provider and policy-maker • 1 policy-maker
Three	4	<ul style="list-style-type: none"> • 4 VP-Net co-investigators

Data collection: Interview process.

Data were collected in three phases. The first phase was a document analysis and interviews, the second phase was semi-structured interviews and the third phase was a focus group combined with a semi-structured interview.

For the purposes of this study, the series of questions focused on the list of indicators of Inclusive Knowledge Translation, and allow the participants to compare their experience at the VP-Net event and the Elements of Inclusive Knowledge Translation (Appendix F).

While each interview was guided by a set of prepared questions aimed at acquiring information pertaining to the research question, I allowed the conversation in both the interviews and the focus group session to develop unaffectedly (Johnson, 2002). Johnson (2002) notes the importance and valuable aspects of digressions, as they are the interests and experiences of the interviewee.

With this in mind, as a researcher I used caution and tried not to control the interview (Whiting, 2008). I worked to establish a relationship with each participant before the formal interview began. It was important for me to show the utmost respect to the participants, their experiences and the stories they shared. As I listened to what the participants felt it means to conduct Inclusive Knowledge Translation through inclusive research, I tried to be inclusive in my practices in terms of the physical, cultural, structural, and environmental accessibility of my interviews, materials and research at large. I worked to ensure the participants felt they were in a safe and open environment.

The data was collected in different modes (in-person interviews, telephone interviews and email interviews). As a researcher I was flexible in the method of data

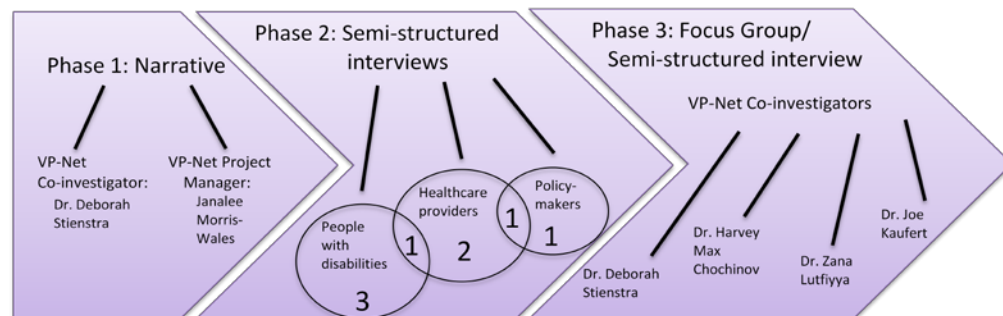
collection. I wanted to conduct interviews that were accessible, not time consuming and easy for participants to complete.

The advantage to having the flexibility of collecting data in a variety of modes allowed individuals residing outside of Winnipeg to participate in my study. In addition, sending questions over email provided accessibility to multiple formats (e.g., read out loud by the computer, printed in Braille). A telephone or email interview is very effective in terms of convenience, and saves transportation time and costs. In addition, an email interview allows the participant to complete their questions at a time that best suits their needs and schedules. A telephone and email interview may also decrease anxiety or fear during an interview.

There are disadvantages to not conducting an interview in person; the researcher is unable to see body language or facial expressions and cannot pick up on environmental cues.

As recommended by Clarke (2006), during the interviews and focus group I kept a journal to reflect on my inner conversations, thoughts and feelings before, during and after each session. As a researcher I did not find my personal knowledge or biases conflicted or collided with the interview data. During or after the interviews and focus group if I had any questions or needed clarification I followed up with the participants via email.

Figure 1

Data Collection Strategy***Record of information.***

All of the interviews and the focus group were audio taped and transcribed verbatim. In addition, as the researcher I created detailed field notes, including documentation of nonverbal behavioral responses such as smiling, nodding heads etc.

The participants were asked if I could take notes during the interview and upon request they were provided an opportunity to see both my field notes and transcripts of the recorded interview.

Each phase was analyzed using thematic analysis to identify the emerging themes from the interview data in order to identify to what extent VP-Net succeeded in conducting Inclusive Knowledge Translation (thematic analysis is outlined in greater detail below).

Phase one.

The narrative interviews conducted over the phone and in person allowed me as the researcher to document the activities VP-Net undertook from its inception. The two participants in phase one identified the key activities and events related to knowledge

translation and described them to me. In addition, I reviewed the VP-Net website, reports, grant applications, and videos as data. I collated and organized all the VP-Net knowledge translation events into a matrix for review and evaluation. Prior to the focus group, I gave the matrix (Appendix B) to each VP-Net co-investigator to confirm the accuracy of the events and so they could re-familiarize themselves with VP-NET's knowledge translation strategy. We used the matrix during the focus group with the VP-Net co-investigators to reflect and draw upon.

Phase two: interview process.

Participants were recruited via email (Appendix C) sent by Dr. Harvey Max Chochinov and signed by Dr. Chochinov and Dr. Stienstra. A second recruitment reminder letter was sent two weeks following the initial recruitment (Appendix C). While there were not sufficient respondents after the initial letter, recruitment of participants for phase two of the study exceeded the initial recruitment goal following the second letter.

For phase two there were a total of eight participants. Many of the participants identified themselves as belonging to more than one community of interest. The participants responded quickly following the second recruitment letter, were eager to participate and provided descriptive interviews.

Participants were given the option of a telephone, in person or email interview. Once the consent form was signed and returned, each participant was given a list of the Elements of Inclusive Knowledge Translation (Appendix F) and the interview questions to be completed and returned by email or fax or to be answered over the phone. Two interviews were conducted on the telephone and the remaining six interviews were conducted by email/fax.

I planned the interviews according to the interview guide approach (Appendix E). I began the interviews with a brief background of my work and a conversation to ensure the participant did not have any questions from the consent form. I explained to each participant the three phases of the study, and described how their perspectives in the interview would help with the evaluation of the VP-Net project and the creation of the Elements of Inclusive Knowledge Translation (Appendix F).

Phase three: focus group process.

The final data collection strategy, stage three of this project was a focus group. Dr. Kaufert was unable to attend the focus group; therefore I conducted an individual semi-structured interview with him. This interview used the same agenda as the focus group agenda to provide consistency throughout this phase (Appendix E).

As described by Krueger (1994), a focus group is “a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, and non-threatening environment” (p. 6). During this phase the participants (the VP-Net co-investigators) reflected on the VP-Net process and compared it to the list of indicators of Inclusive Knowledge Translation. Aligning with the interview guide approach, a focus group agenda was also created (Appendix E).

The focus group agenda helped to facilitate the focus group and listed the open-ended questions that lead the conversation, allowing participants to critically reflect on the VP-Net process and explore whether or not it aligned with the Elements of Inclusive Knowledge Translation.

At the beginning of the focus group, I greeted each participant and offered them coffee, tea, water and snacks. I obtained consent (Appendix D) and started the discussion

by introducing myself, and I provided an overview of the work I had completed to date. In addition, I reminded the participants about the purpose of my project, my research question and what I hoped to get out of the focus group. I distributed the chart outlining all of VP-Net knowledge translation events (Appendix B), the Elements of Inclusive Knowledge Translation (Appendix F), and the focus group agenda (Appendix E), to each participant.

I began the formal part of the focus group by going through the Chart of the VP-Net knowledge translation events (Appendix B). Each participant indicated where there were details to add, change or delete. After addressing the chart, I initiated the conversation with my prepared list of interview questions (Appendix E) and then listened as the participants engaged with each other. The participants were extremely engaged and created an ongoing dialogue with one another. During the focus group I allowed the conversation to evolve naturally, while also ensuring the interview questions were answered.

Data analysis.

Once the data collection was complete, the audio recordings of each interview and focus group were transcribed verbatim. I analyzed the transcripts of the data using thematic analysis to identify the emerging themes (Yin, 1989). Following transcription, I used member checking to ensure I accurately portrayed the perspectives of the participants in the data I collected.

Member checking is “an opportunity for members (participants) to check (approve) particular aspects of the interpretation of the data they provided” (Carlson,

2010, p. 1105). In addition, member checking allows the researcher to ensure her analysis and the participants' experiences align (Curtin & Fossey, 2007).

Member checking was completed for each phase of the study by sending each participant a copy of his or her transcript via e-mail. For the first phase, the transcripts of the document analysis were sent to the former project manager and the co-investigator: Janalee Morris-Wales and Deborah Stienstra. For the second phase, each of the eight participants was sent their own transcript. For the final phase, the three VP-Net team members (Deborah Stienstra, Harvey Max Chochinov and Zana Lutfiyya) who attended the focus group received the focus group transcript to review. Joseph Kaufert received his interview transcript to review. Once the participants read their transcripts and made any necessary changes, I followed-up with them via e-mail regarding any clarifications. All of the participants were able to access the transcripts via email, however, if a participant was not able to read, an accommodation would have been made to have the transcript read out loud to them.

Following member checking, thematic analysis was used to identify emerging themes. Thematic analysis can be defined as "a method for identifying, analyzing and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79).

Thematic analysis was the method used in this research project as it aims to "explore the understanding of an issue or the specification of an idea" (Attride-Stirling, 2001, p. 387). This method uses the themes identified from the transcribed interviews to create themes that "capture something in relation to the research question" (Braun & Clark, 2006, p. 82).

This analysis consisted of two stages of thematic analysis (Braun & Clark, 2006). The entire data analysis was a non-linear, recursive process, moving back and forth through each stage as needed to ensure a clear and complete analysis (Braun & Clark, 2006, p. 93). The first stage of analysis was as described above: finding “patterns of meaning and issues of potential interest” from the transcribed data (Braun & Clark, 2006, p. 92). It was important that as the researcher I simply read the information provided by the participants and refrained from adding my own thoughts or biases.

The second stage of analysis included the themes identified from the interviews in addition to the adapted Elements of Inclusive Knowledge Translation.

Thematic analysis has many advantages that make it the best type of analysis for this project. Thematic analysis is flexible, it is easy to learn and accessible to researchers with varying experience (Braun & Clarke, 2006). The results from thematic analysis are “generally accessible to educated general public” (Braun & Clarke, 2006, p. 114) and it is a method that is used when working with “participants as collaborators” (Braun & Clarke, 2006, p. 114). Utilizing this process achieves this project’s goal to produce results that are accessible to a large amount of the public. In addition, thematic analysis can “highlight similarities and differences across the data set; it can generate unanticipated insights; and it can be useful for producing qualitative analyses suited to informing policy development” (Braun & Clarke, 2006, p. 114). Given the alignment of the aims of the project with the qualities of thematic analysis, it is the desired method of analysis for this project.

The disadvantages of thematic analysis depends more on the researcher and the research question than the methodology itself (Braun & Clark, 2006). In addition, Braun

& Clark (2006) note that thematic analysis rests solely on descriptive analysis if it is not used within a theoretical framework.

I analyzed what themes and categories fit together and how the categories were connected. Coding stopped once the information was exhausted. I interpreted the meanings and attached significance to the findings in my analysis section by offering explanations, drawing conclusions and making inferences.

Implementing various data-collection strategies provided multiple sources of information, which strengthened the credibility of the research as the literature suggests that with the data illustrates the same thing from different sources (Mactavish, Lutfiyya and Mahon, 2000). The findings from this study reflect the perspectives of the individuals who attended the VP-Net events as well as the VP-Net team.

Chapter 4

Findings

To analyze the data, I used thematic analysis to first identify overall emerging themes, then to create subthemes that correspond with the interview questions. Using this method, three overarching themes emerged from the interview and focus group data along with six subthemes that correspond with the interview questions. The three overarching themes that were found to best reflect the data are:

1. Achieving Inclusive Knowledge Translation events;
2. The creation of space for culture shifts towards change and
3. Keeping the conversation flowing.

This chapter is organized around the three themes described above, and the subthemes that align with the interview questions. The narrative/document analysis from phase one of this study provided data that enabled me to create the VP-Net Knowledge Translation matrix (Appendix B). The chart of the VP-Net knowledge translation events was used in phase three as a tool by the VP-Net co-investigators to remind themselves of all of the knowledge translation events, and allow the co-investigators to provide clarity and accuracy to the table. Once the chart of the VP-Net knowledge translation events was complete, I used it to identify VP-Net's entire knowledge translation strategy, to reflect and analyze the events and to determine if they were inclusive.

In phase two, I interviewed a total of eight individuals representing each of the three desired communities of interest: people with disabilities, healthcare providers and policy-makers. Of the eight participants, three self-identified as people with disabilities, three

were healthcare providers (one of whom also self-identified as having a disability), one was a policy-maker and one individual self-identified as both a healthcare provider and a policy-maker. All of the individuals (eight) in the three communities of interest are female thus they are referred to using female personal pronouns. The women in phase two of the study ranged from 34-59 years old. To protect their identities and ensure anonymity, their names are not used in this chapter. In addition to these eight individual interviews, I conducted a focus group with three of the five VP-Net co-investigators (Dr. Deborah Stienstra, Dr. Harvey Max Chochinov and Dr. Zana Lutfiyya) in phase three. Finally, I conducted a one-on-one semi-structured interview with a fourth VP-Net co-investigator, Dr. Joe Kaufert, but regrettably the fifth member, Dr. Jim Derksen, was unable to participate in the data collection stage. The VP-Net group members are not referred to as 'participants', but identified, with permission, by their names.

Theme 1: achieving inclusive knowledge translation.

Half of the participants in phase two (four) representing all of the three communities of interest indicated that they believed VP-Net was successful at reaching Inclusive Knowledge Translation. Of those participants, one individual who self-identified as a healthcare provider and policy-maker indicated that the question regarding the fifth element, 'involving communities from the beginning', could not be answered because she had not been involved in the process from the beginning. Two participants said that they did not know what the goals or outcomes of VP-Net were and were therefore unable to answer the question.

Overall, the participants felt that VP- Net made a genuine effort to achieve Inclusive Knowledge Translation. One participant commented that as a blind person she could not

find the venue and indicated that the images displayed were not audio described. Another participant suggested “outreach across the country maybe could have been made earlier to make people more aware it was occurring prior to finishing.” Another participant indicated that “a good practice used at the meeting was the self-introduction of all the attendees” and a healthcare provider appreciated “the variety of views and exchange of information” and thought that the “take home materials provide(d) a solid base of Inclusive Knowledge Translation.”

As the VP-Net co-investigators reflected on the knowledge translation events, they were in agreement that the project was “very successful” at achieving Inclusive Knowledge Translation and that the work accomplished “created space” for change.

Dr. Stienstra explained in the focus group, “we don’t measure success as getting everybody to do what we were hoping they would do”, she continued, that the goal was to create that space for new knowledge. Although the co-investigators were convinced that their work was inclusive, Dr. Lutfiyya said, “by the end of the grant if we had known some things we know now, [...] we could have been even more inclusive”; indicating that there is always room to be more inclusive in one’s practices.

In terms of accountability, Dr. Lutfiyya explained that, “as a team, we felt accountable to those different communities [disability communities]; it mattered so much what members in those communities would think about us being involved in this type of research”. Dr. Stienstra added, “As a team we feel really responsible for making sure that palliative and end of life care is inclusive.” Overall the VP-Net co-investigators felt accountability was achieved.

Subtheme 1: engagement of participants and researchers.

The second question asked in the phase two interviews was whether the participants felt that VP-Net achieved two-way involvement and collaboration of the participants and researchers in all aspects of the project.

Five participants -- one person with disabilities, two healthcare providers and two policy-makers -- felt two-way exchange was illustrated at the event they attended. These individuals believed the audience actively participated in the events, that the co-investigators were flexible and attentive to what participants said and that both the participants and presenters experienced significant learning. One participant described an example,

I witnessed two way involvement and collaboration at the forum itself. My example would be inviting both vulnerable participants [sic] who had participated in the research to inform a variation [sic] of attendees including both providers and recipients of health care. Gaining the perspective of the voices of those challenged with vulnerabilities was reassuring and these people provided a first-hand account of what it is like for people with disabilities within the health care system and when dealing with end of life issues. I appreciated [the] involvement of the networks and government bodies that represent our population of persons with disabilities within the forum as it provided a forum for questions.

One policy-maker explained that there was dialogue, but that they unfortunately ran out of time to complete their discussion.

A healthcare provider indicated she was unsure, but expected yes, that there was engagement of participants and researchers, as there were “many people of differing

abilities” at the event. Another participant did not know, but explained, “It is clear that some people with disabilities were interviewed to create the video.” One participant with disabilities mentioned that, “Those not connected to the disability movement or connected to disability organizations [who are] the most isolated remain remote from the research process.” Two participants with disabilities felt they did not have enough information, or could not remember the event and therefore were unable to answer the question.

All of the VP-Net co-investigators explained that they tried to ensure two-way collaboration and engagement with different communities. The co-investigators indicated that they were very impressed with the attendance at the events and that the two-way collaboration “exceeded all expectations”.

The team explained that they met with different communities across the country. Dr. Lutfiyya went on to say, “It wasn’t just us talking to people, they were very engaging and bringing their own experiences and communities into the conversation. That indicates two-way.” Dr. Kaufert felt that, “Over the five years there was an increase in dialogue between people in the disability community and people within palliative care.” In addition, Dr. Kaufert said, “One of the things VP-Net did really well was to document the disability communities’ perception of barriers to palliative care and a lot of their concerns about issues like the devaluation of the quality of their lives.”

Although Dr. Jim Derksen was unable to attend the focus group, Dr. Stienstra explained that, “Jim played a really important role in engaging community people and policy-makers both; I think Jim sensed what was appropriate and what would work. Harvey and John Seely did the same thing with the palliative care community.” (The late Dr. John Seely, a palliative care provider and the former dean and professor at the

University of Ottawa, Faculty of Medicine who died in 2009, advised the VP-Net co-investigators during the initial stages of their project through a palliative care provider's lens.)

Subtheme 2: Identifying individuals missing or invisible in current research.

The phase two participants were asked how successful they thought VP-Net was in identifying those missing or invisible in the research and research process.

Two individuals with disabilities, three healthcare providers and one policy-maker (six participants) felt that people who are generally missing or invisible from the vast majority of research were reached by VP- Net. As the Winnipeg event was attended by the Minister of Health, one participant stated that VP-Net was effective at enabling the participants to share their viewpoints clearly with the Minister. On the other hand, this same participant described that, "it remains difficult to contact those most isolated individuals in group homes and institutions". In addition, a participant with disabilities indicated that in the future, "more research with more people with disabilities" is required.

Overall, the participants were pleased with the research process VP-Net undertook. One palliative healthcare provider who attended an event, reported "Considering it is difficult in palliative care to accomplish research and they had the added challenge of identifying missing or invisible in the research, I think they did remarkable. As healthcare professionals, sometimes we get focused on what is going on in front of us. This research opened my eyes more to consider how our program would work for someone with disabilities."

Regarding the general reach of the project, the VP-Net co-investigators reported that they strived to network with as many people as they could to effectively promote the knowledge translation events. The co-investigators described their media campaign as “fairly large”; they made great efforts to publicize their events to as wide an audience as possible. The VP-Net team invited participants by connecting with all of the major disability organizations and ensured each event was free of charge so as to make the events accessible to any and all individuals.

The team of co-investigators listened to what people with disabilities were saying to try and uncover some of the lost/missing/invisible information. They were flexible and adapted their work once the disability community voiced that they needed to have a conversation with the VP-Net team. One example of this was the June 11th and 12th 2007 Think Tank titled, *Wrestling with End-of-Life and People with Disabilities* hosted by VP-Net (Appendix B). Twenty-five participants supported by sign language interpreters and French translators were brought together to address the concerns of the community of people with disabilities around issues they face at end of life (VP-Net 2007 Think Tank Report, June 11 & 12, 2007). This Think Tank was about listening to the community of people with disabilities and representatives from most major Canadian organizations of people with disabilities. As the VP-Net 2007 Think Tank Report indicates, “Many participants stressed the need for the development of further dialogue between the disability and medical communities in order to create a better understanding of the needs and experiences of people with disabilities among both groups.” In addition, two major themes arose: the need to educate doctors and the need for public education to dispel the

myths associated with disability. VP-Net encompassed these emerging needs into their future outcomes and goals.

It was during the Think Tank that the “reclaiming language” section of the project came to be. Reclaiming language became a separate theme of VP-NET, led by Jim Derksen, to identify the ways in which language shapes the experiences of people with disabilities. The project identified three key words – vulnerability, compassion and suffering, and explored what they mean for people with disabilities. The insights gained were developed into a series of YouTube videos developed for the three target audiences – policy makers, palliative care providers and the communities of people with disabilities. (VP-Net YouTube channel: http://www.youtube.com/watch?v=t_DEpBW7gG0).

Although the VP-Net co-investigators all indicated that they believed they did an effective job at including individuals with disabilities, Dr. Kaufert alluded to one community that he believed may have been left out. Dr. Kaufert explained, “The ethics theme did try to embrace Aboriginal people with disabilities and we did some interviews and we ended up doing a publication about the kind of double disadvantage of being Indigenous and entering dying kinds of situations”. Dr. Kaufert explained he would like to continue to look at the Aboriginal perspective and other communities where systemic and cultural barriers are currently preventing individuals from receiving palliative care.

Subtheme 3: barrier-free environment.

The fourth question phase two participants were asked was in relation to barriers and whether the environment the events were held in was accessible and free of barriers. All but one participant who answered this question found the knowledge translation events accessible and free of barriers. Participants from all three communities of interest

felt that the environment was pleasant and one policy-maker said, “The variety of discussion, presentation and materials provided was very helpful, breaks were well timed and nutrition provided was very good, plus being able to tour the gallery was an added bonus.” Two of the three individuals with disabilities said they found the events free of barriers, the breaks were good and the event “went really well.”

One participant with disabilities felt there were gaps in accessibility such as a designated relieving area for service animals and ‘way-finding’ to the venue for those who don’t use sight. Another individual with disabilities explained that although overall she found the event accessible, the required walking distances were a barrier. Regarding venues, one participant and the VP-Net co-investigators indicated that in some cities the room the event was held in could have been bigger in size to accommodate more people and provide greater personal space.

The co-investigators responded the same way as the participants; the lack of physical space at the VP-Net events was often a barrier as it created physical challenges. In addition, the co-investigators indicated that the venue in Toronto wasn’t “nice” and the location in Calgary while considered beautiful, was small. The Halifax venue provided the optimum physical space.

In respect to the audiovisuals, one phase two participant noted that the CD-ROM and the pre-event package provided were good, whereas another participant said, “Videos are not fully accessible, not always audio described. It should also have had ASL as well as the captioning.”

All participants indicated that the breaks were well timed and provided nutrition.

When describing a one-day forum held in 2008 initiated by the Ethics theme of the VP-Net titled, *End-of-Life Ethics & Decision-Making: Current Policy Debates about Withholding and Withdrawing Life-sustaining Treatment* (Appendix B), Dr. Kaufert analyzed the emotional effect of bringing the three communities of interest into the same space to discuss the legal, ethical, medical and disability rights and perspectives on a current policy regarding withholding and withdrawing life-sustaining treatment. Dr. Kaufert explained that the space for change was “friendly” however, “coming into the part of the medical school [for the event] was hard for some people with disabilities and on the healthcare provider side, people found it very hard to come into an audience where they knew a third of the audience were people with disabilities and there were some strong political voices. I was surprised that there was fear on both sides coming into the same ethical space.” The fear of all of the communities involved and the need to create and strengthen trusting relationships will be further explored in the discussion section.

During the focus group discussion the co-investigators explained how the intricacies and the complexities of really including people with disabilities as researchers came to the forefront in the very beginning of the project when they hired Heidi Janz as a post-doctoral fellow. For Dr. Janz, a women with complex disabilities, to move from Alberta to Winnipeg required the coordination and development of a network of individuals and services to ensure that she had adequate home-care, an accessible environment, and adapted technology in order to work through the ongoing challenges and barriers many researchers with disabilities face. Including people with disabilities and ensuring accessibility is part of the mandate of the Disability Studies program therefore the VP-Net team was fortunate that they had the support of the University of Manitoba and Dr.

Derksen to help advocate for what was required for Dr. Janz.

Subtheme 4: did participants understand what they were participating in?

Phase two participants were asked in the fifth question if they understood what they were participating in (or discussing) during the VP-Net events. All the participants but one (seven individuals; two people with disabilities, three healthcare providers and two policy-makers) indicated that they understood what the presenters were saying and the purpose of the event. One participant who identified as a healthcare provider and policy-maker shared, “The face-to-face forum was effective at delivering the message that persons with disabilities are not vulnerable but made vulnerable by our systems and processes and lack of understanding of how these people manage their lives from day to day.” One individual indicated that she enjoyed the session but did not understand what the researchers were going to do with the information they gained from the participants.

Three participants (one person with disabilities, one healthcare provider and one policy-maker) indicated that they understood what they were participating in because they had significant background in the area of disabilities, or were very interested in the subject area. One participant suggested, that although she understood what she was participating in, the use of more plain language would have been beneficial.

Subtheme 5: engagement at events.

During the interviews, participants were asked if they felt they were engaged in the VP-Net events. Engagement in this context refers to the participants’ perception of the adequacy of their involvement in both the VP-Net process and the VP-Net events. All individuals, representing all three communities of interest, who answered the question,

felt that they were engaged in the events they attended. Four of the eight participants responded that they would have liked more information. Participants who requested more information indicated that would have liked additional information earlier on in the research process and would have liked to know the next steps of the project. One participant who identified as a policy-maker and healthcare provider shared how her engagement in the VP-Net event enabled her to put her learning into action. The participant said, “In retrospect I had good information prior to the meeting but lacked government related information and the cross ministry relations that entails persons with disabilities. However, as a result of my attendance this did produce more effort on my part to discuss these issues and involve other ministries.”

One participant with disabilities indicated that although she enjoyed the discussion, “It focused largely on the need for local agencies to network in a more effective way,” and she continued to say, “I don’t believe that the presented information was novel.” Whereas, a policy-maker and healthcare provider remarked, “The engagement method of holding a forum where all interested parties can attend was effective in educating us on each other’s roles but provided a comprehensive review of details about persons with disabilities that many policy makers might overlook in the realm of Palliative and End of Life.”

Other participants appreciated the opportunity to meet everybody and to “get together with like-minded individuals.” They found the group, “compassionate and caring,” and “the presenters were very cordial and well organized.”

When the VP-Net co-investigators were asked if they felt that the participants understood what they were engaging in, Dr. Lutfiyya questioned, “I don’t know how we

measure that frankly” and Dr. Chochinov explained, “In some ways it’s difficult to ensure that participants understand what they are engaging in, because in truth, it being research, we’re figuring it out.” Dr. Chochinov continued, “It really was a process of discovery, I think you can say that people understand what they are getting involved in, or the nature of this research, and a process of inquiry is one thing, but to say that they get it, I think “getting it” is something that evolves over time.”

Dr. Kaufert recalled that prior to the VP-Net End-of-Life Ethics and Decision-Making Forum on June 9, 2008 one-page summaries were available in plain language at a grade 2-3 level (See VP-Net website: <http://www.umanitoba.ca/outreach/vpnet/new.htm>) and individuals with developmental disabilities found these documents very useful. In addition, Dr. Kaufert received feedback from many physicians who indicated that the plain language “cut through the professional and ethical jargon and was very accessible.” Providing these summaries proved that all individuals benefit when an event or resource tool is made accessible to everyone.

Subtheme 6: additional elements of inclusivity.

At the end of the interviews, the phase two participants were asked if there was anything they wanted to add/delete from the Elements of Inclusive Knowledge Translation (Appendix F) they were provided. Four participants (one policy-maker, two people with disabilities and one healthcare provider) said no, that they were satisfied with it. One individual with disabilities indicated that there needs to be more “accessible language.” Another participant who self-identified as a healthcare provider said, “ ‘A *dynamic process of moving research into action*’ is an important element [that] needs

clarification” and one individual responded by asking, how do we “turn that list into practice?”

Finally, participants from all three communities of interest suggested that the list of Elements of Inclusive Knowledge Translation should be “simpler, shorter and contain more plain language.” This feedback helped shape the final Elements of Inclusive Knowledge Translation and indicated to me that the overall content of the Elements of Inclusive Knowledge Translation were accurate.

Theme 2: creation of space for culture shifts towards a change.

Phase two participants were asked in their interviews if they believed that the information and research that was created from the VP-Net events would result in change if it were to be put into action. Seven of the eight participants felt the work VP-Net has done can be successfully put into action.

The participants explained that the VP-Net events were a good start. One participant with disabilities indicated that, “A significant educational shift [is] yet required in the medical establishment to take this on board. Thus far, there has been little movement in this regard. At least the discussion is started.” A policy-maker indicated, “In order to affect change you must have the cultural support and in order to do that you need public engagement and education. I think the public message needs to be there to support the smaller fraction of providers who are leaders in this area.”

An individual who self-identified as both policy-maker and healthcare provider voiced her opinion by saying,

I hope we can affect change as we continue to build policy and do work around palliative and end-of-life however I find that we have a death denying society as

much as we have a society who is unable to empathize with persons who are disabled. We have health care providers who are unaware of the challenges of persons with disabilities and we can do much more to learn about how to support choices without inflicting our judgment. I believe the research, the open communication and venues and forums with a shared approach is key to changing the culture of our society to become more compassionate but one thing I have learned in my short time with government is that culture will always trump policy in the end.

The VP-Net co-investigators spoke about the process they undertook, and the initial actions that occurred to allow them as a team to be comfortable in their own skin, with each other, and with the communities they were targeting for their research (people with disabilities, medical community, ethicists/ policy-makers).

Dr. Chochinov indicated how prior to this research project, he wasn't aware of the dynamic between the medical community and the disability community and the perceived lack of trust and safety some people with disabilities articulated regarding medical practitioners. The co-investigators spoke about the difficulty of bringing two communities (disability community and medical community) that are in conflict together.

Dr. Chochinov explained that during the VP-Net events participants asked to not be called "vulnerable," however Dr. Chochinov described the importance of looking at vulnerability. Dr. Chochinov clarified that it was important to look at vulnerability, not the vulnerability of people with disabilities, but the vulnerability of "us" (healthcare providers and researchers). Dr. Chochinov said, "We are all vulnerable" and each individual needs to come to terms with "our own humanity, mortality and the ability to

yield to a process that you know is out of your control. It's not about knowing, it's about humility."

All VP-Net co-investigators felt that their work over the seven years of the project was successful in regard to: working towards sharing information, working towards change, and putting the information they learned and shared into action. Dr. Chochinov explained, "I look at the medical community and the extent to which we have really been able to penetrate that community in a meaningful way and I say, I wouldn't give us a 10 out of 10, I mean I think we certainly have made inroads." The co-investigators agreed that they have made progress, but that there is always more they could do, and there is opportunity to continue to create change. For example, the videos that are available on the VP-Net website are not part of the curriculum of all palliative care trainees across the country, but there is the potential to circulate them in schools across the country.

In terms of the disability community, as Dr. Stienstra pointed out, nothing can be said without the input of Dr. Derksen, but that in her mind, inroads were made. Dr. Stienstra explained that although the Council of Canadians with Disabilities has a focus on preventing euthanasia and assisted suicide the VP-Net has helped them to increase their awareness of palliative care and the possibility of palliative care as allies. She believed that, "There's a much stronger move in the community living community to address good dying for people with intellectual disabilities."

In addition, Dr. Stienstra received a call from a woman who believed that the work VP-Net is doing is very important and that the resources VP-Net has created will help change the hospice and palliative care movement in Canada. This woman felt that she was "still a bit alone on this," but that with the resources from VP-Net she could move

forward towards making positive changes.

Dr. Kaufert explained how the VP-Net project wasn't trying to "solve" questions or provide answers right away. He stated,

I think the side of it that we were trying to bring into knowledge translation was to say 'we need to bring research that deals with issues that probably aren't resolvable in the present situation,' there probably was no perfect answer, but getting people together in a public forum and making it accessible both to people with disabilities, including people with developmental and cognitive disabilities but also to bring it into the medical community so it wasn't just another disability forum where one or two professionals were present, but you really had 220 people who came into the same room.

In short, the VP-Net co-investigators felt that they, as Drs. Chochinov and Stienstra articulate, "set the process in motion" and "created the knowledge so that others can move it forward". Dr. Chochinov said, "the culture change is about insight, and insight is not just about head, it's about heart."

The VP-Net co-investigators felt that they engaged the participants whom attended the events and that there was as much time for conversation as presentation. Dr.

Lutfiyya explained that they "engaged people [the participants at the events, in all three communities of interest] in a way that at the time felt very hard." The co-investigators agreed that they challenged and "engaged people by pushing through some of the barriers we all have around our professional training, our stance, our everything."

The VP-Net co-investigators explained that their goal was to gain credibility with the different communities and then move the focus to reaching the people on the

frontlines. All of the co-investigators agreed that the model they used was very effective at achieving this goal and they were pleased by the feedback they received from those who attended the events. The co-investigators explained their process as initially trying to create space by bringing in leaders of the communities such as, John Seely, Laurie Beachell [the national coordinator of the Council of Canadians with Disabilities] or Jim Derksen and then focusing on what the individuals intricately involved in the frontlines wanted and needed.

Theme 3: keeping the conversation flowing.

The phase two participant interviews and the focus group suggest that while the VP-Net events appear to have been successful at achieving inclusivity of participants and creating a space for culture change and education, in order to work towards change, new space for change needs to be filled with continuous dialogue to keep the momentum going. As one participant who is a policy-maker indicated, “It’s hard to say from that list, how to turn it into practice,” and, on a positive note, another participant with disabilities said, “At least the discussion is started.”

A participant who identified as a policy-maker and healthcare provider indicated that the VP-Net event “helped me consider issues that I had not fully considered.” In general, participants felt hopeful that the work of VP-Net will help to affect change. One participant suggested,

My experience is that more people who directly represent persons with disabilities within government and also the organizations that support persons with disabilities should be present at these venues to answer questions but also to provide linkages and connections for those who will be interested in continuing the work in our own

province, both health care providers and government related employees. So my thinking is that despite having all the elements in place [for Inclusive Knowledge Translation] we still require a strategy to connect people and resources in a structured way.

One strategy the VP-Net co-investigators suggested to maintain momentum is to show the play, *“Voices at Dying, Dying to be Heard”*, by Heidi Janz, again. The VP-Net co-investigators reflected on the play and expressed that they felt that as a knowledge translation event, it was a very powerful type of presentation and that it presented research findings in a way that “confronted and engaged people at a heart, or emotional level as well as at a head or intellectual level.” All of the co-investigators felt the play was a very effective tool in terms of knowledge translation and see significant benefits resulting from it being performed again.

The VP-Net co-investigators were in agreement that the VP-Net project has shaped the way they conduct themselves as researchers, the way they present at conferences or events, and the perspectives that they offer to each of their research teams. During the focus group, the VP-Net co-investigators reflected on some “next steps” that they have individually taken and ways that VP-Net has shaped the future of their work.

Dr. Kaufert explained that his work post-VP-Net project is leading him in two directions. Firstly, he plans to hold a follow-up meeting on diversity and current policy to bring together the disability community and other cultural communities who have different perspectives on end-of-life ethics. Secondly, Dr. Kaufert intends to study the systemic and cultural barriers that are preventing individuals, including people with disabilities from “making it into palliative care.”

During the focus group, Dr. Chochinov reflected on his current work and said, “I think the big lessons for me about VP-Net are about the importance of you as whole persons” and he reflected on spending time with Jim Derksen and Heidi Janz and how much they have taught him.

Dr. Chochinov explained that he is working on a number of projects that are informed by previous work in VP-Net. One project is examining issues of personhood and “how can you place personhood on the radar of medical healthcare providers?” Another research project with Dr. Pat Martens focuses on schizophrenia. The “Patient-Dignity Question” research as well as a project where a framework of questions that patients and families can be given so they are able to engage in meaningful conversations, also are grounded by this work. Dr. Chochinov repeatedly reflected that these are simply a few samples, but recognized that the knowledge gained from VP-Net shaped the way he approached all of his work.

Dr. Lutfiyya, along with Dr. Schwartz, has continued to work on both discourse and imagery analyses of various portrayals of people with disabilities in movies, newspapers and governmental policies. Dr. Lutfiyya is the current Associate Dean of Graduate & Professional Programs, and Research, and a Professor in the Faculty of Education. Dr. Karen Schwartz, is a Master’s graduate from the Disability Studies program and a PhD in Education, both at the University of Manitoba. In addition, Dr. Karen Schwartz is a research facilitator at the University of Manitoba and has worked on a number of projects with VP-Net.

Dr. Stienstra has used her knowledge from the VP-Net project to work in the area of Aboriginality and disability. In part Dr. Stienstra is looking at traditional indigenous

worldviews, and recognizing that often they have a more inclusive approach to people with disabilities and how that can help inform practices around the world.

In addition Dr. Stienstra is looking at the Vulnerability model (Stienstra and Chochinov, 2006) and how it can be used to help girls, boys, women and men with disabilities in fragile and conflict affected countries.

In conclusion, these findings indicate that through the final four VP-Net knowledge translation events and the resources and tools provided, a broad range of individuals were reached. The VP-Net team got the conversation flowing, created dialogue and was able to educate individuals in many different communities.

Discussion

Many results in the findings align with the current literature and thematic frameworks outlined earlier. In this study I address many of the gaps identified in the literature review related to both research with people with disabilities and knowledge translation. The findings illustrated the responses from the participants during the semi-structured interviews and focus group. The discussion will draw upon my interpretation, as the researcher, of the findings and how the findings relate to the theoretical frameworks, and what has or has not been published in the current literature. This section identifies three areas: Elements of Inclusive Knowledge Translation achieved; Researchers and power relationships; and Benefits of knowledge translation.

The first area, Elements of Inclusive Knowledge Translation, in alignment with theme one of the findings, illustrates how VP-Net successfully achieved the Elements of Inclusive Knowledge Translation. Inclusive knowledge translation requires more than a

checklist of elements. The two subsequent areas: Researchers and power relationships, and Benefits of knowledge translation align with themes two and three in the findings section. These areas illustrate how the findings address key gaps identified in the literature and directions for implementing Inclusive Knowledge Translation.

Given the lack of literature on knowledge translation and people with disabilities, the findings demonstrate important evidence that can be used to ensure people with disabilities are included in the research and knowledge translation processes. The purpose of this study is to answer the research question: “Using the indicators of Inclusive Knowledge Translation (IKT), to what extent does VP-Net succeed in conducting Inclusive Knowledge Translation?”

To answer the research question, this project created the Elements of Inclusive Knowledge Translation (Appendix F) drawing from the literature, evaluated VP-Net and its knowledge translation strategy in light of these, and revised the elements to ensure they signify what representatives of three communities of interest-- people with disabilities, healthcare providers and policy-makers, identified as Inclusive Knowledge Translation.

In this study, I identified and addressed the following points that summarize the results of my literature review related to the involvement of people with disabilities in research and knowledge translation:

1. In general, people with disabilities are invisible in the research process and are not identified as contributing to the creation of knowledge or as users of knowledge;
2. Knowledge translation research on disability portrays people with disabilities as objects of study;

3. Knowledge translation has not been conducted with people with disabilities identified as active participants in the research and knowledge exchange process;
4. Knowledge translation approaches assume that all people are non-disabled and as a result do not identify or address barriers to accessing knowledge, information and research that some people may face.

The findings in this study not only address these points from the literature but also demonstrate how the three communities of interest would like Inclusive Knowledge Translation to be conducted.

Elements of inclusive knowledge translation achieved.

The responses in the interviews suggest that VP-Net did a remarkable job at achieving the Elements of Inclusive Knowledge Translation (Appendix F). VP-Net was largely successful in the ways in which the events were conducted and the resources were created and distributed. VP-Net worked against some physical structural issues, however their model of Inclusive Knowledge Translation appears to have been a success. Could this knowledge translation strategy be replicated? Based on the findings I would say, “Yes”, and the Elements of Inclusive Knowledge Translation can be used as a guide to help other teams and individuals successfully achieve an inclusive research and knowledge translation model.

Uncovering individuals not identified in research.

As indicated in the literature review, there is limited research conducted that is inclusive of people with disabilities and knowledge translation. What little exists focuses on translating knowledge about disability and impairment as an object of study, rather

than on translating knowledge with people with disabilities.

As reflected above in subtheme two of the findings section, the participants in this study felt that overall the VP-Net co-investigators were successful at uncovering and including individuals who were not identified in the literature. While there is always room for improvement, and as one participant indicated, often the individuals who are the hardest to reach remain left out of the research process. That being said, VP-Net made a concerted effort to listen to the feedback from the participants at the knowledge translation events and to be flexible throughout their project so as to uncover and include the many individuals who were previously invisible in the literature.

The overall goal of this study was to evaluate if VP-Net was successful at achieving Inclusive Knowledge Translation. In this project I also wanted to reflect upon inclusivity in the research process. To that end, a secondary aspect of this project was to work together with people with disabilities to ensure their voices were heard and their needs met when creating the Elements of Inclusive Knowledge Translation.

As a researcher, I must recognize that although I tried to include people with disabilities from the conception of my project (by meeting with Jim Derksen), it was my responsibility to create the initial list of Elements of Inclusive Knowledge Translation based on the current literature, emancipatory research methods and the social model of disability, and therefore people with disabilities were not a part of this initial process. Once this list was formulated I used it as the basis for conducting interviews with individuals from the three communities of interest. The participants were asked whether they felt the elements I created were accurate, and what they would like to see changed, added or deleted. My project strived to achieve inclusivity by including individuals from

the three communities of interest (people with disabilities, healthcare providers and policy-makers), listening to their suggestions and then applying them to my list of elements. The participants were then given the opportunity to review the amended list of Elements of Inclusive Knowledge Translation and at that time were asked if they believed this new list met their requirements (Appendix F).

It was an important goal of this project to ensure that the Elements of Inclusive Knowledge Translation were representative of what the participants in this study, from the three communities of interest, believed were an accurate list of elements to portray true inclusivity. As Bowen & Graham (2013) state, “if we want to conduct research that is useful, and will be used, we need to listen to the needs of patients, families, and providers, as well as managers and policy-makers within the health system” (p. S6). Based on the findings this goal was achieved.

Research is often done on people with disabilities, but because this study went beyond the norm by including people with disabilities throughout the research process, giving them a voice, there was avid interest. During the recruitment stage, once the recruitment emails (Appendix C) were distributed to the three communities of interest, the participants responded quickly. There were more responses than I anticipated: individuals were eager to participate in this study and were willing to share above and beyond what the interview questions asked. Often marginalized groups such as those with disabilities are experienced advocates; this study was seen an excellent opportunity to advocate for their community and ensure their voices were heard. Not only were people with disabilities asked to participate in this study but they were also asked for their

opinions on how VP-Net did at achieving inclusivity at their events as well as on the Elements of Inclusive Knowledge Translation (Appendix F).

In addition, as described in greater detail below, all of the participants in my study had previously participated in one VP-Net knowledge translation event and therefore a relationship with the VP-Net co-investigators was already established. The participants were aware from the previous VP-Net events that the environment would be a “safe ethical space”.

Engagement.

VP-Net illustrates a critical element in the literature—sustained relationships and two-way communication.

Over half (five) of the phase two participants felt that two-way engagement existed between the researchers and the participants. One example of successful two-way engagement was the End-of-Life Ethics and Decision-Making Forum hosted by VP-Net in 2008. This public forum worked to “provide an ethical safe space” (Kaufert, Schwartz, Wiebe, Derksen, Lutfiyya, & Richert, 2013, p. 4), where participants were able to “step out of allegiances and speak with impunity” (Ermine, 2007, p. 202). During this forum, the disability and medical communities came together in a mutual space to share their “sides” and explain their thoughts and concerns regarding end-of-life care.

Participants at the forum indicated they felt the conversation was “a starting point for more dialogue,” (Kaufert et al., 2013, p. 8) and the forum as a whole was seen as a “potential starting point for building conversation that would facilitate revising the policy (regarding withholding and withdrawing life-sustaining treatment) with broader consultation on its legal and ethical validity” (Kaufert et al., 2013, p.8).

The VP-Net team brought in disabled researchers to speak and share their experiences at the Spring Institute in 2006. These are two examples of engagement, in addition to the fact that there were many other events that brought healthcare providers, people with disabilities and policy-makers into the same room. VP-Net broke new ground in terms of Inclusive Knowledge Translation with each community of interest sharing their thoughts, experiences and desires in a safe space.

In addition, the literature suggests that policy issues are constantly absent from the research plans, whereas in this study, policy and decision-makers along with the Minister of Health in Manitoba attended the final knowledge translation events in an effort to alter this pattern.

The literature emphasizes that personal contact between researchers and policy-makers, including interactive meetings, are reported to be more effective than printed reports and reviews (Jacobson et al., 2003; Lomas, 2000; Grimshaw et al., 2001; Granados et al., 1997; Grimshaw et al., 2004). This face-to-face contact builds trust between key individuals (Bowen et al., 2005; DeRoeck, 2004; Lomas, 2000; Ross et al., 2003; Vingilis et al., 2003; Whitehead et al., 2004). VP-Net was successful at achieving interactive meetings; high-level healthcare executives, policy-makers and healthcare providers attended the events, engaged in dialogue and indicated that they brought the information back to their workplaces and shared what they learned.

The VP-Net team was successful at working to bring these differing communities (people with disabilities, healthcare providers and policy-makers) together in the same room, to express their concerns within palliative and end-of-life care and to share ideas, solutions and comments on how to work towards a cultural change. The VP-Net co-

investigators might not have found all of the solutions to the problem, but they brought these individuals together, which could be said to be the hardest part of the process. The team set the process in motion and created tools and resources for the participants of the events to bring back to their communities, their work places and their families to continue to share and spread the knowledge.

Flexibility.

VP-NET demonstrated one of the key elements, flexibility, that Graham (2010) suggests is necessary to achieve Knowledge Translation. VP-Net designed an array of different knowledge translation events and products and maintained the ability to adjust and adapt their methodological framework as their project progressed. During the VP-Net project, the individuals in the disability communities that the team was working with indicated that they did not want to be called “vulnerable”. The VP-Net co-investigators recognized that the term “vulnerable” was a problem, and to address and discuss the problem. VP-Net hosted a Think Tank: *Wrestling with End-of-Life and People with Disabilities*. It was during this Think Tank that the reclaiming language theme of the VP-Net project was established, to illustrate how language, including the word vulnerability, shapes our perceptions.

Taking the time to stop their project and listen to what people with disabilities were saying was a test of humility and the strength of character of the researchers for the VP-Net team. By pausing their work and recognizing that something they were doing was not right and required changing, the VP-Net co-investigators earned a great deal of trust from the individuals with disabilities who spoke out. I think this process was critical to VP-Net’s success. As stated above, although the VP-Net team included Jim Derksen, a

man with disabilities, from the onset, the team had several barriers to overcome. By sitting down and listening to the wishes, comments and concerns of people with disabilities, such as being called “vulnerable”, the relationship between researchers, the medical community and people with disabilities, that was once filled with mistrust, was evolving with a new found respect.

Having Dr. Chochinov as a co-principle investigator was an excellent addition to the team, however his inclusion came with barriers that needed to be addressed at the onset of the project. Dr. Chochinov, a psychiatrist and world-renowned palliative care researcher at CancerCare Manitoba, brought a strong contribution of knowledge, expertise and direct contact with palliative and end-of-life-care. The challenge of having Dr. Chochinov as a co-investigator was that historically, many disabled people have not felt trusted, respected or appreciated by physicians (especially psychiatrists). The assumption that doctors, including Dr. Chochinov, would continue this disrespect created a perceived barrier between the VP-Net team and people with disabilities. As indicated in the previous section, the VP-Net team had to confront this issue head-on before they could move forward.

After much introspection, listening, and the willingness of members of the disability community to tell their stories, Dr. Chochinov began to understand the damage, hurt, marginalization, exclusion and barriers that the medical community (for the most part) had created for many people with disabilities. It took deep reflection, analysis, open-minds, humility and the ability to accept criticism to move forward on how to prevent these issues from continuing to occur. As Dr. Chochinov explained, one must understand that, “you have to really break through that resistance you know, that you are part of the

problem. That doesn't mean that you are a bad [person], it means that you are human and that you have biases and that you have prejudices and that you have preconceived notions and that's a hard message. Maybe that's why it takes time to penetrate consciousness that we are part of the problem which also, you know, the flip side is that there is the potential that we can be part of the solution". In order to facilitate this process, Dr. Chochinov needed stories to listen to. It is important to value the contributions of those with disabilities, including Jim Derksen, Heidi Janz and the many individuals who participated in VP-Net events who shared their stories and experiences. This process took dedication, desire, flexibility and humbleness of a member of the medical community, as well as courage and strength of individuals with disabilities to reflect on past actions and work towards implementing changes for the future.

Flexibility requires researchers to be open-minded and to listen to what their participants are saying. As researchers, they must relinquish some power and acknowledge that if they truly want to be inclusive of those engaged in the process, a willingness and desire to amend pre-established research projects is required. When researchers say there is only one way to do things, we structure people out.

Including people with disabilities.

People with disabilities are often entirely left out of the research process, but in the case of this study, when given the opportunity to be heard, these individuals had a lot to say to work towards creating a change (Oliver, 1992). It is evident from the findings that both VP-Net and my project were successful at breaking the silence around the inclusion of individuals with disabilities in knowledge translation and the research process. As described above, within the VP-Net project, power relations between non-

disabled researchers and disabled researchers remained notwithstanding the VP-Net team, included people with disabilities from the very beginning of the project. In order to be fully inclusive in research and knowledge translation, this project has taught me that including people with disabilities as participants or researchers in a research project is not enough: people with disabilities must be full participants, and given the chance to provide feedback when they are the individuals whom the outcomes will affect the most. Some key factors that helped make this happen were flexibility, relinquishing of power, establishing relationships, humility and using resources strategically.

The inclusion of researchers with disabilities as co-investigators of the VP-Net project, as well as, bringing in the Post-doctoral fellow Heidi Janz and participants with disabilities, demonstrated the complexities of true inclusion and accessibility. VP-Net was able to achieve this because of the forethought, resources and willingness of allies within and outside the University of Manitoba in addition to the commitment from the Disability Studies program.

In accordance with the principle of engaged scholarship, in order to achieve true collaboration, the perspectives of multiple stakeholders must be integrated (Van de Ven & Johnson, 2006). If people with disabilities aren't included then true *Engaged Scholarship* is not reached.

The women with disabilities in my study all indicated that in the future they would like to be involved in more studies. This finding is not surprising to me given the lack of research that includes people with disabilities.

Buy-in (involving the right individuals).

As the literature suggests, getting ‘buy-in’ at the highest levels is critical to mobilizing knowledge within organizations (The Canadian Institutes of Health Research, 2006). VP-Net did this by establishing “executive-level buy-in” within each community of interest and then working with those individuals to recruit participants for each event. For example, as noted above the VP-Net co-investigators strategically included leaders in the communities of interest from the onset of their project such as, Laurie Beachell, Jim Derksen, and John Seely. As well, attendees at the final knowledge translation events included the Manitoba Minister of Health, government officials from Nova Scotia, Ontario and Alberta, health services executives, health authorities, caregivers, hospice workers and individuals from the Multiple Sclerosis Society and CNIB.

The Canadian Health Services Research Foundation (1999) stressed the importance of involving decision-makers from the beginning of the research process and creating initiatives to foster researcher-decision-maker relationships and interdisciplinary teams, which the VP-Net team excelled at from the onset.

During the focus group, The VP-Net co-investigators described the time they spent working to cultivate a strong relationship with and to understand the perspective each individual brought to the project. Dr. Stienstra explained, “In order to have true knowledge translation you must create meaningful relationships and in order to achieve that, there must be a safe, free, space that is free of barriers and the ability for all parties involved to understand their own responsibility and vulnerability.”

This finding is consistent with the research demonstrating that it is essential for researchers and decision-makers to establish a working relationship with each other to

foster successful knowledge translation initiatives and desirable research (Thompson et al., 2006).

The VP-Net team was successful at engaging individuals, communities and organizations that were stakeholders in their project by holding forums, think tanks, workshops, meetings, courses and the like, prior to the final five knowledge translation events. This strategy worked to foster and establish relationships with participants and ensure they were getting the right information. The VP-Net co-investigators identified their audiences (people with disabilities, caregivers, family members, palliative healthcare providers and policy-makers), and invited individuals at the highest possible level within each community of interest (Ministers, Deputy Ministers, Hospital Chiefs, Executive directors of organizations). The VP-Net team used this strategy so that these high-level individuals could then direct their staff to attend and share the invitation with their contacts. The VP-Net events were held in the afternoon on a weekday; lunch was provided to ensure individuals did not have to attend a work-related event outside of the workday. The VP-Net co-investigators strived to make the events enticing and appealing in order to attract a large audience.

In my study, I also worked to establish relationships with the participants and create an environment that the participants felt was safe, accessible and flexible. I was fortunate that all of the participants in my study had attended at least one VP-Net event; the VP-Net co-investigators had established a rapport with these individuals, a connection that helped me establish a relationship with the participants.

In addition, I tried to use other tactics to cultivate a relationship with the participants and allow them to feel relaxed and respected. These tactics include: an

interview guide approach to create the flow of conversation in a calm organized environment; flexibility in my interview method to ensure accessibility; the opportunity to socialize; discussion of the VP-Net project and how my project aligned with the VP-Net events the participants attended.

The conversation continuously flowed and included enhanced social engagement and jokes within the focus group, showing the effectiveness of these tactics in working to establish a positive relationship with the participants and a creating a trusting environment for engagement during the interview.

Language.

Both the literature and the findings illustrate how important it is to ensure comprehension and thus engagement. To do this requires plain and accessible language (Graham et al., 2006). According to the findings, the phase two participants indicated that VP-NET was successful at ensuring participants from all three communities of interest understood what the VP-Net events were about and the type of research they were participating in. However, where VP-Net could have improved was on the language; participants from all three communities of interest indicated that more clear and plain language would have been helpful to ensure all individuals were able to understand the material.

Clear and plain language can have many meanings. For the purposes of this study, clear and plain language means using words that will reach members on any educational level, words that the intended readers will know and explaining any unfamiliar words (CUPE, 2011; Canadian Labour Congress, 2007). This includes: using point-form when possible; listing the most important information first; writing in a tone that is talking *to*

the readers, not *at* them; using concrete, active, positive words; using simple sentences; avoiding jargon, acronyms and abbreviations; using bias-free, inclusive language; organizing the literature with headings so readers can quickly and easily find what they need; and using a large font (Canadian Labour Congress, 2007).

In addition, during the focus group, Dr. Stienstra reminded me that often “words and terms do not mean the same thing to everyone”. For example, accessibility does not mean the same thing to all individuals. Why is this important? Because it is essential that when trying to translate knowledge, share knowledge, listen to others and teach others, we must ensure that what we are asking is simply described so all individuals can understand the communication being shared. This links back to ensuring researchers create a safe, open, trusting environment and establish a relationship with participants so that if the participants do not understand something they can ask the researcher and the researcher can provide clarity. As well, this links back to researchers being flexible and adapting or adjusting their work to meet the needs of the participants in ways they desire.

Putting research into action.

One of the core elements within all definitions of knowledge translation is to ensure that research is put into practice or a real-world application (Graham et al., 2005). Of the eight phase two participants, seven women believed that the work that VP-Net achieved would be put into action. I was not surprised by VP-Net’s commitment to achieve Inclusive Knowledge Translation at their events because each of the co-investigators has been immersed in disability studies, disability advocacy and working towards full inclusion. However, this significant finding explains that the team’s aspirations translated into an accessible, inclusive and ground-breaking event.

Participants in my study, who attended at least one VP-Net knowledge translation event, indicated that after the event they shared what they learned with their co-workers, family, and friends. Another piece of evidence of how the knowledge from a VP-Net event was put into action was learned via a phone call that Dr. Stienstra received: A woman called Dr. Stienstra because she wanted to share how important the work VP-Net did was and how sad she was that she was unable to attend the final Winnipeg knowledge translation event. This woman, shared a very personal account of how she had engaged with both disability and palliative care in her life in a number of different settings and how she thinks that the work VP-Net has been doing, especially the resources that have been shared, will help to change the hospice and palliative care movement in Canada. This woman went on to say that she continues to feel a little bit alone on this topic, however she felt that with the resources provided by VP-Net she could move forward on addressing changes in palliative and end-of-life care for people with disabilities. Stories like this are very telling of true knowledge being put into real-life practice.

Given the lack of studies that reported a “real-world” application, having the three communities of interest engaged in the knowledge translation events and indicate during the interviews of my evaluative study that they returned to their places of work and shared the resources, methods and tools provided from the VP-Net event is a finding that demonstrates achieving a critical stage of knowledge translation.

Was VP-Net successful at achieving the Elements of Inclusive Knowledge Translation? In reviewing the results found in the subthemes in Theme 1 of the findings, it is clear that VP-Net successfully achieved the Elements of Inclusive Knowledge Translation. However, Inclusive Knowledge Translation is more than a checklist of

elements. To achieve Inclusive Knowledge Translation requires addressing research power relationships and the benefits of knowledge translation.

Researchers and power relationships.

The literature includes embedded assumptions regarding the characteristics of researchers and research users. Current research assumes that all individuals are able-bodied and much like one another. The literature assumes that all individuals can read and write English or French, have a certain level of reading comprehension, and have accessibility to translate materials into a variety of formats such as Braille or an audio reading (Stienstra, 2012).

There are implicit power relationships between the researchers and the researched, in the current definition of knowledge translation (Zarb, 1992). Stone & Priestley (1996) demonstrate how through emancipatory research individuals without disabilities can contribute to disability research as allies and uncover the embedded assumptions. One of the key elements of emancipatory research is collaboration between researchers and research users to reduce the power relations (Zarb, 1992). This area demonstrates the ways in which VP-Net worked towards the creation of space within themselves and their project.

Although the VP-Net team strived to include people with disabilities in all aspects of their work, the team both replicated and reinforced the traditional power imbalances imbedded in research. The team includes: Dr. Harvey Max Chochinov, a medical doctor in psychiatry; an internationally recognized leader in palliative care research and a Professor of Psychiatry, Community Health Sciences, and Family Medicine; Dr. Deborah Stienstra, a Professor in Disability Studies at the University of Manitoba; Dr. Zana

Lutfiyya the Associate Dean (Research and Graduate Programs) & Professor of the Faculty of Education; Dr. Joseph Kaufert, a community health researcher, medical anthropologist and Professor in the department of Community Health Sciences, Faculty of Medicine and the Department of Anthropology at the University of Manitoba and Jim Dersken, a disability activist, wheelchair user, the Former executive director of Manitoba government's Disability Issues Office and policy advisor to the Council of Canadians with Disabilities.

By including people with disabilities VP-Net disrupted traditional exclusion of people with disabilities from the research process. Jim Derksen was treated like a co-investigator, he led the *Reclaiming Language* theme, and was paid through the research funding to play a key role in the VP-Net project. Therefore, I would conclude that the VP-Net subverted the system. Yet, the four main co-investigators are still within universities, they get to hold the research money, and it is only when they have 'good will' or intent to include, that inclusion happens. This leaves the four "academics" in the driver's seat – a continuing power imbalance. As a general lesson for researchers, I think it takes both intent from traditional academic researchers to be inclusive, as well as a change in funding agencies to enable community partners to have the same or similar access to resources and control over research funds, as do the academics. If these two changes are made, there will be a significant shift forward.

As a non-disabled researcher trying to disrupt the dominant discourse and create elements that will help others establish inclusive research, knowledge translation strategies and models, I developed the foundation of the Elements of Inclusive Knowledge Translation (Appendix F) from the principles of emancipatory research and

the social model of disability. While I used theory and frameworks from disability studies and disability research, I also developed a list of elements that directly impacts people with disabilities. As a non-disabled researcher it was my goal to be an ally and consult with people with disabilities about these elements. When I asked the participants if they felt that the list of Elements of Inclusive Knowledge Translation (Appendix F) that I created were accurate, or if they wanted to add anything, almost all of them gave positive feedback and felt the elements accurately portrayed what they believed identifies Inclusive Knowledge Translation. This response assured me, that I listened to and heard the desires and beliefs of the individuals with disabilities who were involved in this project.

These findings indicate the ability of allies working together with people with disabilities to uncover the embedded assumptions about the characteristics of researchers and research users. The VP-Net co-investigator team is made up of people with disabilities, healthcare providers, policy-makers, advocates, academics and researchers, all of whom bring a different lens and talent to the team and use their power to subvert unequal research relations.

Benefits of knowledge translation.

This area aligns with the social model of disability and creating knowledge translation that is accessible to all individuals. The literature suggests that healthcare providers, policy-makers and researchers often believe knowledge translation is beneficial, but are not able to commit to the amount of time that is required to achieve successful knowledge translation (Mitton et al., 2007). The phase two participants who self-identified as healthcare providers (three), indicated that prior to the VP-Net events

they were all unaware of the challenges faced by a person with disabilities. As one woman suggested, “We can do much more to learn about how to support choices without inflicting our judgment.”

As demonstrated by the VP-Net events, knowledge translation sessions do not need to be lengthy or cumbersome. The VP-Net events took place in a single afternoon and included a complimentary lunch. VP-Net proved that providing YouTube videos and plain language summaries on their website as well as on a provided USB key are very helpful ways to retrieve a useful tool. As described above, VP-Net intentionally invited high-level healthcare providers and policy-makers as well as their own personal and organizational contacts in order to reach their targeted audiences.

The literature reports that when healthcare providers and policy-makers attend knowledge translation events, such as the ones hosted by VP-Net, they were informed of issues they had “not fully considered” and they “learned new information and skills; they transferred knowledge to the workplace; and reported that the information they learned had a positive impact on the residents they cared for” (MacDonald et al., 2008; Canadian Health Services Research Foundation, 1999). This finding aligns with the responses from the participants in this study, as both policy-makers and healthcare providers expressed the wealth of information they ascertained and that they hoped the work of VP-Net would effect change.

The Canadian Health Services Research Foundation (1999) indicates that decision-makers often feel research is not always relevant to practice-based issues and the lack of timely results creates barriers to using evidence-based findings. Individuals from all three communities of interest in my study indicated the opposite of this research

finding. The participants felt that this work was very timely and appropriate. They believed the work of VP-Net was a start to creating an educational and cultural shift towards change for people with disabilities in research and healthcare.

The VP-Net knowledge translation events demonstrated how sharing knowledge through multiple formats such as a play, can touch people and reach their hearts. In 2006, the play, “Voices at Dying: Dying to be Heard” by Heidi Janz was performed at the 16th International Congress of the Terminally Ill at McGill University in Montreal, Quebec. At this international conference each delegate received a copy of the special issue of the *Journal of Palliative Care* (Chochinov, 2006). Knowledge translation was achieved in two formats: by watching the play and by attaining a copy of the journal which delegates were able to bring home with them. The emotional and intellectual confrontation of “Voices at Dying: Dying to be Heard” reminds us that knowledge is not just about facts. As Dr. Chochinov articulated:

Knowledge is more nebulous, I think the insight here with respect to the play is we had to deliver something that would not just speak to their head but that would really speak to their heart. They [the audience] needed to be moved in a way that they started to question themselves and question their worldview. It is an interesting aspect of knowledge translation that is not just about giving people more information, it is about moving them. You can give them all the facts in the world; each of us will die, each of us are prone to certain kind of chronic conditions or illness, this is how many of us will encounter disability, those are facts, but the knowledge translation strategy that we used took those facts and had to somehow, personalize it and make it an emotional experience in order for them

[the audience] to begin to look at their own emotion and to look at their own attitudes, outlook, biases.

In order to successfully initiate and facilitate knowledge translation it takes more than simply knowing and sharing information. As Dr. Chochinov describes, to create space for new knowledge in your mind, you need to have space in your heart.

Conclusion

Did VP-Net project achieve inclusive knowledge translation?

The literature review outlined many gaps in the current research. From the knowledge translation and disability studies literature and the perspectives of what people with disabilities, healthcare providers and policy-makers believe it means to *fully* include people with disabilities in research, at events and to conduct successful Inclusive Knowledge Translation, I created the Elements of Inclusive Knowledge Translation (Appendix F). This project analyzed whether or not VP-Net was successful at addressing these gaps and achieving Inclusive Knowledge Translation.

While VP-Net had some gaps, the team was successful at achieving Inclusive Knowledge Translation. Many aspects contributed to the success of VP-Net achieving Inclusive Knowledge Translation including: the ability of the group of co-investigators to reflect upon their project and data as it unfolded, their flexibility and their willingness to immerse themselves in the project as a whole. The VP-Net co-investigators examined their own vulnerability and humility; they held team meetings and sessions at the onset of the project to collectively analyze where and how they might be excluding people with disabilities in their work.

The ability of the highly regarded and well-established VP-Net co-investigators to examine and reflect upon their work and listen to what the needs and desires of the disability community has proven to be a successful endeavor. Dr. Chochinov expressed, “Culture change is about insight, and insight is not just about head, it’s about heart.” Therefore, before change can be made, individuals who create new knowledge and information intended for others to move forward need to recognize that space first needs to be created within the researcher, the healthcare provider and the policy-maker.

Chapter 5

Conclusion

The goal of this project was to answer the research question “Using the indicators of Inclusive Knowledge Translation (IKT), to what extent does VP-Net succeed in conducting Inclusive Knowledge Translation?” In addition, this project aimed to develop the list of Elements of Inclusive Knowledge Translation (Appendix F) to be used as a guide for researchers when they embark on a new project. The purpose of the Elements is to create a clear list of indicators that, when they are achieved, will produce a research project that has been inclusive of individuals with a variety of abilities.

Lessons and limitations.

Throughout this study there were many lessons learned and limitations discovered that could be addressed in future studies. In general, the lessons learned involved recruitment criteria, pacing and framing of interview questions, accessible materials and flexibility required to address differences.

Lessons learned from my research.

One lesson from this research is that recruitment criteria needed to be more comprehensive. For example, in the recruitment email I could have included asking individuals how many VP-Net events they attended, and then selected individuals with similar attendance records. During the recruitment stage, some individuals responded to the email by saying they “Did not feel they were suitable for my project as they only attended one event.” The result is that some participants in my study attended only one

event, and therefore could only speak to their singular experience. However, several participants in my study attended multiple events and participated in different aspects of VP-Net for many years. This inconsistency created a disparity in the results, however it was not a significant difference because this study analyzed the VP-Net events as a whole.

A second lesson was that interview questions needed to be paced and framed to enable easy comprehension by the participants. For example, as I conducted my interviews, I listed all of the elements and then asked the patients at the end if they wanted to add, delete or change any elements. This method was unreasonable as it was difficult for participants to remember the list of elements by memory and then reflect upon them. Although, I sent the interview questions (Appendix E) and list of Elements of Inclusive Knowledge Translation (Appendix F) to each participant to review in advance, during the interview I did not give the participants adequate time to digest or comprehend each element. After I realized this mistake, I altered the way in which I conducted the final interviews; I paused after each element and asked how the participant felt about the individual element. Additional time during the interview might have allowed for a deeper understanding from participants of the elements, however the original versions were too lengthy and complex.

In addition to more time, the *Clear Language Checklist* from The Canadian Labour Congress (2007) indicates, using point-form, words that the participants are familiar with and explaining any unfamiliar words would have been a more effective strategy to ensuring the participants understood the Elements of Inclusive Knowledge

Translation. I amended the language and format of the Elements of Inclusive Knowledge Translation to simpler words and I made them point-form.

A third lesson was that interview and consent materials should be available in multiple, accessible formats. For example, when I distributed the consent forms, interview questions and Elements of Inclusive Knowledge Translation to the participants prior to the interview a participant brought an important point to my attention regarding accessible formatting. The original distribution of the documents was sent via email and the documents were saved as a PDF. It was brought to my attention that many accessible technology software programs are not compatible with PDF documents. I did not know about this barrier, therefore sending PDF documents was an oversight on my part. This problem was solved when I resent the documents as a Word file.

A final lesson from this research is that interviewers require flexibility to allow for and address differences in understanding. For example, when I asked participants if they “felt engaged in the process?” some of the participants did not understand what this meant. Some participants did not understand what the term *engaged* meant, and others weren’t sure to which *process* I was referring. During the interview when participants indicated they did not understand a term or to what I was referring, I was able to explain it verbally. This was a successful strategy to address differences in understanding but may not always be successful especially in situations where there is not a common language between participant and interviewer. Other participants felt that too much time had passed since they attended the VP-Net events and were therefore unable to recall their experiences. One solution to this could have been to provide a brief summary of the

events in different cities, including: the speakers, the location, the number of people in attendance, and the menu of the meal provided.

Personal lessons learned.

In addition to the general lessons learned, I also took away personal lessons that will help me to become a better, more inclusive researcher. I discovered the importance of being self-aware and reflective as a researcher, and how to share knowledge beyond a written article.

I learned throughout this project the need to recognize humanity and to have humility. A common trend in the interviews and focus group was the desire for medical communities to learn humility and earn trust within disability communities. It is important as the researcher to bring these same characteristics to the research process.

The co-investigators taught me that another way to share knowledge effectively is to tell stories. Often text written on paper, or an audio recording does not grab people's attention. As demonstrated through the play by Heidi Janz, there are many alternative but equally effective ways to create that shift in thinking and to deepen knowledge.

Personal stories can create an emotionally fertile soil within an individual and it is once the soil is ready that an individual is receptive to new information. At this point the sharing of new information can then be transformative.

Limitations.

Limitations arose during the course of my research project including the clarity of language, self-selection of participants and overlap between the participants in my study and my thesis committee.

The initial language of the Elements may have created a comprehension barrier to participants and therefore was a limitation. According to the feedback from the participants (from all three stages) the language of the Elements of Inclusive Knowledge Translation needed to be shorter and simpler and some elements needed to be altered. The Elements of Inclusive Knowledge Translation were given to each participant in advance through email. The majority of the interviews took place over the telephone and it appeared that the participants had not read the Elements in advance. Therefore, the Elements of Inclusive Knowledge Translation were read out loud during the telephone interview. It is unclear whether some participants fully understood what they heard. One adaptation I could have made is to create an audio and/or a visual of each element and included that in the email prior to the interview for participants. This would have allowed the participants to pause and evaluate each element at their own pace. During and after the interviews were conducted, I amended the elements to shorter, clearer and simpler language (Appendix F).

A second limitation of the study was that the participants were self-selected and were drawn from only the final Knowledge Translation events in Calgary, Winnipeg, Toronto and Halifax. Including a greater number and wider range of participants who had attended earlier knowledge translation events during the VP-Net project would have provided richer evidence; however, that was beyond the scope of this project.

A final limitation is that my supervisor and two thesis committee members were also participants in my study. This overlap of roles could be viewed as a conflict of interest. The responses from these participants were significant in the formation of my analysis section as they represented over half the participants in their phases (Dr.

Stienstra was one of two individuals in phase one, and Dr. Stienstra, Dr. Lutfiyya and Dr. Kaufert were three of four participants in the focus group). I was conscious of the potential conflict between their role as VP-Net co-investigators and thesis committee members. They also discussed the potential for a conflict of interest before they agreed to participate in the thesis committee and came to the conclusion that since they were not the only source of data for the evaluation, the benefits outweighed the potential risk for conflict. To address and minimize the potential conflict, my methodology and analysis were developed to ensure they were not the only source of data evaluating VP-Net and their answers were analyzed in conjunction with the other participants and data sources to produce the final outcomes of my study. While the intersection between my supervisor, my thesis committee, the participants in my study and the project being evaluated in my study presented a limitation, having all of these key individuals intimately involved also provided a large amount of data and a unique perspective on the project from the inside as well as the outside.

Final words.

The results of this research project suggest that before researchers can begin to understand, reflect and create space for the Elements of Inclusive Knowledge Translation each researcher needs to look within and reflect on their own research, their own practices, thoughts and beliefs of inclusion. Working on this project alongside the VP-Net team has taught me that, before a researcher can work to include people with disabilities in their research, they need to ensure inclusion in their own lives. It is at this point, when the space in their mind is created, that a researcher can move onto the Elements of Inclusive Knowledge Translation and incorporate them in their work.

The results also suggest that using flexibility is a critical part of research. Thus, rather than seeing the Elements of Inclusive Knowledge Translation as the end goal of this project and representative of the three communities of interest, the Elements will continue to evolve as we continue to address different situations in humanity.

It is my dream that researchers will use and continue to refine this short list of Elements of Inclusive Knowledge Translation and engage with people with disabilities to listen to their stories of exclusion and the power of inclusion. In doing so, my hope is that this will set in motion the process of inclusion, linking their head and hearts. There remains a gap in the literature regarding people with disabilities and knowledge translation. The Elements of Inclusive Knowledge Translation is one way to address this gap. I challenge researchers to include and address the Elements of Inclusive Knowledge Translation in their research and be part of the change towards more inclusive knowledge and research.

Appendix A

Terms

Terms of putting knowledge into action that are identified in the literature, where they are most used and their key components.

Term	Definition	Creator of Term	Where term is used	Key Components
Knowledge translation	The exchange, synthesis and ethically-sound application of knowledge- within a complex system of interactions among researchers and users- to accelerate the capture of the benefits of research for Canadians through improved health, more effective health services and products, and strengthen the health care system.	CIHR 2000	Canadian Healthcare	Emphasizes the interplay and reciprocal action between research creators and knowledge users.
	A dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the healthcare system	CIHR 2008	Canadian Healthcare	Emphasizes that knowledge translation is about applying research knowledge to improve the health care system. Indicates that thought needs to be given to the information that is translated and to the audience it is being shared with.

	The effective and timely incorporation of evidence-based information into the practices of health professionals in such a way as to effect optimal health care outcomes and maximize the potential of the health system.	The University of Toronto, Faculty of Medicine, Knowledge Translation Program 2004		The importance of integrating evidence-based information into clinical health care practices
	The synthesis, exchange, and application of knowledge by relevant stakeholders to accelerate the benefits of global and local innovation in strengthening health systems and improving people's health.	The World Health Organization 2005		Translation of knowledge will be by relevant stakeholders
	The multidimensional, active process of ensuring that new knowledge gained through the course of research ultimately improves the lives of people with disabilities, and furthers their participation in society.	The National Institute on Disability and Rehabilitation Research (NIDRR) 2005		Includes people with disabilities as beneficiaries of research (not necessarily as active knowledge exchangers)
	The collaborative and systematic review, assessment, identification, aggregation and practical application of high-quality disability and rehabilitation research by key stakeholders (i.e., consumers, researchers,	The National Center for the Dissemination of Disability Research (NCDDR) 2005		This definition is context-specific to people with disabilities as users and stakeholders. The NCDDR definition clearly states that the interaction is collaborative and two-way.

	practitioners, policy makers) for the purpose of improving the lives of individuals with disabilities.			
Knowledge transfer	A systematic approach to capture, collect and share tacit knowledge in order for it to become explicit knowledge. By doing so, this process allows for individuals and/or organizations to access and utilize essential information, which previously was known intrinsically to only one or a small group of people	Government of Alberta 2007	Outside healthcare fields	The process of transmitting knowledge to stakeholders to use. Criticized, as a unidirectional process of knowledge flowing from producers to stakeholders, and interpreted as the first step of disseminating knowledge to stakeholders but does not imply putting it into action.
Knowledge exchange	Collaborative problem-solving between researchers and decision-makers that happens through linkage and exchange. Effective knowledge exchange involves interaction between decision-makers and researchers and results in mutual learning through the process of planning, producing, disseminating, and applying existing or new research in decision-making.	The Canadian Health Services Research Foundation (CHSRF)	Health Services Researchers and Policy/Decision-Makers	To acknowledge researchers and decision-makers co-existing in terms of culture and perspectives on research and knowledge. interaction between researchers and decision-makers during the entire knowledge-to-action process.

Knowledge mobilization	Moving knowledge into active service for the broadest possible common good. Here knowledge is understood to mean any or all of (1) findings from specific social sciences and humanities research, (2) the accumulated knowledge and experience of social sciences and humanities researchers, and (3) the accumulated knowledge and experience of stakeholders concerned with social, cultural, economic and related issues	The Social Science and Humanities Research Council of Canada (SSHRC) 2009		The goal of SSHRC's initiatives is to provide stakeholders and all individuals who benefit from research results to have the information when they need it.
Research utilization	Including a variety of interventions aimed at increasing the use of knowledge to solve human problems	T. E. Backer 1993	Nursing	Definiton is focused on "solving human problems"
	The use of research findings in any and all aspects of one's work as a registered nurse	Estabrooks 1998		
	A process of using findings from conducting research to guide practice	Titler et al. 1999		
	The process by which scientifically produced knowledge is transferred to practice	Brown 1999		

	Research utilization is a specific kind of knowledge utilization whereby the knowledge has a research base to substantiate it. It is a complex process in which knowledge, in the form of research, is transformed from the findings of one or more studies into instrumental, conceptual, or persuasive utilization.	Estabrooks 2006		Putting knowledge into action
Implementation research	The scientific study of methods to promote the systematic uptake of clinic research findings and other evidence-based practices into routine practice and, hence, to improve the quality and effectiveness of health care.		United Kingdom and Europe	
Dissemination & Diffusion	Transmission of knowledge to increase stakeholders' awareness.			
Translational research	The transfer of science discoveries into clinical applications			Transferring of information into practice
Continuing education	Enhancing health care professionals' clinical competence			Increasing knowledge in practice

Appendix B

VP-NET Knowledge Translation Activities

VP-NET Knowledge Translation Activities

Date	Activity/ Initiative	Communities Engaged	Results/ Products Generated
2004	Letter of intent to be approved for Grant by CIHR	- VP-Net co-investigators - Funding agency	
July 2004	Received Letter of Award for CIHR Grant: New Emerging Teams- Palliative and End of Life Care		
2004-2006	Partnership with Council of Canadians with Disabilities (CCD)	- People with disabilities - CCD - Major disability organizations in Canada	- Jim Derksen as a member of VP-Net team
2005	Making a Will to Live: A Workbook for you, your proxy or substitute decision-maker and your doctor about the value of your life and your preferences in critical care situations		- Wiebe, R. (2005). Making a Will to Live: A Workbook for you, your proxy or substitute decision-maker and your doctor about the value of your life and your preferences in critical care situations. <i>Manitoba League for Persons with Disabilities</i> , Winnipeg, Manitoba, Canada.
October 5-	National Cancer	- Palliative Care providers	- Stienstra, D. (2005, October, 5-6). <i>National</i>

6, 2005	Research Institute (NCRI) Supportive and Palliative Care International Workshop		<i>Cancer Research Institute (NCRI) Supportive and Palliative Care International Workshop</i> Conference Presentation. Birmingham, UK.
November 3-4, 2005	Canadian Association for Community Living national conference	<ul style="list-style-type: none"> - People with disabilities - Disability activists - Disability organizations 	<ul style="list-style-type: none"> - Stienstra, D., & J. Derksen. (2005, November, 3-4). <i>End of Life Care and Decision-making</i>. Presented at the Canadian Association for Community Living national conference, Saskatoon, SK.
January-April 2006	VP-Net team co-taught a course in the Interdisciplinary Master's Program in Disability Studies at the University of Manitoba: Special Topics: End of life care in people with disabilities	<ul style="list-style-type: none"> - Students - VP-Net co-investigators - People with disabilities - Clinician - Policy makers - University of Manitoba - Professors 	
June 12-13 2006	Spring Institute: A Good life until the End: Palliative Care and People with Disabilities	<ul style="list-style-type: none"> - 66 participants - People working in palliative care - Members of the Canadian disability rights community - Dr. John Seely advised VP-NET from his perspective as a clinician - Michael Harlos: Head of Palliative Medicine at the 	<ul style="list-style-type: none"> - A number of presentations were made into a special issue in the Journal of Palliative Care: - Stienstra, D., & Chochinov, H. M. (2006). Vulnerability, disability, and palliative end-of-life care. <i>Journal of palliative care</i>, 22(3), 166. - This issue was distributed to all attendees of the 16th International Congress on the Care of the Terminally Ill

		<p>University of Manitoba and Medical Director of the WRHA's Palliative Care Program spoke at the Institute.</p> <ul style="list-style-type: none"> - Paul Daeninck: a palliative care physician, spoke at the institute - Adrienne Asch, Judith Heumann and Dr. Carol Gill all contributed 	
June 2006	<i>Voices at Dying, Dying to be Heard</i> , a one-act play by Dr. Heidi Janz	<ul style="list-style-type: none"> - People working in palliative care - Members of the Canadian disability rights community 	<ul style="list-style-type: none"> - Performed at the VP-Net Spring Institute in June 2006 - Performed at the 16th International Congress on the Care of the Terminally Ill in September 2006 - Janz, H. (2006, September). <i>Voices at Dying: Dying to be Heard</i>. Montreal, Quebec: McGill University.
September 2006	Presentation at the 16th International Congress of the Terminally Ill	<ul style="list-style-type: none"> - People working in palliative care - Members of the Canadian disability rights community 	<ul style="list-style-type: none"> - Chochinov, H.M., Stienstra, D., Lutfiyya, Z.M., Kaufert, J.M. & Derksen, J. (2006, September). <i>Advancing the dialogue: Disability and end of life care</i>. Paper presented at the 16th International Congress of the Terminally Ill, McGill University, Montreal, Quebec.
June 11-12	Think Tank: Wrestling	<ul style="list-style-type: none"> - 25 participants along with sign 	<ul style="list-style-type: none"> - Vulnerable Persons and End of Life New

2007	with End-of-Life and People with Disabilities	<p>language and French translators</p> <ul style="list-style-type: none"> - People with disabilities - Palliative care and other healthcare providers - Representatives of most major Canadian organizations of people with disabilities - Council of Canadians with Disabilities - Canadian Association for Community Living - Independent Living Canada - People First Canada - DisAbleD Women's Network - Catherine Frazee, from Disability Studies at Ryerson University, contributes to a community-based perspective - Dr. John Seely advised VP-NET from his perspective as a clinician 	<p>Emerging Team. (2007). <i>VP-Net 2007 Think Tank Report, June 11 & 12, 2007</i>. Winnipeg, MB: Lindsey Troschuk, Claire Atherton, Lea Neufeld.</p> <ul style="list-style-type: none"> - Synthesis and documentation of the knowledge and experiences of participants' vulnerability during end-of-life - A place to address the concerns of the community of people with disabilities around euthanasia and assisted suicide - Sign language and French translators - Dialogue created about the importance of appropriate and accessible palliative care for people with disabilities - From the Think Tank, the idea of Reclaiming Language was developed
2007	A,B,C & D of Dignity Conserving Care	<ul style="list-style-type: none"> - People with disabilities - Palliative care professionals 	<ul style="list-style-type: none"> - Chochinov, H.M. (2007). Dignity and the essence of medicine: the A, B, C and D of Dignity Conserving Care. <i>British Medical Journal</i>, 335 (7612),184-187.
January-April 2008	VP-Net team co-taught a course in the	<ul style="list-style-type: none"> - Students - VP-Net co-investigators 	

	Interdisciplinary Master's Program in Disability Studies at the University of Manitoba: Special Topics: End of life care in people with disabilities	<ul style="list-style-type: none"> - People with disabilities - Healthcare providers - Policy makers - University of Manitoba - Professors 	
September 2008	VP-Net brochure		<ul style="list-style-type: none"> - http://www.umanitoba.ca/outreach/vpnet/about.htm
October 27, 2008	Canadian Hospice Palliative Care Conference	<ul style="list-style-type: none"> - Palliative care providers 	<ul style="list-style-type: none"> - Stienstra, D. (2008, October 27). <i>Vulnerable Populations and Hospice Palliative Care</i>. Challenge Panel. Canadian Hospice Palliative Care Conference, Charlottetown, PEI.
December 2010	Knowledge Translation Grant awarded	<ul style="list-style-type: none"> - VP-Net co-investigators - People with disabilities - Healthcare providers - Policy makers 	
May 18, 2011	WRHA Palliative Care Educational Rounds	<ul style="list-style-type: none"> - 30 people - Palliative care providers 	<ul style="list-style-type: none"> - Chochinov, H.M, J. Derksen, D. Stienstra and J Kaufert. (2011, May 18). Better Care for All: Disability and End of Life Care. WRHA Palliative Care Educational Rounds. - Presentation, Web-Cast, discussion

June 19-22 2011	Canadian Public Health Association Meeting, Toronto, ON.	- 10 people	- Stienstra, D. (2011, June, 22). <i>Heightened Vulnerabilities and Better Care for All: Disability and End-of-life Care</i> . Presentation at Canadian Public Health Association Meetings, Montreal, QC. - Available: http://resources.cpha.ca/CPHA/Conf/Data/2011/A11-206e.pdf
November 24, 2011	Knowledge Translation Event: Halifax, N.S.	- 22 people - People with disabilities - Family members of people with disabilities - Healthcare policy makers - Healthcare practitioners	- Chochinov, H.M., Stienstra, D., Lutfiyya, Z., Kaufert, J., & Derksen, J. Vulnerable Populations NET Including: Good Palliative Care for All, Halifax November 26, 2011. - Presentation and Discussion
November 25, 2011	Knowledge Translation Event: Toronto, ON.	- 20 people - People with disabilities - Family members of people with disabilities - Healthcare policy makers - Healthcare practitioners	- Chochinov, H.M., Stienstra, D., Lutfiyya, Z., Kaufert, J., & Derksen, J. Vulnerable Populations NET Including: Good Palliative Care for All, Toronto November 27, 2011. - Presentation and Discussion
January 12, 2012	Knowledge Translation Event: Winnipeg, MB.	- 38 people - People with disabilities - Family members of people with disabilities - Healthcare policy makers - Healthcare practitioners	- Chochinov, H.M., Stienstra, D., Lutfiyya, Z., Kaufert, J., & Derksen, J. Vulnerable Populations NET Including: Good Palliative Care for All, Winnipeg January 12, 2012. - Presentation and discussion

January 20, 2012	Knowledge Translation Event: Calgary, AB.	<ul style="list-style-type: none"> - 43 people - People with disabilities - Family members of people with disabilities - Healthcare policy makers - Healthcare practitioners 	<ul style="list-style-type: none"> - Chochinov, H.M., Stienstra, D., Lutfiyya, Z., Kaufert, J., & Derksen, J. Vulnerable Populations NET Including: Good Palliative Care for All, Calgary January 20, 2012. - Presentation and discussion
February 2012	Special issue for the Journal of Palliative & Supportive Care		<ul style="list-style-type: none"> - Stienstra, D., & Chochinov, H. M. (2012) Palliative Palliative Care for Vulnerable Populations. <i>Journal of Palliative & Supportive Care</i>, 10(1), 37-42 <p>This Journal included:</p> <ul style="list-style-type: none"> - Chochinov, H. M., Cann, B., Cullihall, K., Kristjanson, L., Harlos, M., McClement, S. E., Hack, T.F., and Hassard, T. (2012). Dignity Therapy: A Feasibility Study of Elders in Long-term Care. <i>Journal of Palliative and Supportive Care</i>, 10(1), 3-15. DOI: http://dx.doi.org/10.1017/S1478951511000538. - Chochinov, H.M., Stienstra D. (2012). Vulnerability and Palliative Care. <i>Journal of Palliative and Supportive Care</i>, 10, 37-42. - Steinstra, D. & Chochinov, H.M. (2012). Palliative

			Care for Vulnerable Populations. <i>Palliative and Supportive Care</i> , 10(1), 37-42.
March 2012	Final Video “Big Ideas”	<ul style="list-style-type: none"> - People with disabilities - Healthcare providers 	- http://www.youtube.com/watch?v=t_DEpBW7gG0
May 2012	Disability Rights Promotion International Conference	<ul style="list-style-type: none"> - 20 people 	
July-September 2012	Ongoing distribution of VP-NET Knowledge Translation Packages	<ul style="list-style-type: none"> - People with disabilities - Family members of people with disabilities - Healthcare policy makers - Healthcare practitioners 	- USB keys complete with all project results, videos, and relevant publications from the project
2012	Distribution of VP-Net Knowledge Translation Event Packages	<ul style="list-style-type: none"> - In total 123 people in Halifax, Toronto, Winnipeg and Calgary - People with disabilities - Family members of people with disabilities - Healthcare policy makers - Healthcare practitioners 	- Participants distributed 75 additional packages of information
Ongoing	VP-Net Website for free downloadable information	<ul style="list-style-type: none"> - People with disabilities - Family members of people with disabilities - Healthcare policy makers - Healthcare practitioners 	- http://www.umanitoba.ca/outreach/vpnet/
	- VP- Net has attempted to change the way people think about disability, vulnerability and end-of-life care		

	<ul style="list-style-type: none">- Create a dialogue between the disability and palliative care community – a dialogue that is virtually unprecedented- VP-Net expanded the framework of palliative care, highlighting the influence of social, political and historical issues that influence health care delivery- VP-Net lead to the understanding of autonomy (personhood)
	<ul style="list-style-type: none">- Insights from publications and knowledge translation events were shared with palliative care clinicians and disability consumer groups- This built bridges between these disparate communities

Dignity Conserving Care Knowledge Translation Activities

Date	Activity/ Initiative	Communities Engaged	Results/ Products
2004	Engagement of multiple stakeholder groups	<ul style="list-style-type: none"> - Clinicians - Policy-makers - Organizations of people with disabilities 	<ul style="list-style-type: none"> - Institutes and workshops to share and further develop the understanding of vulnerability, disability and end-of-life care issues
2005	Presentation at the National Institutes of Health State of Science Conference		<ul style="list-style-type: none"> - Chochinov, H.M. (2005, December). <i>Improving Care at the End of Life</i>. Presentation at the National Institutes of Health State of Science Conference, Washington, DC.
2006	Disability and End-of-Life Care: Let the Conversation Begin	<ul style="list-style-type: none"> - People with disabilities - Healthcare providers - Dr. Carol Gill, Dr. Linda Kristjanson and Dr. Irene Higginson also contributed 	<ul style="list-style-type: none"> - Chochinov, H.M., & Derksen, J. (2006). Disability and end-of-life care: let the conversation begin. <i>Journal of Palliative Care</i>. 22(3):175-182. Interview by Harvey Max Chochinov.
2006	Dignity in the terminally ill: revisited		<ul style="list-style-type: none"> - Chochinov, H.M., Kristjanson, L., Hack, T., Hassard, T., McClement, S., & Harlos, M. (2006). Dignity in the terminally ill: revisited. <i>Journal of Palliative Medicine</i>, 9(3), 666-672.
2006	Presentation at the 8th World Congress of Psycho-		<ul style="list-style-type: none"> - Houmann, J., Rydahl, S., Kristjanson, L., Chochinov, H.M., & Groenvold, M. Implementaion and evalluation of Dignity Therapy in Denmark:

	Onocology		Experiences and cultural challenges. 8th World Congress of Psycho-Onocology. 2006.
2007	Formulation of the A, B, C and D of Dignity Conserving Care		<ul style="list-style-type: none"> - Chochinov, H.M. (2007). Dignity and the essence of medicine: The A, B, C and D of Dignity Conserving Care. <i>British Medical Journal</i>. 335(7612):184-187. - This project lead to a major knowledge translation project funded by the Winnipeg Regional Health Authority (\$5 million for the first two years), working towards operationalizing Dignity Conserving Care as a means of transforming the culture of health care throughout the health authority.
2007	Burden to others and the terminally ill		<ul style="list-style-type: none"> - Chochinov, H.M., Kristjanson, L., Hack, T., Hassard, T., McClement, S., Harlos, M. (2007). Burden to others and the terminally ill. <i>Journal of Pain and Symptom Management</i>, 34(5), 463-71.
2007	Presentation on The A, B, C and D of Dignity Conserving Care	<ul style="list-style-type: none"> - People with disabilities - Palliative care providers - Healthcare providers 	<ul style="list-style-type: none"> - Dignity and the Essence of Medicine. 2007 John Taylor Family Foundation Visiting Artist, Rochester, Minnesota; 2007 December 4
2008	The Patient Dignity Inventory: A novel way of measuring dignity related		<ul style="list-style-type: none"> - Chochinov, H.M., Hassard, T., McClement, S., Hack, T., Kristjanson, L., Harlos, M., Sinclair, S., & Murray, A. (2008). The Patient Dignity Inventory: A novel way of measuring dignity related distress

	distress in Palliative Care		in Palliative Care. <i>Journal of Pain and Symptom Management</i> , Dec. 36(6), 559 – 571.
2011	Dignity-Conserving Care – A New Model for Palliative Care: Helping the Patient Feel Valued		- Chochinov, H.M. Dignity-Conserving Care – A New Model for Palliative Care: Helping the Patient Feel Valued. Chapter 27 (pp 353-362) in: <i>Care at the Close of Life: Evidence and Experience</i> . McPhee, S.J., Winker, M.A., Rabow, M.W., Pantilat, S.Z., Markowitz, A.J. (eds). McGraw Hill 2011.
2011	The Dignity Therapy: Final Words for Final Days		- Chochinov H. The Dignity Therapy: Final Words for Final Days. New York, NY: Oxford University Press, 2011.
2012	Editorial in Palliative and Supportive Care		- Chochinov, H.M. Vulnerability and palliative care. Editorial in <i>Palliative and Supportive Care</i> , 2012 10: 1-2.
2012	Dignity Therapy: A Feasibility Study of Elders in Long-term Care		- Chochinov, H.M., Cann, B., Cullihall, K., Kristjanson, K., Harlos, M., McClement, S.E., Hack, T., & Hassard, H. (2012). Dignity Therapy: A Feasibility Study of Elders in Long-term Care. <i>Journal of Palliative and Supportive Care</i> , 10, 3-15.
2012	Comparative health care use patterns of people with schizophrenia near the end of life: A population-based study in Manitoba,		- Chochinov HM, Martens PJ, Prior HJ, Kredentser MS. (2012). Comparative health care use patterns of people with schizophrenia near the end of life: A population-based study in Manitoba, Canada. <i>Schizophrenia Research</i> . 2012 Nov; 141(2-3):241-246. August 20.

	Canada		
2012	The Patient Dignity Inventory: Applications in the oncology setting		- Chochinov, H.M., McClement, S., Hack, T., McKeen, N., Rach, A., Gagnon, P., Sinclair, S., & Taylor-Brown, J. The Patient Dignity Inventory: Applications in the oncology setting. <i>Journal of Palliative Medicine</i> , Vol. 15, No. 9, September 2012: 998- 1005.
2012	Vulnerability and Palliative Care		- Chochinov H.M., Stienstra D. (2012). Vulnerability and Palliative Care. <i>Journal of Palliative and Supportive Care</i> , 10: 37-42. -
2012	Presentation at the 19th International Congress on Palliative Care	- People with disabilities - Palliative care providers - Healthcare providers	- Dignity at the End of Life. (Keynote) October 10, 2012. 19th International Congress on Palliative Care, Montreal, PQ.
2012	Dignity in Care Project, Winnipeg Regional Health Authority		- Thompson, G., & Chochinov H. (2012). Understanding the Meaning of Dignity in Care in Personal Care Homes. <i>Dignity in Care Project</i> , Winnipeg Regional Health Authority.
2012	Dignity Conserving Care Research Summary		- Dignity Conserving Care Research Summary. Available: http://www.umanitoba.ca/outreach/vpnet/new.htm
Ongoing	Dignity Conserving Care Final Report: Research results		- VP-Net website http://www.umanitoba.ca/outreach/vpnet/dpc.htm

Policy Knowledge Translation Activities

Date	Activity/ Initiative	Communities Engaged	Results/ Products
2004	Finding Our Way Home: Housing Options in Inner-City Winnipeg for People with Disabilities Who Are Dying		- Stienstra, D., & Wiebe, R. (2004). <i>Finding Our Way Home: Housing Options in Inner-City Winnipeg for People with Disabilities Who Are Dying</i> . Canadian Centre on Disability Studies.
Summer and Fall 2005	Twenty (20) key informant interviews	Individuals with responsibility for palliative care policies and disability-related policies in the Canadian federal government, and the provincial governments of Alberta, Manitoba, Ontario and Newfoundland	- Policy summary available on the VP-Net website: http://www.umanitoba.ca/outreach/vpnet/new.htm
Summer and Fall 2005	Focus Groups done in partnership with CCD, Jim Derksen facilitating	People with disabilities in Edmonton, Alberta; Winnipeg, Manitoba; Ottawa, Ontario and St. John's, Newfoundland	- Discussion and identification of key issues for people with disabilities in accessing and using palliative and end of life care - Five fact sheets on: Vulnerability, Service provision, Decision Making, Informal Caregivers, Symptom Management. Available online: http://www.umanitoba.ca/outreach/vpnet/about-research-findings.htm
2006	Five Fact Sheets	- People with disabilities	- Five easy to read fact sheets on: Vulnerability,

		<ul style="list-style-type: none"> - Policy makers - Healthcare providers 	<p>Service provision, Decision Making, Informal Caregivers, Symptom Management</p> <p>http://www.umanitoba.ca/outreach/vpnet/about-research-findings.htm</p> <ul style="list-style-type: none"> - Distributed at all knowledge translation events - Available on the VP-Net website - Possible public policy advocacy strategies - Key outcomes of the research
April/May 2007	Community Forums to share the research findings and five fact sheets done in partnership with CCD, Jim Derksen facilitating	<ul style="list-style-type: none"> - People with disabilities - Palliative care providers - Policy makers - Edmonton, Winnipeg, Ottawa, St. John's 	<ul style="list-style-type: none"> - The held community forums and shared both the findings of the research and five fact sheets, which highlighted key outcomes of the research and suggested possible public policy advocacy strategies - Presentation and discussion
October 28, 2008	Hospice Palliative Care Conference, Charlottetown, PEI.		<ul style="list-style-type: none"> - Stienstra, D. (2008, October 27). <i>Vulnerable Populations and Hospice Palliative Care</i>. Challenge Panel. Presented at the Canadian Hospice Palliative Care Conference, Charlottetown, PEI.
2011-2012	Distribution of Five Fact Sheets	<ul style="list-style-type: none"> - People with disabilities - Policy makers - Healthcare providers 	<ul style="list-style-type: none"> - http://www.umanitoba.ca/outreach/vpnet/about-research-findings.htm
2012	Policy Issues, Palliative Care, and People with Disabilities Research Summary		<ul style="list-style-type: none"> - Stienstra, D., A. D'Aubin and J. Derksen. "Heightened vulnerabilities and better care for all: Disability and end-of-life care" <i>Journal of Palliative and Supportive Care</i>. 10,1 (Feb. 2012), 17-26.

			<ul style="list-style-type: none">- Policy Issues, Palliative Care, and People with Disabilities. Available: http://www.umanitoba.ca/outreach/vpnet/new.htm
			<ul style="list-style-type: none">- Identification of critical gaps in existing policies and programs related to palliative and end-of-life care- Gaps include: inequalities of continuity and coordination between disability-related supports and palliative care; disparities in decisions about when in-hospital care is required as a result of disability-related conditions (e.g. ventilator use); lack of recognition of disabled people as care providers, not only care recipients

Ethics and Decision-Making Knowledge Translation Activities

Date	Activity/ Initiative	Communities Engaged	Results/ Products
2004	Collaboration with Rhonda Wiebe, researcher and community activist	<ul style="list-style-type: none"> - Research - People with disabilities - Medical students 	- To ensure strong community collaboration in addition to developing innovative modules on disability perspectives on independent living and end-of-life care for first year medical students at the University of Manitoba
2007	Presentation at the Health, Ethics and Law Grand Rounds		- Kaufert J, Wiebe R, Derksen J. (2007, February, 14). <i>Alternative Frameworks for Decision-Making</i> . Presented at the Health, Ethics and Law Grand Rounds, Health Sciences Centre, Winnipeg, MB.
2007	Presentation at the Canadian Hospice and Palliative Care Conference		- Kaufert, J., Lutfiyya, Z., & Wiebe, R. (2007, November, 6) <i>Living, Dying and Disability: Media Portrayals and the Developing Professional Gaze</i> . Presented at the Canadian Hospice and Palliative Care Conference, Toronto, ON.
2007	Presentation in a research workshop, 2007 Canadian Hospice and Palliative Care Association Conference	<ul style="list-style-type: none"> - Healthcare providers 	- Kaufert, J., Wiebe, R. and Labine, L. (2007, November) <i>Developing the Professional Gaze: How Medical Students Learn about Disability and End-of-life</i> . Paper presented in a research workshop, 2007 Canadian Hospice and Palliative Care Association Conference, Toronto, ON.
2008	One-Day Forum: End-of-Life Ethics & Decision-Making:	<ul style="list-style-type: none"> - Healthcare providers - People with disabilities - Family members of 	- Kaufert, J., Schwartz, K., Wiebe, R., Derksen, J., Lutfiyya, Z., & Richert, D. (2013). Making “ethical safe space” in the translation of contested knowledge: The role of

	Current Policy Debates about Withholding and Withdrawing Life-sustaining Treatment	<p>individuals with disabilities</p> <ul style="list-style-type: none"> - Policy makers - Greg Webster involved in the planning work-group 	<p>community debate in defining end-of-life decision ethics. <i>Palliative and Supportive Care</i>, 11, 1-11. Doi: 10.1017/S1478951512000806</p> <ul style="list-style-type: none"> - Vulnerable Persons and End of Life New Emerging Team Ethics Theme. (2008). <i>End-of-Life Ethics and Decision-Making: Current Policy Debates about Withholding and Withdrawing Life-Sustaining Treatment Prepared for the Canadian Institutes for Health Research</i>. Winnipeg, MB: Rhonda Wiebe and Lea Neufeld (Eds.). - Available: http://www.umanitoba.ca/outreach/vpnet/about-events-ethicsevent.html - Plain Language Summaries: http://www.umanitoba.ca/outreach/vpnet/plainlanguage.html - Speakers and panelists presented legal, ethical, medical and disability rights perspectives on a current policy debate that has national implications. - Specifically the forum addressed the College of Physicians and Surgeons of Manitoba's 2007 statement on Withholding and Withdrawing Life-Sustaining Treatment
2009	Poster Presentation at the Canadian Conference of Medical Educators	- Conference of Medical Educators	<ul style="list-style-type: none"> - Wiebe, R., Stewart, G., Kaufert, J., & Derksen, J. (2009, May 3-4). <i>Introducing Medical Students to Perspectives on Independent Living and the Experiences of Persons with Disabilities</i>. Poster Presentation at the Canadian Conference of Medical Educators, Edmonton, AB. - Enhanced current curriculum content for under-graduate medical students regarding the fact that healthcare

			providers have little if no education about social constructions of disability and how barriers impede access
2010	End-of-life ethics and disability: differing perspectives on case-based teaching		- Kaufert, J., Wiebe, R., Schwartz, K., Labine, L., Lutfiyya, Z. M., & Pearse, C. (2010). End-of-life ethics and disability: differing perspectives on case-based teaching. <i>Medical Health Care and Philosophy</i> , 13,115-126.
2012	Religion, Spirituality Medical Education and Hospice Palliative Care		- Bramadat, P., & Kaufert, J. (2012) Religion, Spirituality Medical Education and Hospice Palliative Care. In P., Bramadat, H., Coward, & K., Stajduhar. (Eds.), <i>Beyond Traditions: Spirituality in Hospice Palliative Care</i> . State University of New York Press, in press.
2012	Seeking physical, cultural, ethical, and spiritual “safe space” for a “good death”		- Kaufert, J., Wiebe, R.,Lavalley, M., Kaufert, P. (2012). Seeking physical, cultural, ethical, and spiritual “safe space” for a “good death”. In H. Coward & K. I. Stajduhar (Eds.), <i>Religious understandings of a “good death” in hospice palliative care</i> (pp. 231-256). Albany: State University of New York Press.
2012	Ethics and End-Of-Life Care for Persons with Disabilities Research Summary		- Ethics and End-Of-Life Care for Persons with Disabilities . Available: http://www.umanitoba.ca/outreach/vpnet/new.htm
2013	Making “ethical safe space” in the translation of contested knowledge: The role of community debate		- Kaufert, J., Schwartz, K., Wiebe, R., Derksen, J., Lutfiyya, Z., & Richert, D. (2013). Making “ethical safe space” in the translation of contested knowledge: The role of community debate in defining end-of-life decision ethics. <i>Palliative and Supportive Care</i> , 11, 1-11. Doi:

	in defining end-of-life decision ethics		10.1017/S1478951512000806
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Social Valuation Knowledge Translation Activities

Date	Activity/ Initiative	Communities Engaged	Results/ Products
		Dr. David G. Race contributed to the work in this theme	
2005	Special imagery in the film Million Dollar Baby: An analysis based on Wolf Wolfensberger's Social Role Valorization		- Schwartz, K., Lutfiyya, Z.M. & Hansen, N. (2005). Special imagery in the film Million Dollar Baby: An analysis based on Wolf Wolfensberger's Social Role Valorization. <i>Disability Studies Quarterly</i> , 25(3).
2007	Presentation at the at the Canadian Hospice and Palliative Care Conference	- People with disabilities - Healthcare providers	- Kaufert, J., Lutfiyya, Z., Wiebe, R. (2007, November 6). <i>Living, Dying and Disability: Media Portrayals and the Developing Professional Gaze</i> . Presented at the Canadian Hospice and Palliative Care Conference, Toronto, ON.
2007	Presentation at the Canadian Hospice and Palliative Care Conference		- Lutfiyya, Z.M., & Schwartz, K. (2007, November, 6). <i>Whose end of life is it anyway? Media portrayals of people with disabilities at end of life</i> . Presented at the Canadian Hospice and Palliative Care Conference, Toronto, ON
2009	False images: Reframing the end-		- Lutfiyya, Z.M., Schwartz, K.D., & Hansen, N. (2009). False images: Reframing the end-of-life portrayal of disability in the film Million Dollar Baby in Sandra Shapsay (Ed.), <i>Movies and Bioethics</i> (225-241), Johns

	of-life portrayal of disability in the film <i>Million Dollar Baby</i>		Hopkins University Press, Baltimore, Maryland.
2009	‘What lay ahead...’: A media portrayal of disability and assisted suicide		- Schwartz, K., & Lutfiyya, Z.M. (2009). ‘What lay ahead...’: A media portrayal of disability and assisted suicide. <i>Journal of Research in Special Educational Needs</i> , 9(1), 27-38. Doi: 10.1111/j.1471-3802.2009.01113.x
2012	“In Pain Waiting to Die”: Everyday Understandings of Suffering		- Schwartz, K. D., & Lutfiyya, Z. M. (2012). “In Pain Waiting to Die”: Everyday Understandings of Suffering. <i>Journal of Palliative Care</i> , 10(1), 27-36.
2012	Social (de) Valuation Research Summary		- Social (de) Valuation . Available: http://www.umanitoba.ca/outreach/vpnet/new.htm

Reclaiming Language Knowledge Translation Activities

Date	Activity/ Initiative	Communities Engaged	Results/ Products
2009	Knowledge tools to share amongst people with disabilities to 'reclaim' language that devalues disability to more positive language practices	<ul style="list-style-type: none"> - People with disabilities - Catherine Frazee, from Disability Studies at Ryerson University, contributes to a community-based perspective 	<ul style="list-style-type: none"> - Helps to identify and change public discourse around disability and end-of-life
January 2012	Reclaiming Language Videos to meet different audiences	<ul style="list-style-type: none"> - People with disabilities 	<ul style="list-style-type: none"> - Videos for: General audience, healthcare practitioners audience, policy maker audience - http://www.youtube.com/watch?v=hQvc_QMLg6E&feature=plcp - http://www.youtube.com/watch?v=YRLTpyzUwLQ - http://www.youtube.com/watch?v=F_x_p1zqedE - http://www.youtube.com/watch?v=-Pcx_NJxBug

New Initiatives Knowledge Translation Activities

Date	Activity/ Initiative	Communities Engaged	Results/ Products
2009	Disability and Cancer Care: Additional funding from the Canadian Partnership Against Cancer	Paul Daeninck: a palliative care physician, helped VP-Net explore the interface between disability and cancer.	<ul style="list-style-type: none"> - An ancillary study on how experiences of disability (both pre-existing and as a result of cancer) affected cancer care. - The results illustrated the importance how the understanding disability will result in benefits for all cancer patients. People with disabilities experienced delayed detection and diagnosis of cancer, had complicated treatment experiences and adverse medication interaction as a result of their disability. Attitudinal, physical and information barriers continue to exist in cancer care for people with disabilities. - Links between disability and cancer care were created
2009	Women with Schizophrenia		<ul style="list-style-type: none"> - A series of studies we conducted amongst women with schizophrenia demonstrated how this population is under-screened for cancer of the breast and cervix/uterus. These findings have now been reported in Schizophrenia Research.
2009	Are cervical cancer screening rates different for women with schizophrenia? A Manitoba population- based		<ul style="list-style-type: none"> - Martens, P., Chochinov, H.M., Prior, H.J., Fransoo, R., & Burland, E. (2009). Are cervical cancer screening rates different for women with schizophrenia? A Manitoba population- based study. Schizophrenia Research. Aug;113(1): 101-6.

	study		
2009	Does a diagnosis of schizophrenia reduce rates of mammography screening? A Manitoba population-based study		- Chochinov, H.M., Martens, P., Prior, H.J., Fransoo, R., Burland, E. (2009). Does a diagnosis of schizophrenia reduce rates of mammography screening? A Manitoba population-based study. Schizophrenia Research. Aug; 113(1): 95-100.
2010	Report on Addressing disability in Cancer Care		- Annable, G., Stientra, D., & Chochinov, H.M. Addressing disability in Cancer Care. Canadian Partnership Against Cancer. March 2010.
2012	Comparative health care use patterns of people with schizophrenia near the end of life: A population-based study in Manitoba, Canada.		- Chochinov, H.M., Martens, P., Prior, H.J., & Kredentser, M.S. (2012). Comparative health care use patterns of people with schizophrenia near the end of life: A population-based study in Manitoba, Canada. Schizophrenia Research. 2012 Nov;141(2-3):241-246. August 20.
Submitted	Comparative mortality rates, cause and place of death of people with schizophrenia: A population-based study in Manitoba, Canada.		- Martens, P.J., Chochinov, H.M., & Prior, H.J. Comparative mortality rates, cause and place of death of people with schizophrenia: A population-based study in Manitoba, Canada. Schizophrenia Research.

*****All of the VP-Net Co-investigators indicated they have used their learnings and findings from the project in the way they present, teach and share knowledge. These initiatives have not been included in this table as they are beyond the scope of this study

Appendix C

Recruitment Emails

Initial Recruitment Email

Subject: VP-Net Follow-up

Body:

Greetings from the VP-Net team! We would like to once again thank you for your participation over the past year at the VP-Net events. We welcome any feedback about these events and our work around palliative and end of life care and people with disabilities.

One of our students, Eleni Wener is conducting a project on the knowledge translation strategy VP-Net used. Eleni is examining the assumptions in current research practices and how to make the sharing of knowledge and information more accessible and inclusive to everyone.

Based on the current literature, Eleni has created a list of indicators of "Inclusive Knowledge Translation" and she would like your feedback, comments and opinions about if you believe VP-Net was successful in meeting these indicators.

The project Eleni is embarking on is groundbreaking and we hope to share it with the public, healthcare providers and policy-makers to foster a future of best practices and stakeholder-driven in Inclusive Knowledge Translation.

As part of her research Eleni is looking for people with disabilities, healthcare providers and policy-makers to engage in a BRIEF interview. The interview will allow you to provide your opinion on the indicators Eleni has created and will be no longer than 30-45 minutes.

We encourage you to contact Eleni at wenereleni@gmail.com or 204.292.7167 and participate in this brief conversation to both help change the face of knowledge translation strategies and help with this research project. More information regarding participation is attached.

We appreciate your support and continued participation with the VP-Net project.

Dr. Deborah Stienstra and Dr. Harvey Max Chochinov

Second Recruitment Email

Subject: Reminder for VP-Net participants

Body:

Greetings once again from the VP-Net Team!

We would like to remind you of the groundbreaking work that Eleni Wener is embarking on.

Please take some time to review the past email that was sent (below) and we encourage you to participate in this project.

Your interview will be no longer than 30-45 minutes or if you prefer the information can be done through email.

We encourage you to contact Eleni at wenereleni@gmail.com or tel: [204.292.7167](tel:204.292.7167) and participate in this brief conversation to both help change the face of knowledge translation strategies and help with this research project. More information regarding participation is attached.

Dr. Deborah Stienstra and Dr. Harvey Max Chochinov



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Attachment to First and Second Recruitment Email

Dear VP-Net Participants,

I hope this letter finds you well. As you may recall, the Vulnerable Persons and End of Life New Emerging Team (VP-Net) was a five-year research project that brought together a team of investigators to explore the availability and accessibility of end-of-life care for people who experience socially-constructed vulnerability. VP-NET particularly targeted policy makers in health/palliative care as well as disability, palliative care providers, and the disability community using the theme: *Including: Good Palliative Care for All*.

From Nov 2011 to January 2012, knowledge translation sessions were held in Halifax, Toronto, Winnipeg and Calgary. Having attended one of these sessions, you are aware that they focused on: rethinking vulnerability, inclusive palliative care, ethical decision-making and meanings of words and pictures. VP-Net strived to conduct an Inclusive Knowledge Translation strategy, however there is yet to be an evaluation on if their goals were achieved. All individuals who attended a VP-Net knowledge translation session agreed to share their email addresses and have the list distributed to all participants. I attended the knowledge translation session held in Winnipeg and therefore I received the distributed participant list.

I am a graduate student doing a research project, examining the assumptions in current research practices and how to make the sharing of knowledge and information more accessible and inclusive to everyone. Based on the current literature I have created a list of indicators of Inclusive Knowledge Translation and I would like your feedback, comments and opinions if you believe VP-Net was successful at meeting these indicators.

I am looking for: people with disabilities, policy-makers and healthcare providers who want to share opinion on the VP-Net process and if YOU believe it was an inclusive experience. By participating, it will not be a big time commitment (30-45 minutes). Simply an in person conversation or via telephone, email or Skype and you will provide the insight needed for me to understand what YOU truly think.

The concept of Inclusive Knowledge Translation is a new and innovative way to translate, share, exchange and disseminate research knowledge.

This information may be used to inform new policies, future research projects and the successful spread of important findings. This research project has been approved by the Joint Faculty Research Ethics Board at the University of Manitoba.

If you are interested in participating in this study or would like to find out more information please contact Eleni Wener at (204) 292-7167 or wenereleni@gmail.com

Thank you for your consideration,
Eleni Wener

Appendix D

Consent Forms



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Consent Form: Interviews Phase 1

Project: Inclusive Knowledge Translation

Researchers: Eleni Wener, Masters Student (wenereleni@gmail.com), Disability Studies, WRTC

Approved by: University of Manitoba Joint Faculty Research Ethics Board

Complaints: Human Ethics Secretariat, 474-7122 (margaret_bowman@umanitoba.ca)

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I am doing an exploratory study, learning about the experiences of people with disabilities, policy-makers and healthcare providers with research and the sharing of research findings to understand how to share (translate) knowledge in accessible and inclusive ways. The focus of this research is to uncover the underlying assumptions that currently exist in the literature and identify barriers and facilitators to sharing knowledge and information.

The interview should take between 30-45 minutes. However, if you have a lot of information to share, it could take longer. I will ask you questions about your experiences at the VP-Net Events and your perspective of research and how to put knowledge into practice.

You are volunteering to participate so you can stop the interview at any time and you are free to **not** answer any question you don't want to. All information will be kept confidential. Only my research supervisor and I will be able to see your responses related to your name. The University of Manitoba may also look at the research records to see that the research is being done in a safe and proper way.

The information you give will be combined with the information collected from other narrative. Once all of this information has been collected and analyzed, I will create a final report. After I transcribe your interview, I will send you a copy of the transcript, via

email or mail, in order for you to verify its accuracy. As well, I will send you a copy of the themes, via email or mail, to give you the opportunity to provide your comments. If you would like a copy of the final report, one can be sent directly to you following the completion of this project. The timeline that will be created from this interview will be shared with the VP-Net co-investigators before their focus group so they can recall of the steps the VP-Net team undertook.

Your signature on this form indicates that you consent to this interview. The researcher will use a tape recorder during the interview, unless you request that I not use it.

This research will be used for my master's thesis. There will be no monetary compensation provided to participants. However, the researcher will engage in reciprocity for their time, by contributing her time to work with the VP-Net team after this project to ensure these Elements of Inclusive Knowledge Translation are shared with researchers, community organizations, put on VP-Net's website and sent to Knowledge Translation at the Canadian Institute of Health Research (CIHR).

There are minimal risks for participants. Supports will be provided to all participants, in the event that a participant becomes distressed or emotionally upset during or after the interviews.

Your signature on this form indicates that you have understood the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have any questions please contact Eleni Wener (wenereleni@gmail.com) at any time.

This research has been approved by the Joint Faculty Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 204-474-7122. A copy of this consent form has been given to you to keep for your records and reference.

I _____ (print name) understand what the study is about and what participation involves and the signature below means that I agree to participate.

(Signature)

(date)

(Signature of interviewer)

(date)

I wish to remain anonymous: YES NO

In order to verify accuracy the transcripts will be sent to you over the next few months for your approval. Would you also like to receive a copy of the themes which emerge to review and provide feedback if necessary?

YES

NO

I anticipate that the final report will be available at the end of May, 2012. Would you like a copy of the final report?

YES

NO

If yes for either question, please indicate how we can send the material to you by providing the best method here:

E-mail: _____

Address: _____



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Consent Form: Interviews Phase 2

Project: Inclusive Knowledge Translation

Researchers: Eleni Wener, Masters Student (wenereleni@gmail.com), Disability Studies, WRTC

Approved by: University of Manitoba Joint Faculty Research Ethics Board

Complaints: Human Ethics Secretariat, 474-7122 (margaret_bowman@umanitoba.ca)

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I am doing an exploratory study, learning about the experiences of people with disabilities, policy-makers and healthcare providers with research and the sharing of research findings to understand how to share (translate) knowledge in accessible and inclusive ways. The focus of this research is to uncover the underlying assumptions that currently exist in the literature and identify barriers and facilitators to sharing knowledge and information.

The interview should take between 30-45 minutes. However, if you have a lot of information to share, it could take longer. I will ask you questions about your experiences at the VP-Net Events and your perspective of research and how to put knowledge into practice.

You are volunteering to participate so you can stop the interview at any time and you are free to **not** answer any question you don't want to. All information will be kept confidential. Only my research supervisor and I will be able to see your responses related to your name. The University of Manitoba may also look at the research records to see that the research is being done in a safe and proper way.

The information you give will be combined with the information collected from other narrative. Once all of this information has been collected and analyzed, I will create a final report. After I transcribe your interview, I will send you a copy of the transcript, via email or mail, in order for you to verify its accuracy. As well, I will send you a copy of the themes, via email or mail, to give you the opportunity to provide your comments. If

you would like a copy of the final report, one can be sent directly to you following the completion of this project.

Your signature on this form indicates that you consent to this interview. The researcher will use a tape recorder during the interview, unless you request that I not use it.

This research will be used for my master's thesis. There will be no monetary compensation provided to participants. However, the researcher will engage in reciprocity for their time, by contributing her time to work with the VP-Net team after this project to ensure these Elements of Inclusive Knowledge Translation are shared with researchers, community organizations, put on VP-Net's website and sent to Knowledge Translation at the Canadian Institute of Health Research (CIHR).

There are minimal risks for participants. Supports will be provided to all participants, in the event that a participant becomes distressed or emotionally upset during or after the interviews.

Your signature on this form indicates that you have understood the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have any questions please contact Eleni Wener (wenereleni@gmail.com) at any time.

This research has been approved by the Joint Faculty Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 204-474-7122. A copy of this consent form has been given to you to keep for your records and reference.

I _____ (print name) understand what the study is about and what participation involves and the signature below means that I agree to participate.

(Signature)

(date)

(Signature of interviewer)

(date)

I wish to remain anonymous: YES NO

In order to verify accuracy the transcripts will be sent to you over the next few months for your approval. Would you also like to receive a copy of the themes which emerge to review and provide feedback if necessary?

YES

NO

I anticipate that the final report will be available at the end of May, 2012. Would you like a copy of the final report?

YES

NO

If yes for either question, please indicate how we can send the material to you by providing the best method here:

E-mail: _____

Address:



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Consent Form: Focus Group Phase 3

Project: Inclusive Knowledge Translation

Researchers: Eleni Wener, Masters Student (wenereleni@gmail.com) , Disability Studies, WRTC

Approved by: University of Manitoba Joint Faculty Research Ethics Board

Complaints: Human Ethics Secretariat, 474-7122 (margaret_bowman@umanitoba.ca)

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I am doing an exploratory study, learning about the experiences of people with disabilities, policy-makers and healthcare providers with research and the sharing of research findings to understand how to share (translate) knowledge in accessible and inclusive ways. The focus of this research is to uncover the underlying assumptions that currently exist in the literature and identify barriers and facilitators to sharing knowledge and information.

The focus group should take between 1-2 hours. However, if you have a lot of information to share, it could take longer. The narrative and document analysis has been provided to you in advance. I will ask you questions regarding if you believe the Elements of Inclusive Knowledge Translation were achieved by the VP-Net process.

You are volunteering to participate so you can stop the interview at any time and you are free to **not** answer any question you don't want to. All information will be kept confidential. Only my research supervisor and I will be able to see your responses related to your name, however you are aware that as a co-investigator your name in relation to the VP-Net project is public information. The University of Manitoba may also look at the research records to see that the research is being done in a safe and proper way.

The information you give will be combined with the information collected from other interviews. Once all of this information has been collected and analyzed, I will create a

final report. After I transcribe your interview, I will send you a copy of the transcript, via email or mail, in order for you to verify its accuracy. As well, I will send you a copy of the themes, via email or mail, to give you the opportunity to provide your comments. If you would like a copy of the final report, one can be sent directly to you following the completion of this project.

Your signature on this form indicates that you consent to this interview. The researcher will use a tape recorder during the interview, unless you request that I not use it.

This research will be used for my master's thesis. There will be no monetary compensation provided to participants. However, the researcher will engage in reciprocity for their time, by contributing her time to work with the VP-Net team after this project to ensure these Elements of Inclusive Knowledge Translation are shared with researchers, community organizations, put on VP-Net's website and sent to Knowledge Translation at the Canadian Institute of Health Research (CIHR).

There are minimal risks for participants. Supports will be provided to all participants, in the event that a participant becomes distressed or emotionally upset during or after the interviews.

Your signature on this form indicates that you have understood the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have any questions please contact Eleni Wener (wenereleni@gmail.com) at any time.

This research has been approved by the Joint Faculty Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 204-474-7122. A copy of this consent form has been given to you to keep for your records and reference.

I _____ (print name) understand what the study is about and what participation involves and the signature below means that I agree to participate.

(Signature)

(date)

(Signature of interviewer)

(date)

In order to verify accuracy the transcripts will be sent to you over the next few months for your approval. Would you also like to receive a copy of the themes which emerge to review and provide feedback if necessary?

YES

NO

I anticipate that the final report will be available at the end of May, 2012. Would you like a copy of the final report?

YES

NO

If yes for either question, please indicate how we can send the material to you by providing the best method here:

E-mail: _____

Address: _____

Appendix E

Interview Guides

Interview Guide- Phase 1

The former project manager and co-investigator will provide the researcher with as much documentation of the process that is available.

1. Please describe the process VP-Net undertook.
2. Are there any steps in the process that you recall were not documented?
3. Are there specific aspects of the process you believe contribute to the VP-Net events being inclusive and accessible?
 - a. If so, please describe them

Interview Guide- Phase 2

Name:

Age:

Please identify yourself as (select as many that apply):

- ☐ Person with a disability
- ☐ Policy-maker
- ☐ Healthcare provider

Research Questions

These questions are tools and guidelines to explore your personal experience during the VP-Net process and your perception of inclusivity. Any information that you would like to share that is not addressed in the questions, please do so. You are welcome to decline answering any question or end the interview at anytime without explanation.

Knowledge translation can be defined as the process or interaction that occurs between researchers and research users to share information and research findings to put this knowledge into action (CIHR, 2000; NIDDR, 2005, NCDDR, 2007). Knowledge translation is used to identify and close the gap between what information we know, and what we do with that knowledge (Graham, 2010).

1. Given the provided list of indicators of Inclusive Knowledge Translation do you think VP-Net was successful in reaching Inclusive Knowledge Translation?
2. Do you think VP-Net achieved two-way involvement and collaboration of participants and researcher in all aspects of the project?
 - a. If so, can you give me an example?
3. How do you think VP-Net did in identifying those missing or invisible in the research and research process?
 - a. Can you give me an example?

- b. If you don't think VP-Net was successful at achieving this indicator do you have a suggestion of what they could have done to achieve it?
- 4. Did you feel the session held in your city was able to meet your needs and was free of barriers?
 - a. Was the environment accessible?
 - b. Were there accessible formats?
 - c. Were there enough breaks?
 - d. If not, what barriers did you encounter?
- 5. As a participant at the VP-Net session, did you feel you were engaged in the process and knew what you were participating in?
 - a. Would you have liked additional information?
 - i. If so, in what areas?
- 6. Is there anything not covered in this list of indicators that you think would illustrate Inclusive Knowledge Translation?
 - a. If so, what?

Focus Group Guide- Phase 3

The focus group will occur after the VP-Net process has been analyzed. A summary of the narrative will be given to all of the VP-Net co-investigators (five individuals) in advance of the focus group to refresh their memories on the entire process that was undertaken. During the focus group the co-investigators will reflect on the following questions.

The questions are tools and guidelines to explore your personal perspectives on the VP-Net process and if the intended outcomes were achieved. Any information that you would like to share that is not addressed in the questions, please do so. You are welcome to decline answering any question or end the interview at anytime without explanation.

1. Based on the list of the Elements of Inclusive Knowledge Translation, do you think the process VP-Net undertook was considered *inclusive*?
 - a. What elements do you think were achieved?
 - b. What elements do you think were lacking?
2. Given the list of the Elements of Inclusive Knowledge Translation, are there any elements you would add?
3. Based on the process that was outlined, are there any elements of the VP-Net process you would like to add?

Supports:

- Crisis Line - 24 Hour Crisis Line **(204) 786-8686**
- Toll free **1-888-322-3019** TTY **(204) 784-4097**
- Manitoba Farm & Rural Support Services Stress Line: 1-866-367-3276
- Manitoba Farm & Rural Support Services Online counselling: www.ruralsupport.ca

Drop-In Counselling is available in the following communities:**Central/Downtown** (Klinik on Broadway)

545 Broadway, R3C 0W3

Mondays & Wednesdays Noon – 7:00 p.m.

Tuesdays, Fridays & Saturdays Noon – 4:00 p.m.

Transcona/River East/Elmwood (Access Transcona)

845 Regent Avenue West, R2C 3A9

One block west of Plesis Road

Tuesdays Noon – 7:00 p.m.

Times subject to change. Please call the Drop-In Line, (204) 784-4067, for current times and site closures or e-mail us at: dropin@klinik.mb.ca

Appendix F

Elements of Inclusive Knowledge Translation

1. Uncovering missing or invisible individuals in research
2. Engaging participants and researchers
3. Enabling flexibility
4. Providing accountability to communities involved
5. Involving communities from the beginning
6. Ensuring the right research is being done
7. Ensuring plain and clear language
8. Matching deliverables/ tools/ resources with communities' needs

Appendix G

Joint-Faculty Research Ethics Board Ethics Approval Certificate



**Research Ethics
and Compliance**

Office of the Vice-President (Research and International)

Human Ethics
208-194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Phone +204-474-8880
Fax +204-269-7173

APPROVAL CERTIFICATE

October 30, 2012

(Advisor - D. Stienstra)

TO: Eleni Wener
Principal Investigator

FROM: Wayne Taylor, Chair 
Joint-Faculty Research Ethics Board (JFREB)

Re: Protocol #J2012:163
"Inclusive Knowledge Translation"

Please be advised that your above-referenced protocol has received human ethics approval by the **Joint-Faculty Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement (2). **This approval is valid for one year only.**

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- If you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to the Office of Research Services, fax 261-0325 - please include the name of the funding agency and your UM Project number. This must be faxed before your account can be accessed.
- If you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Quality Management Office may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/orec/ethics/human_ethics_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.

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Research and Evaluation Branch Citizenship and Immigration Canada and Corporate

Performance and Evaluation Division Social Sciences and Humanities Research

Council.

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