



Inclusive Knowledge Translation

Eleni Wener¹, M.A.

Deborah Stienstra¹, Ph.D.
¹University of Manitoba, Disability Studies



Introduction

This three-phase qualitative 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. This research project was guided by the research question: "Using the indicators of inclusive knowledge translation (IKT), to what extent does VP-Net succeed in conducting inclusive knowledge translation?"

Vulnerable Persons and End of Life New Emerging Team (VP-Net)

- 5 year research project funded by CIHR

- Explored the availability and accessibility of end-of-life care for people who experience socially-constructed vulnerability.

- 4 themes: clinical, policy, ethics and social/cultural issues in end of life care.

- VP-NET targeted policy makers in health/palliative care, 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.

- Knowledge translation events held in Halifax, Toronto, Winnipeg and Calgary from November 2011 to January 2012.

Objectives

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

- The assumptions that are currently embedded in knowledge translation;
- The elements of inclusive knowledge translation;
- Current knowledge translation strategies such as VP-Net and evaluate if it was inclusive;
- Additional recommendations Canadian people with disabilities, policy-makers and healthcare providers have regarding how to conduct inclusive knowledge translation.

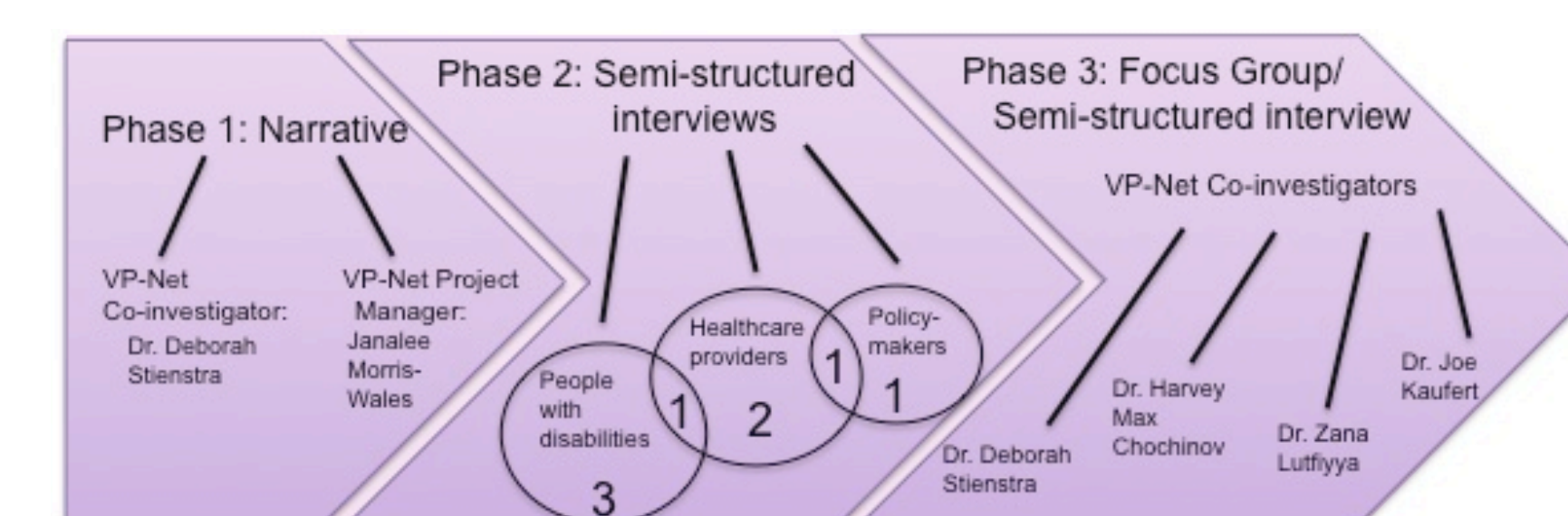
Acknowledgments

The authors would like to thank the individuals who agreed to participate in this study. This research was possible due to the work of the VP-Net Team and the Disability Studies Department at the University of Manitoba.

Table 1: Study participants

Phase	Number of Participants	Community of Interest
One	2	- VP-Net project manager - VP-Net co-investigator
Two	8	- 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	- 4 VP-Net co-investigators

Methods



Findings

Theme 1: Achieving Inclusive Knowledge Translation

Description: This theme encompassed participants views on if VP-Net achieved the Elements of Inclusive Knowledge Translation. Participants were asked if they wanted to add/delete anything from the *Elements of Inclusive Knowledge Translation*.

"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." - Palliative care healthcare provider

"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."
- Healthcare provider and policy-maker

Theme 2: Creation of Space for Culture Shifts Towards a Change

Description: Participants were asked in their interviews if they believed that the information and research that was created from the VP-Net events would be put into action with a goal for change. Seven out of a total of eight participants felt the work VP-Net has done will be useful for action.

"...Set the process in motion [and] created the knowledge so that others can move it forward. The culture change is about insight, and insight is not just about head, it's about heart." - Dr. Harvey Max Chochinov

Theme 3: Keeping the Conversation Flowing

Description: The VP-Net events appear to have been successful at achieving inclusivity of participants and creating a space for culture change. Participants who self-identified as healthcare providers (4), indicated that prior to the VP-Net events they were unaware of challenges persons with disabilities encounter.

"We can do much more to learn about how to support choices without inflicting our judgment." - Healthcare provider and policy-maker

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."

Elements of Inclusive Knowledge Translation

- Uncovering the missing or invisible in research
- Engaging participants and researchers
- Enabling flexibility
- Providing accountability to communities involved
- Involving communities from the beginning
- Ensuring the right research is being done
- Ensuring plain and clear language
- Matching deliverables/ tools/ resources with communities' needs

Conclusions

- Inclusive Knowledge Translation is a new and innovative concept.

- This study adds to the current research on knowledge translation and fills the gap regarding people with disabilities in the research process.

- This study provides insight into the real-life experiences of people with disabilities and the "research-world".

Conducting Inclusive Knowledge Translation:

1. Before a researcher can work to include people with disabilities in their research, they need to ensure inclusion in their own lives.

- Once space in your mind is created a researcher can move onto the Elements of Inclusive Knowledge Translation and incorporate them in their work.

2. Flexibility is key.

- The Elements of Inclusive Knowledge Translation are forever evolving to continuously meet the needs of humanity