

PROMISING PRACTICES FOR ENGAGING PEOPLE WITH SPINAL CORD INJURIES IN KNOWLEDGE MOBILIZATION

Tory Bowman¹, Heather L. Gainforth², Shane N. Sweet³, Peter Athanasopoulos¹, Nancy Xia¹, Dr. Mark Bayley⁴

¹Spinal Cord Injury Ontario, ²School of Health and Exercise Sciences, University of British Columbia – Okanagan, ³Department of Kinesiology and Physical Education, McGill University and Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal, ⁴University Health Network – Toronto Rehabilitation Institute

INTRODUCTION

- Recent calls have emphasized the importance of including people with spinal cord injuries (“consumers”) as partners in all stages of research (Cox et al, 2011).
- Canada’s Strategy for Patient-Oriented Research (SPOR) recognizes that a patient-oriented approach can lead to improvements in patient experience with the health system and health outcomes (Telford et al, 2004).
- Community-based organizations can help engage consumers in the knowledge mobilization process. Organizations have effectively developed initiatives and trained staff and peer volunteers to mobilize research evidence and share self-management strategies. (Gainforth et al, 2015).
- There remains an evidence gap in how to achieve and evaluate effective consumer involvement in knowledge mobilization and the effects of doing so (Nilsen et al, 2013).

PURPOSE

- To outline the need to engage consumers in the knowledge mobilization process and their desire to be involved.
- To propose a model and evaluation framework for consumer engagement in knowledge mobilization.

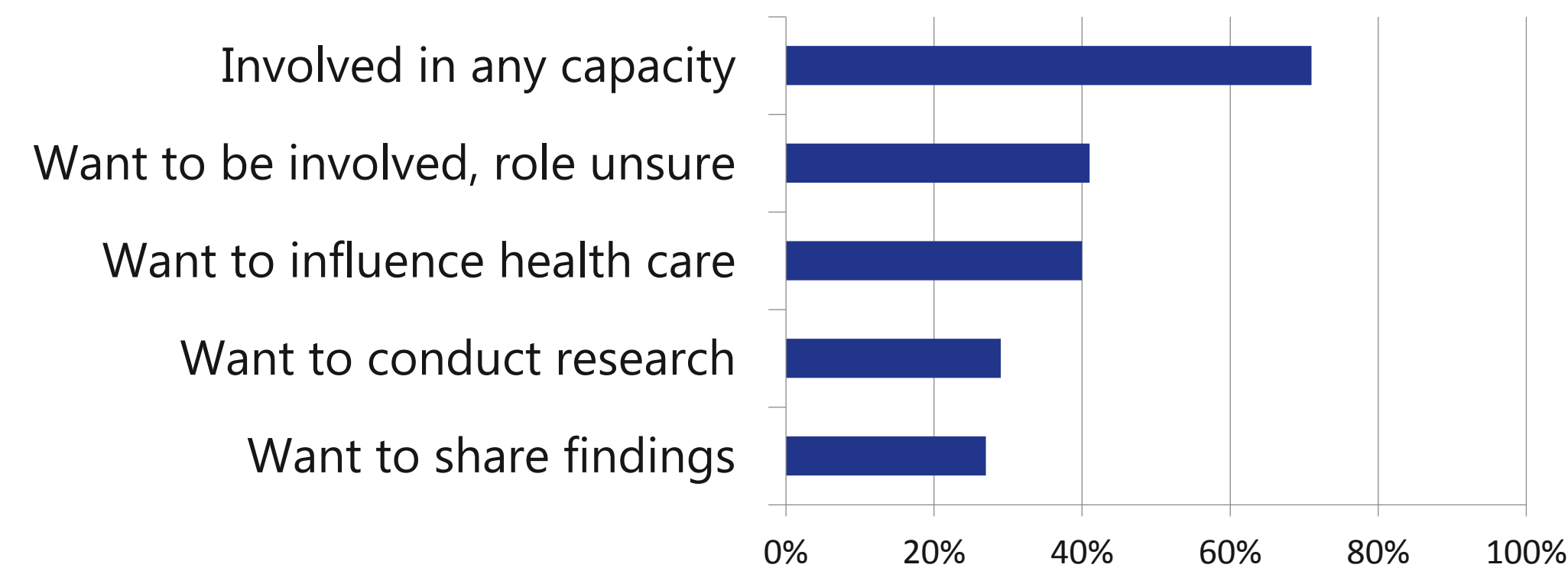
CONTEXT AND METHOD

- Our team includes academic researchers and community organization leaders with collective experience in:
 - stakeholder engagement via the Ontario SCI Solutions Alliance,
 - community-based knowledge mobilization relating to pressure sore prevention and treatment (Spinal Cord Injury Ontario, 2015),
 - examining the dissemination and uptake of the Physical Activity Guidelines for People with SCI within community-based organizations.
- Sources of data result from the team’s collective experience examining research engagement and knowledge mobilization in the SCI community.
- The PanCanadian Survey was developed by the NtoN Patient Engagement Team and distributed by organizations that support people with brain and spinal cord injuries across Canada.
- A total of 375 people answered the survey which included 153 adults with SCI.

RESULTS

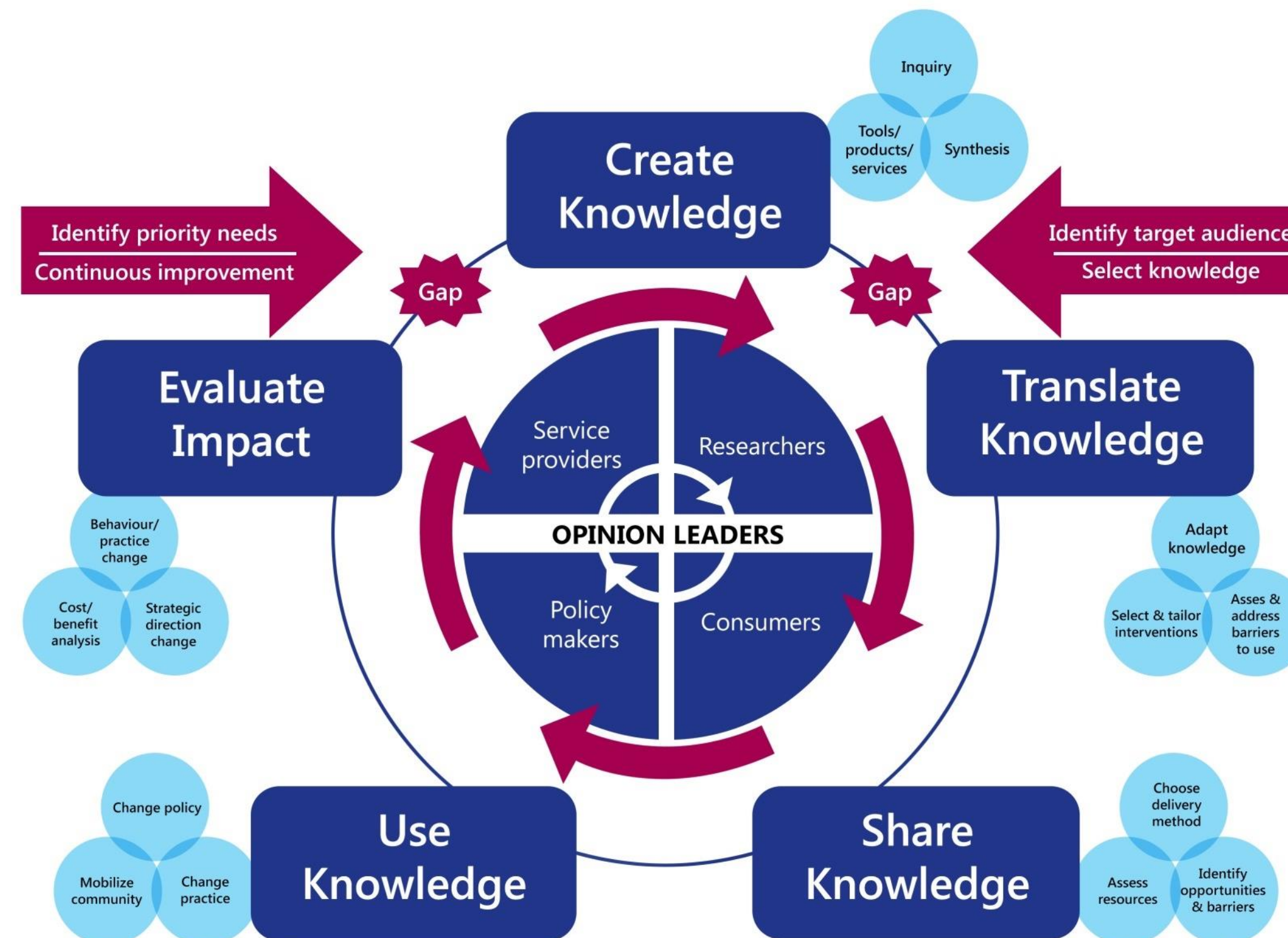
- Need:** 68 percent of people with SCI answered the question regarding their involvement in a consumer-research network.

PEOPLE WITH SPINAL CORD INJURIES WANT TO BE INVOLVED IN RESEARCH AND KNOWLEDGE MOBILIZATION



- Model:** Spinal Cord Injury Ontario designed a customized knowledge-to-action model that includes consumers as opinion leaders and engages key stakeholders (Graham et al, 2006).

CUSTOMIZED KNOWLEDGE-TO-ACTION MODEL



- Evaluation Framework:** The research team has successfully adapted the RE-AIM framework to examine the process of knowledge mobilization within SCI community-based organizations (Sweet et al., 2014).

ADAPTED RE-AIM FRAMEWORK TO EVALUATE AND MONITOR CONSUMER ENGAGEMENT IN KNOWLEDGE MOBILIZATION

RE-AIM	DESCRIPTION
REACH	The proportion and representativeness of consumers who are willing to participate and actively engage in knowledge mobilization.
EFFECTIVENESS	For each phase of the customized knowledge-to-action model: an assessment of the extent to which consumers felt they (a) were engaged in the knowledge mobilization process, and (b) actively mobilized knowledge.
ADOPTION	The proportion and representativeness of organizations that engaged consumers in knowledge mobilization.
IMPLEMENTATION	The extent to which organizations adhered to guidelines for engaging consumers in knowledge mobilization.
MAINTENANCE	(1) Proportion and representativeness of consumers who are still involved in knowledge mobilization at least six months later. (2) The proportion and representativeness of organizations that continue to engage consumers in knowledge mobilization at least six months later.

NEXT STEPS

- This model and framework shows promise as methods of achieving and evaluating consumer involvement in knowledge mobilization.
- We believe this is the first attempt to design a consumer engagement framework specific for knowledge mobilization in the SCI community.

ACKNOWLEDGEMENTS

We acknowledge Spinal Cord Injury Canada and its Corporate Members as the source of the PanCanadian Survey Identifying Research Priorities and Preferred Consumer Involvement in the NtoN Network data.

CONTACT: Tory Bowman, tory.bowman@sciontario.org or 1-877-422-1112 ext. 254