Rising the Tide: Practicing the Art and Developing the Science of Integrated Knowledge Translation

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#ktconnects @hgainforth
Rising The Tide

Practicing the Art and Developing the Science of Integrated Knowledge Translation

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School of Health and Exercise Science, ICORD Principal Investigator
Michael Smith Foundation for Health Research Scholar
We are stuck on repeat

How it's supposed to work:

1. Write grant
2. Get $
3. Do research
4. Publish results
   
   Repeat

WWW.PHDCOMICS.COM
We are stuck on repeat

We are sacrificing real world impact.
Integrated Knowledge Translation (IKT)

“How can I help?”

Spinal Cord Injury British Columbia
Integrated Knowledge Translation (IKT)

“HOW CAN I HELP?”

Bourke, Chernesky, Gainforth, Shepherd, 2018
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Bourke, Chernesky, Gainforth, Shepherd, 2018
A rising tide...

Health promotion, behaviour change, knowledge translation, and spinal cord injury
A rising tide... lifts all boats

We need to change the system
1. Provide an overview of IKT concepts and frameworks

2. Discuss the emerging science examining IKT research partnerships

3. Discuss recommendations for developing meaningful IKT partnerships
Across Research Disciplines and Populations

- Youth Sport
- Diabetes & Chronic Disease
- Brain Injury
- Spinal Cord Injury

INTEGRATED KNOWLEDGE TRANSLATION (IKT)
Across Research Disciplines and Populations

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INTEGRATED KNOWLEDGE TRANSLATION (IKT)
Spinal Cord Injury (SCI) 101

• Damage to the spinal cord due to trauma or disease

• Increase in life expectancy

• ~86,000 Canadians

• Few efforts have focused on promoting healthy behaviours
Integrated Knowledge Translation (IKT)

“How Can I Help?”

Spinal Cord Injury British Columbia
Partnered Projects

What is the magic of SCI peer mentorship?
Partners: SCI BC, SCI Alberta, SCI Ontario, SCI Canada, Abilities New Brunswick

How can we support people aging with SCI to participate in society?
Partners: SCI BC, SCI Alberta, SCI Ontario; Graduate Student: Emily Giroux

How can we support family and friends of people with SCI?
Partners: SCI BC, SCI Alberta, SCI Ontario; Graduate Student: Rhyann McKay

What was the impact of the RHI’s Praxis Conference?
Partner: Rick Hansen Institute
“So, packing into the SCI community to share data, disseminate data and information and to gain input on the design of trials or the design of implementation. Actually, having people with SCI as partners in all of these different aspects could really, I mean and they can enhance recruitment for other trials. They can spread the word about clinical interventions that are trying to be implemented into hospitals or clinical care. They can be influential on their communities about that. I mean there's so many ways that people with spinal cord injuries can be helpful.”

- Praxis Attendee
“We need the system to change”

“Nothing about us without us”
Tokenism

When a person with SCI or organization is asked to endorse, and therefore legitimize, research programs over which they have little real control.
How can I help?

1. Conduct research that helps us understand how to combat tokenism and meaningfully engage people with spinal cord injury in research.

2. Develop and evaluate tools, resources, and interventions to support meaningful IKT research partnerships for three target audiences:
   - Researchers
   - Research Users
   - Research Funders
The Black Box of Partnership

What fosters meaningful partnerships?

What are the outcomes and impacts of partnerships?
The Black Box of Partnership

IKT Guiding Principles for Conducting and Disseminating SCI Research

Advancing the Science of Integrated Knowledge Translation with Health Researchers and Knowledge Users
Leads: Kathryn Sibley and Heather Gainforth

Integrated Knowledge Translation Research Network
Lead: Ian Graham
Partner: Michael Smith Foundation for Health Research

Canadian Disability Participation Project
PI: Kathleen Martin Ginis; KT Lead: Heather Gainforth; Postdoctoral Researcher: Femke Hoekstra
The Black Box of Partnership

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A rising tide lifts all boats

Integrated Knowledge Translation (IKT) Guiding Principles
Our Leadership Panel

A team of multidisciplinary SCI researchers, clinicians, organizations, funders, and research users with IKT experience.
Knowledge-to-Action Framework

- Developed to provide conceptual clarity regarding the key aspects of KT

- Two interacting phases:
  1. Knowledge Creation
  2. Action Cycle

(Graham et al., 2006)
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Knowledge Creation

Knowledge Inquiry & Synthesis

- Review of Reviews
- Scoping Reviews
- Interviews with IKT Champions
- Delphi Consensus Methods
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- Scoping Reviews
- Interviews with IKT Champions
- Delphi Consensus Methods
A review protocol on research partnerships: a Coordinated Multicenter Team approach

Hoekstra*, Mrkla*, Sibley, Nguyen, Vis-Dunbar, Neilson, Crockett, Gainforth*, Graham*

In Press in Systematic Reviews
A review protocol on research partnerships: a Coordinated Multicenter Team approach

Hoekstra*, Mrklas*, Sibley, Nguyen, Vis-Dunbar, Neilson, Crockett, Gainforth*, Graham*
Reviews of the IKT Literature

Review of Reviews
Hoekstra et al.

- **84 reviews describing research partnerships**

- **166 principles extracted**
  - 17 overarching principles
  - E.g. Partners are flexible and creative in their collaborative research activities.

- **116 strategies**
  - 11 overarching strategies
  - E.g. Use a variety of methods to facilitate communication (e.g. email, discussion, surveys, photovoice).
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Advancing Consensus Methods

- Community-based Delphi with SCI peer mentors

- Compare Consensus Methods in IKT (BC Support Unit)
  - PI: Nelly Okele; Cols: Banner-Lukaris, Plamondon, Sibley

- Large Scale Community-Based Delphi Methods with the SCI Community
  - >2500 people in the SCI community
Advancing Consensus Methods

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Knowledge Creation

3 Knowledge Product
- AGREE II Guiding Principle Meeting

Leadership Panel
Action Cycle

- Implement and Evaluate the Guiding Principles

- Three Target Audiences:
  1. Researchers
  2. SCI Stakeholders
  3. Funders

(Graham et al., 2006)
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Three Target Audiences:

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(Graham et al., 2006)
Together we will rise the tide

Develop, implement, and evaluate the first integrated knowledge translation guiding principles for conducting and disseminating research in partnership with the spinal cord injury community.
1. Provide an overview of IKT concepts and frameworks

2. Discuss the emerging science examining IKT research partnerships

3. Discuss recommendations for developing meaningful IKT partnerships
Rising The Tide

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Guidance in the meantime...

- Michael Smith Foundation for Health Research

Commitment Issues: Part 1
Posted on January 17, 2017

Commitment Issues: Part 2
Posted on January 25, 2017
From a community perspective

• Arrive early and get to know me and my organization
• Listen carefully
• Speak the same language
• Be relevant
• Bring value
• Be respectful
From a researcher perspective

- Start by asking ‘How can I help?’
- Foster an equal partnership
- Be compassionate
- Be in it for the long-term
- Report and evaluate
Engage Early, Engage Often

HOW TO ENGAGE PEOPLE WITH LIVED EXPERIENCE IN SCI RESEARCH

**RESEARCH QUESTION**
- Collaborate to develop and refine a question that matters to people with SCI.

**FUNDING APPLICATION**
- Involve people with SCI in the grant development and review process.

**ANALYZE DATA & PUBLISH**
- Integrate people with SCI as equitable members of the research team.

**CONDUCT RESEARCH**
- Partner to design a study that people with SCI want to participate in.

**ENGAGE EARLY, ENGAGE OFTEN.**

**HOW CAN I HELP?**

**DOs AND DON'Ts: OUR RECOMMENDATIONS**

- Engage broadly — “If you’re not one person with SCI, you’re not one person with SCI.”
- Avoid tokenism — Meaningfully involve people with lived experience throughout the entire research process.
- Set clear expectations — Establish rules of engagement early on and revisit them regularly.
- Be aware of power dynamics — Ensure all team members respect each other’s contributions.
- Treat everyone fairly — Compensate everyone for their time, travel, expertise, and efforts.
- Recognize experience — People who live with SCI are experts at living with SCI, and their knowledge needs to be honoured, explored, and integrated.

**RESOURCES**

- RCI Consumer Program Roadmap — [achthanseninstitute.org](http://achthanseninstitute.org)
- ICTY Guiding Principles — [alzblog.eth.org](http://alzblog.eth.org)
- NACR — [nacc.org/our-nacc](http://nacc.org/our-nacc)
- IAP2 Spectrum of Engagement — [iap2.org](http://iap2.org)
- Engage 2020 Action Catalogue — [actioncatalogue.ca](http://actioncatalogue.ca)
- George and Paya Ye Public & Patient Engagement Mapping Tool — [chims.ca](http://chims.ca)

**CONTACT US**

Bourke, Chernesky, Gainforth, Shepherd, 2018
DOs AND DON’Ts: OUR RECOMMENDATIONS

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- Treat everyone fairly — Compensate everyone for their time, travel, expertise, and efforts
- Recognize experience — People who live with SCI are experts at living with SCI, and their knowledge needs to be honoured, explored, and integrated
- Build capacity — Support people with SCI to gain the necessary knowledge, opportunities, and skills to be meaningfully engaged in the research process
- Remember that everyone has ownership — Partners are co-authors
Rising The Tide
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- Dr. Wolfe Tetzlaff

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Thank You

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Questions?
Your feedback is important to us

Please take a few moments to share your thoughts on today’s webinar. Your comments and suggestions help to improve the resources we offer and to plan future webinars.

A survey link will be posted in the chat panel and emailed shortly after the webinar.
More resources

- For more information on KT and to explore our resources, visit www.msfhr.org/our-work/activities/knowledge-translation

- Archived webinar recordings: www.msfhr.org/ktconnects

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www.arthritisresearch.ca