



THE UNIVERSITY OF BRITISH COLUMBIA

Rising The Tide

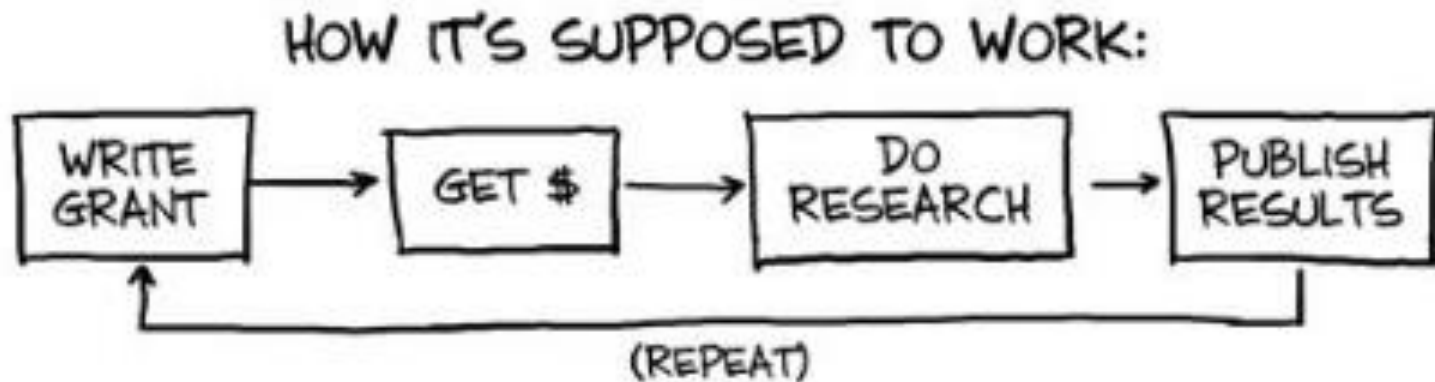
*Practicing the Art and Developing the Science
of Integrated Knowledge Translation*

Dr. Heather Gainforth

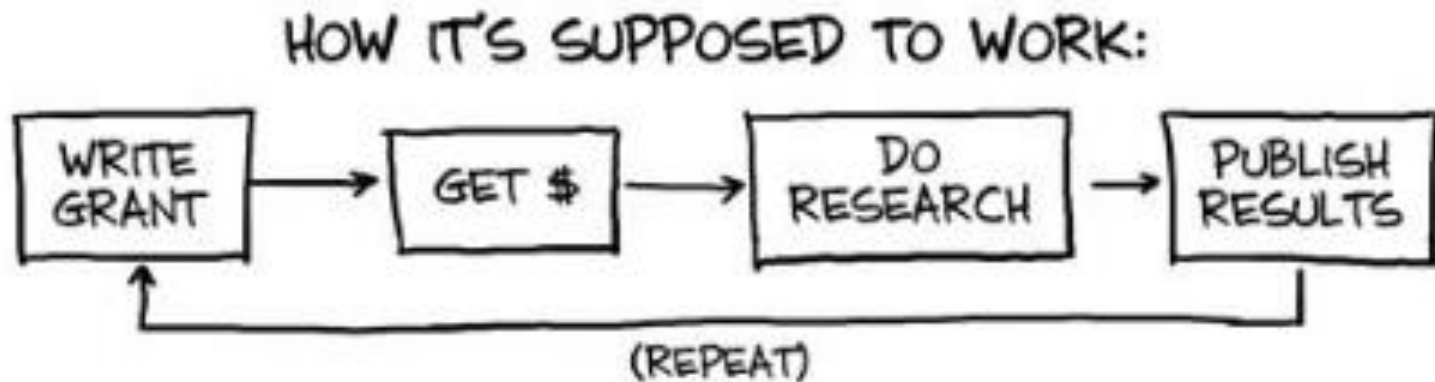
@hgainforth

*School of Health and Exercise Science, ICORD Principal Investigator
Michael Smith Foundation for Health Research Scholar*

We are stuck on repeat



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)

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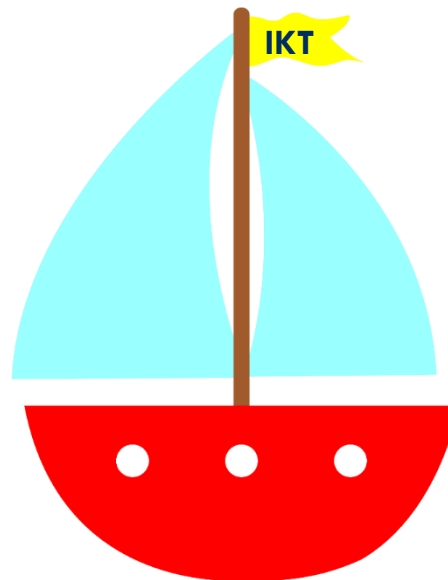


Integrated Knowledge Translation (IKT)

“HOW CAN I HELP?”

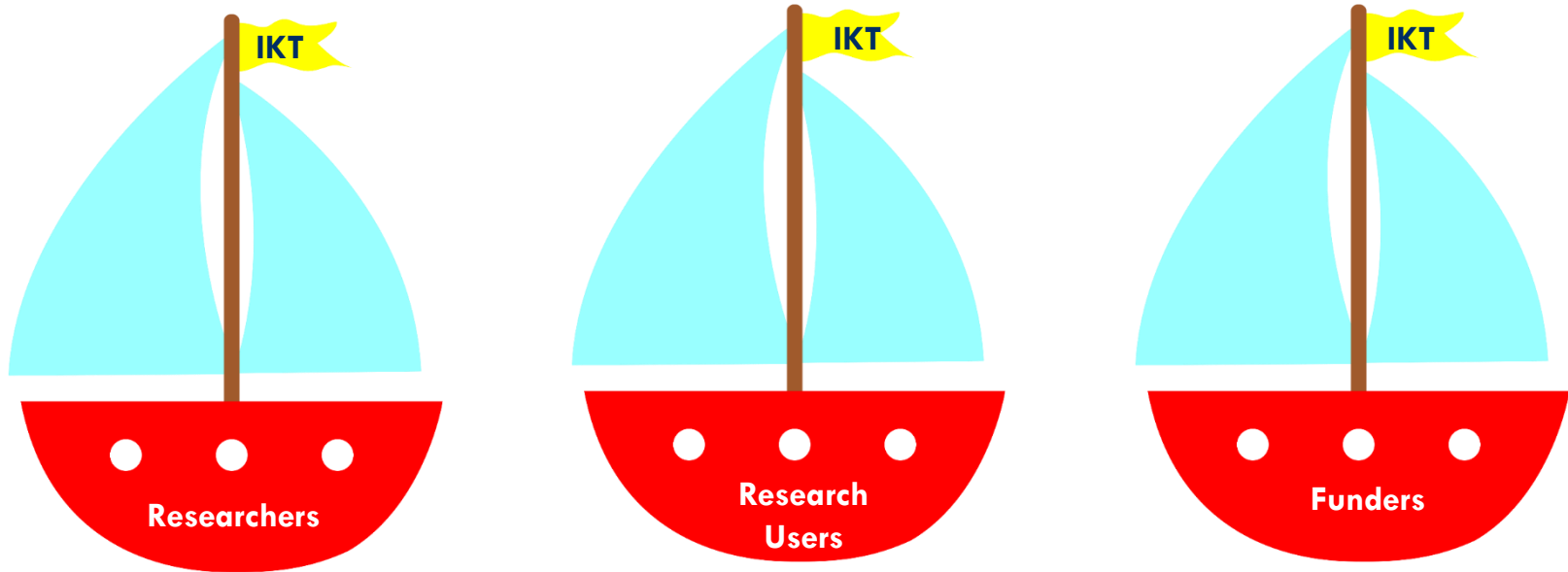


A rising tide...



Health promotion, behaviour change,
knowledge translation, and spinal cord injury

A rising tide... lifts all boats



We need to change the system

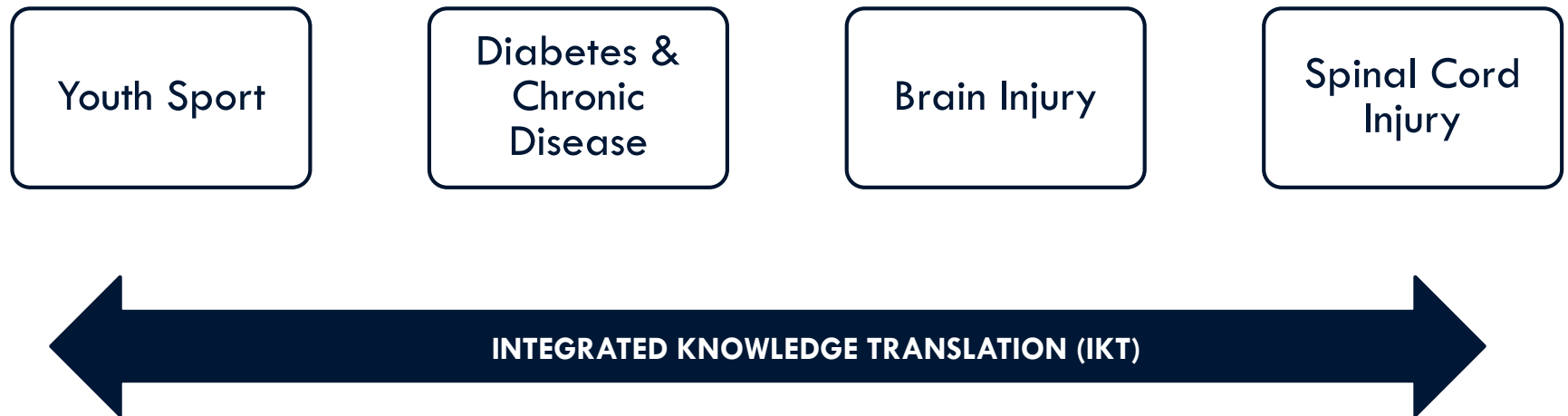


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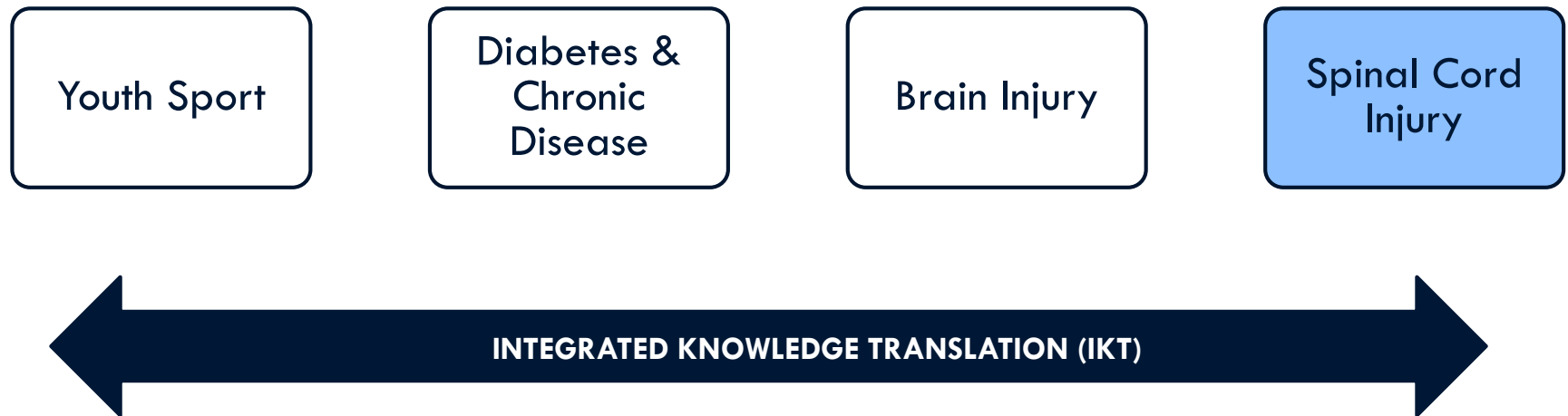
Rising The Tide

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

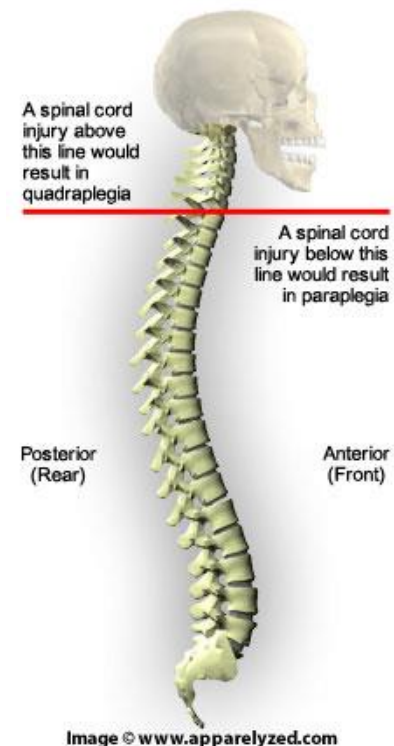


Across Research Disciplines and Populations



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



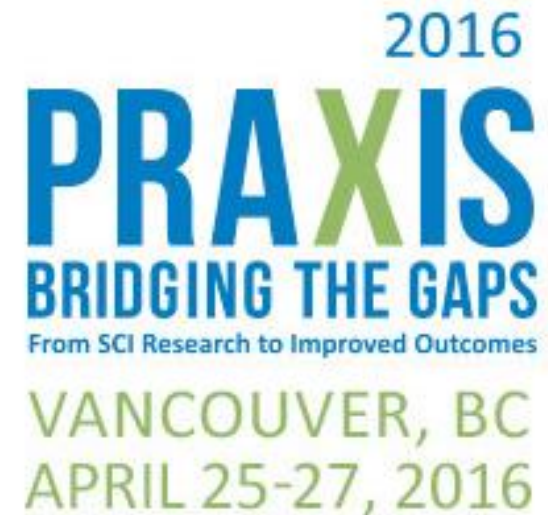
What was the impact of the RHI's Praxis Conference?

Partner: Rick Hansen Institute

Praxis 2018 – Engagement is Needed

“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 SCl 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



The Black Box of Partnership



IKT Guiding Principles for Conducting and Disseminating SCI Research

Partners: ICORD, Michael Smith Foundation for Health Research, North American SCI Consortium, Ontario Neurotrauma Foundation, Ontario SCI Alliance, Rick Hansen Institute, SCI Alberta, SCI BC, SCI Canada, SCI Ontario



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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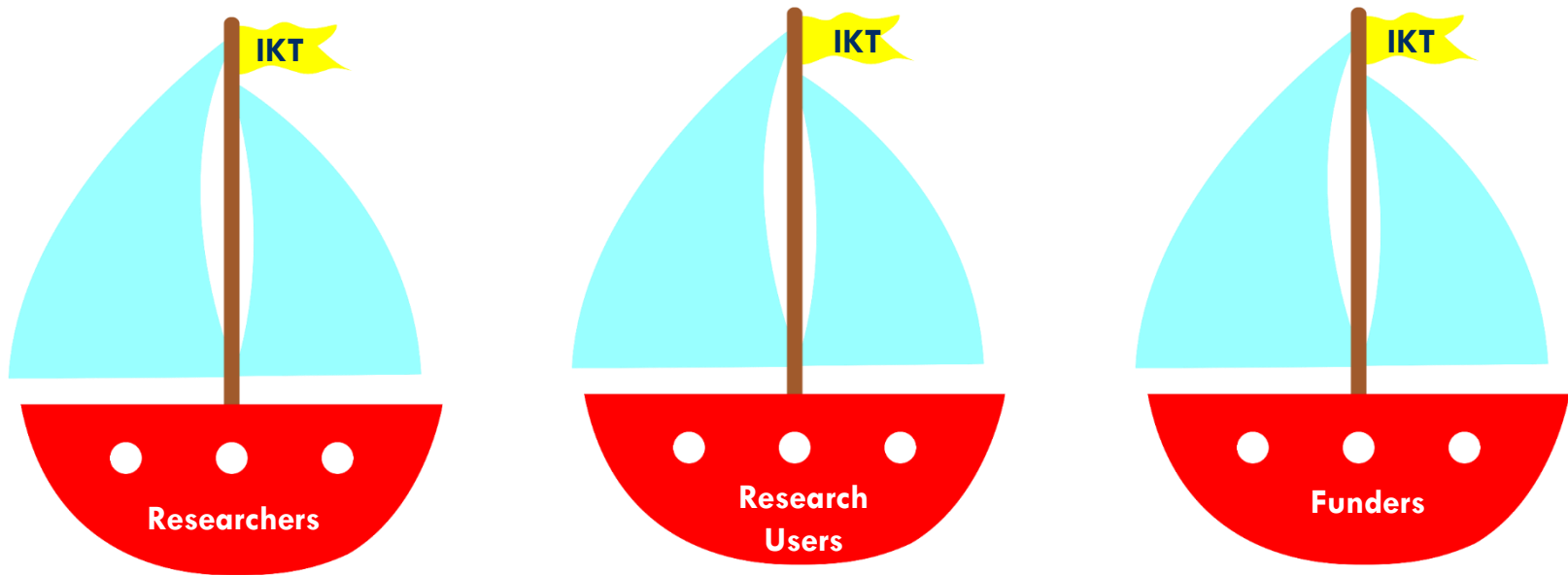
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A rising tide lifts all boats



Integrated Knowledge Translation (IKT) Guiding Principles



Our Leadership Panel

A team of multidisciplinary SCI researchers, clinicians, organizations, funders, and research users with IKT experience.

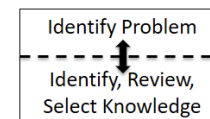


Knowledge-to-Action Framework

- Developed to provide conceptual clarity regarding the key aspects of KT
- Two interacting phases:
 1. Knowledge Creation
 2. Action Cycle

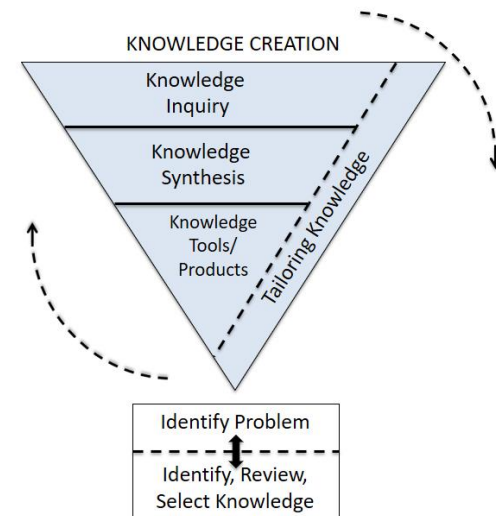
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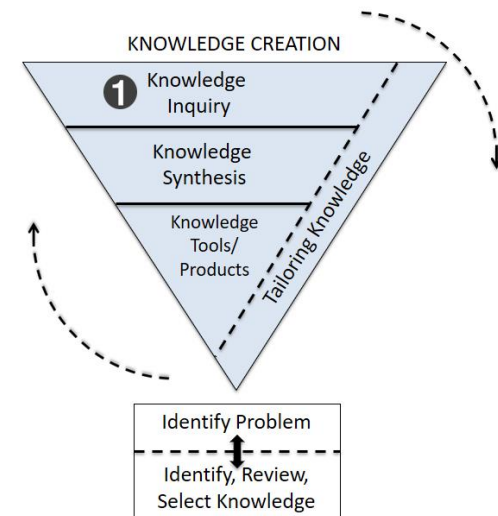
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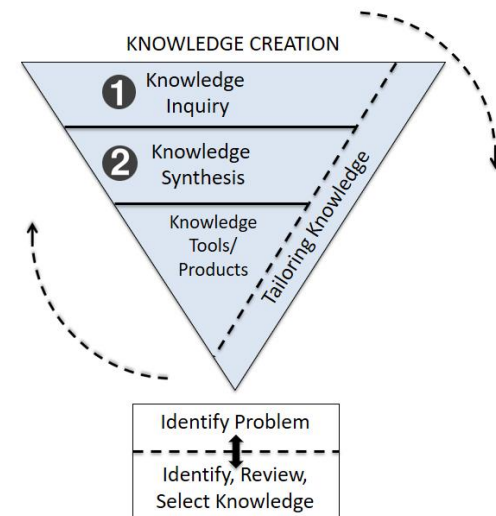
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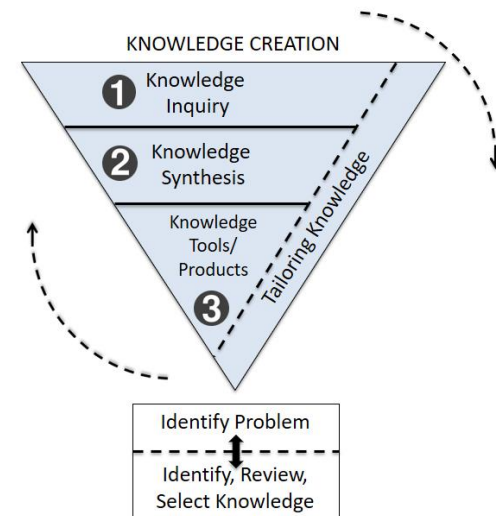
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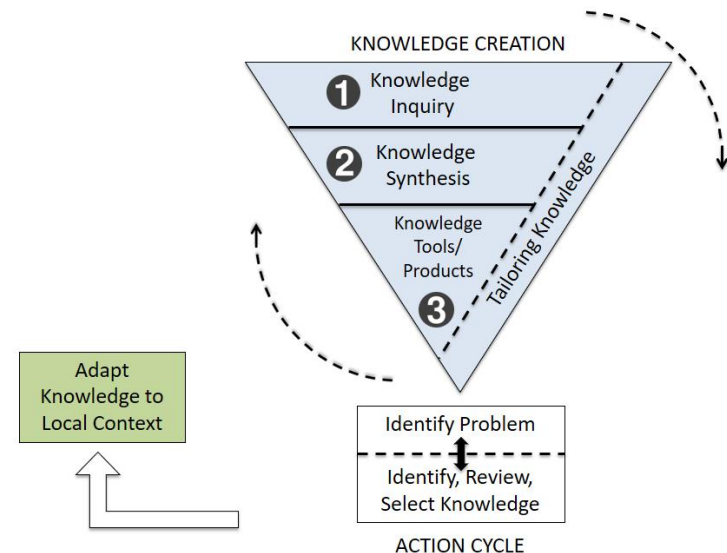
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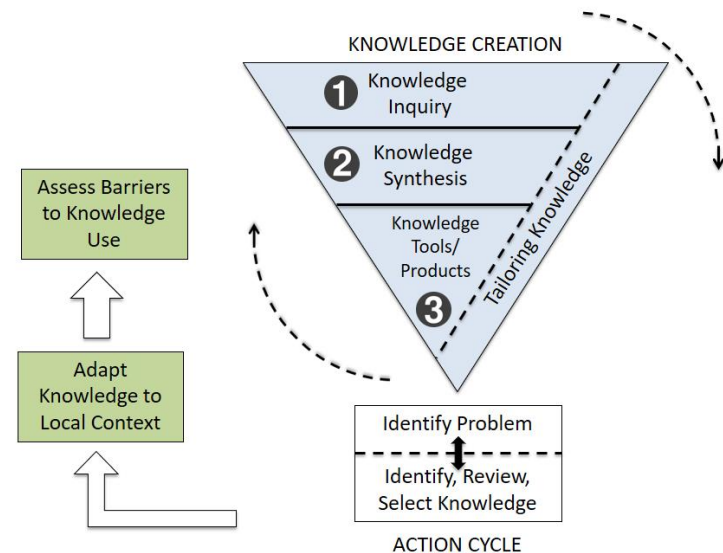
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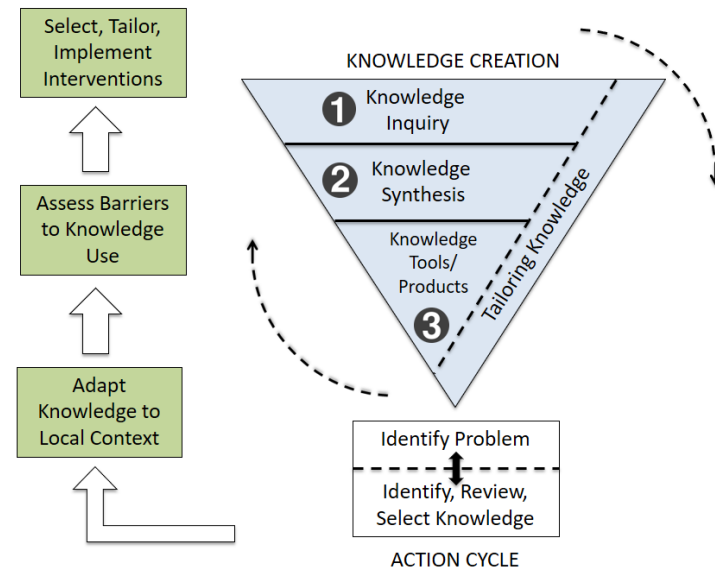
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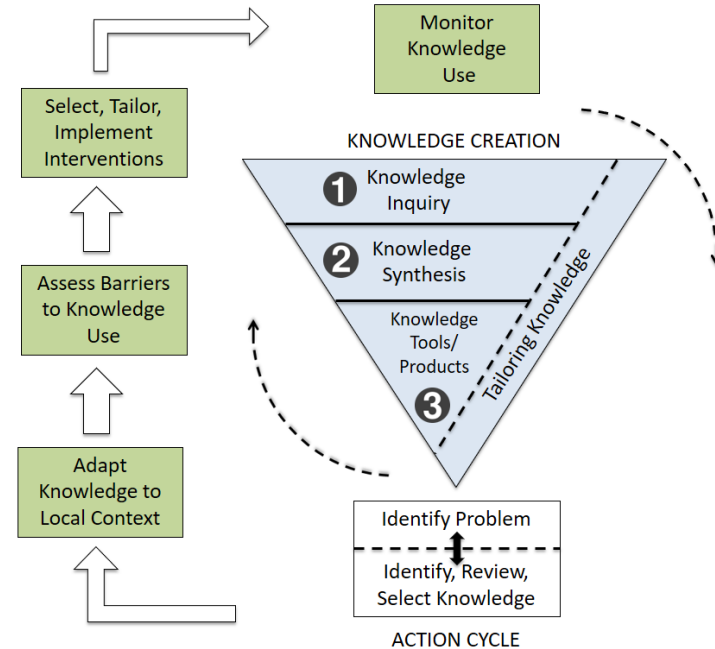
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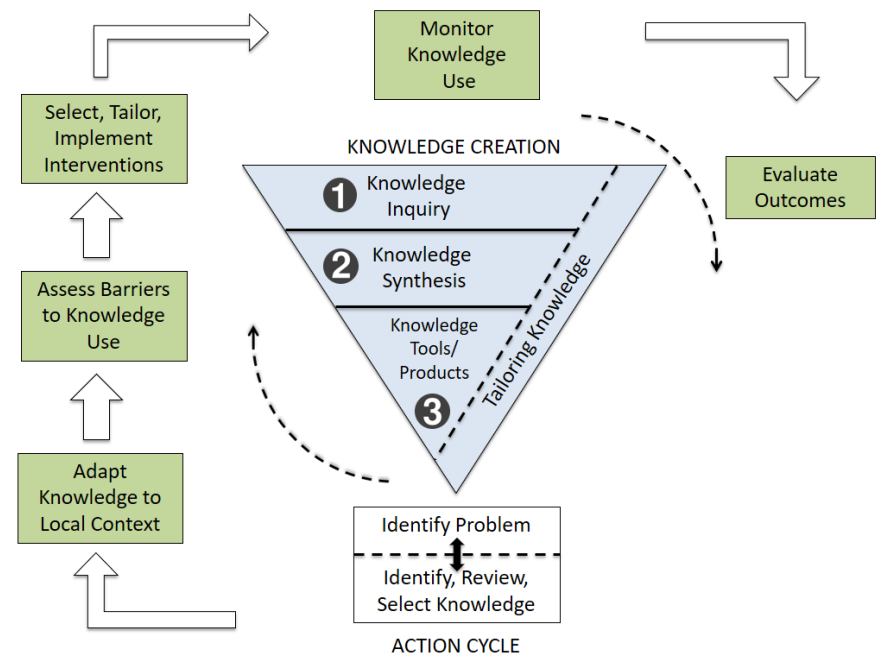
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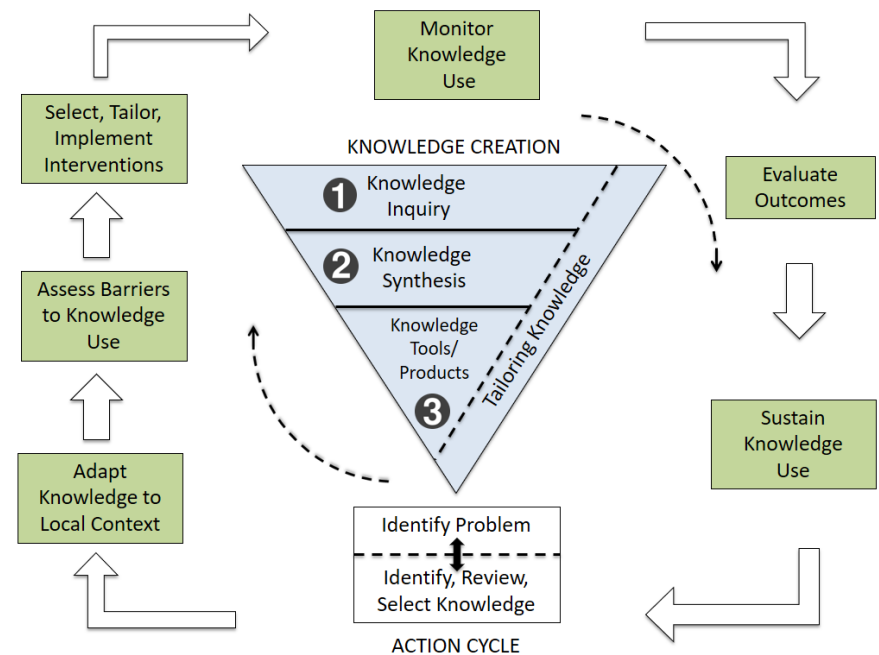
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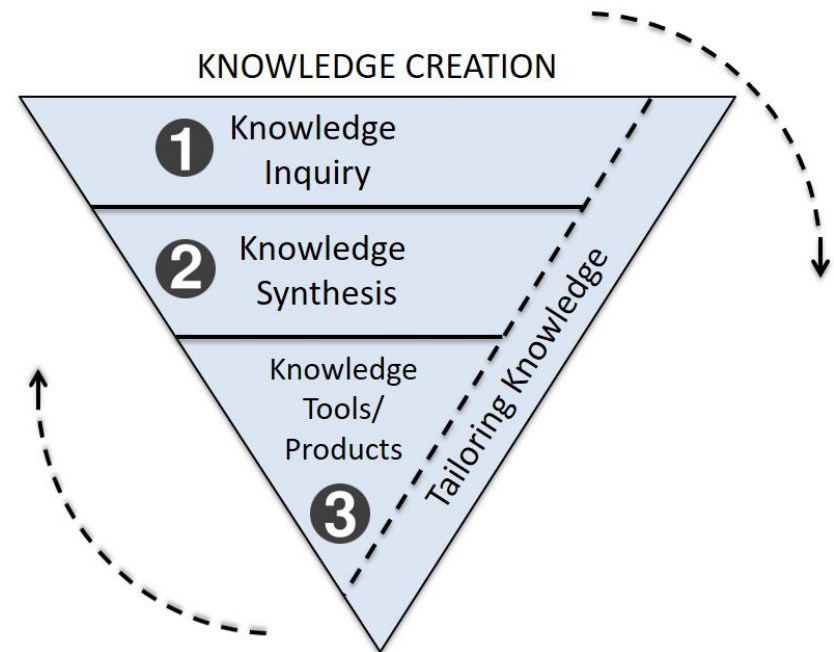


(Graham et al., 2006)

Knowledge Creation

Knowledge Inquiry & Synthesis

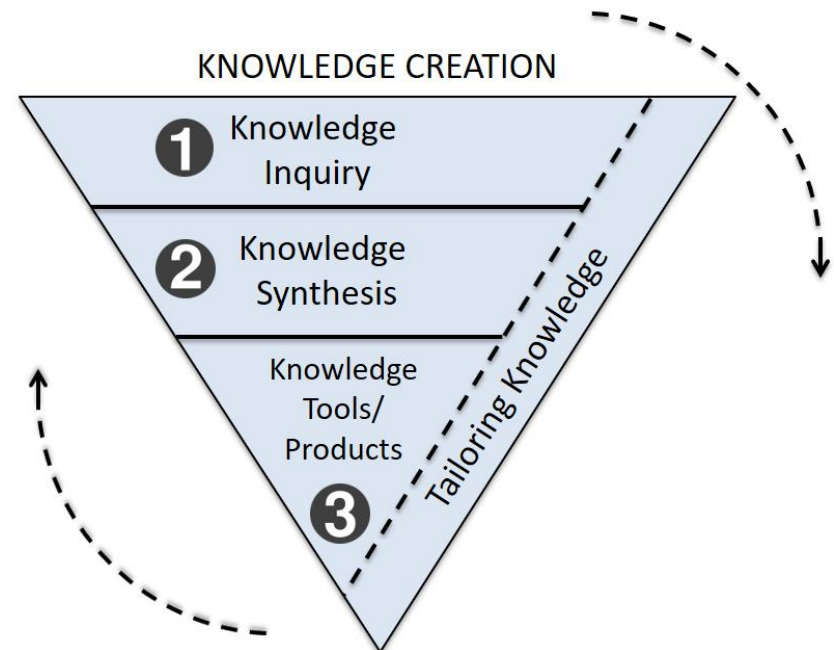
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- Scoping Reviews
- Interviews with IKT Champions
- Delphi Consensus Methods



Knowledge Creation

Knowledge Inquiry & Synthesis

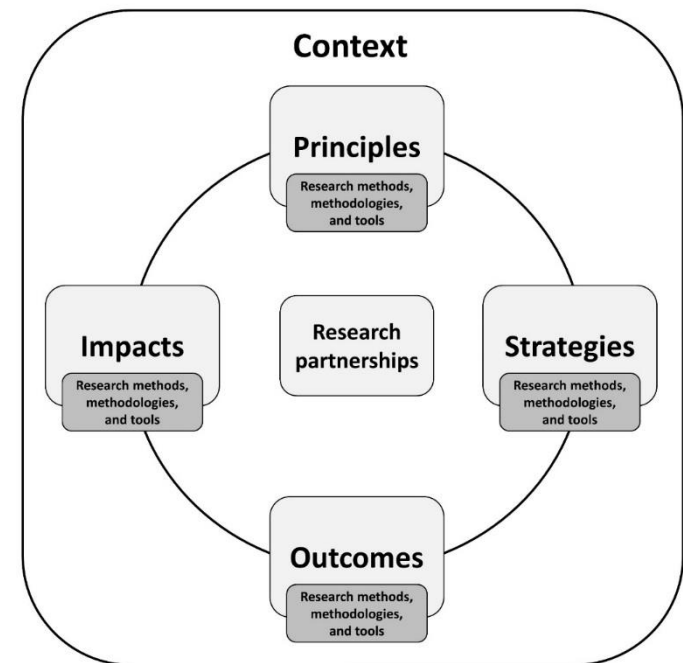
- **Review of Reviews**
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Reviews of the IKT Literature

A review protocol on research partnerships: a Coordinated Multicenter Team approach

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

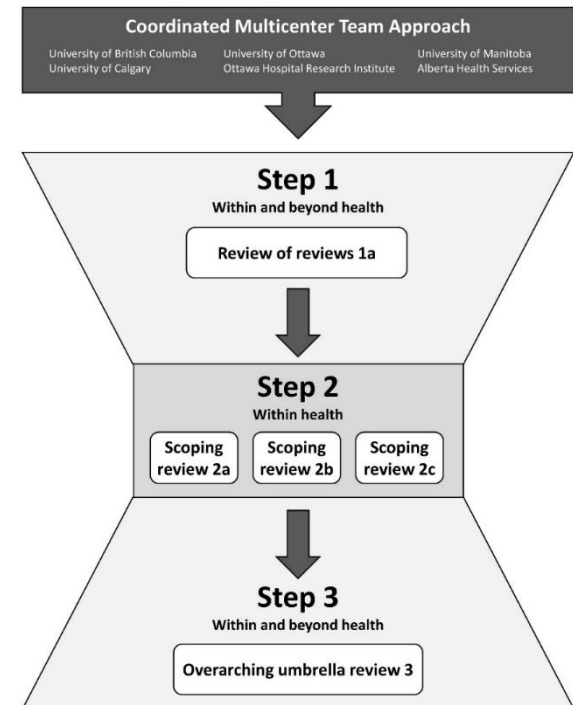


In Press in Systematic Reviews

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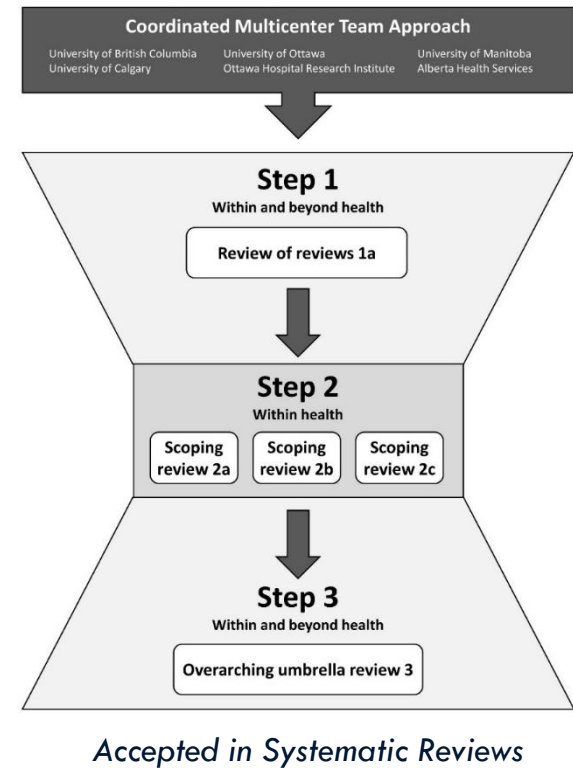
Reviews of the IKT Literature



Review of Reviews

Hoekstra et al.

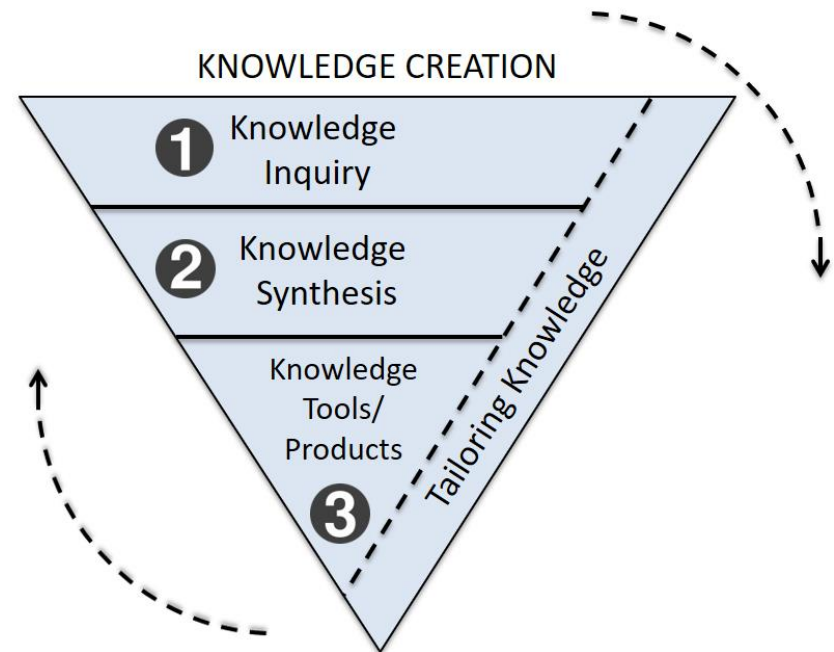
- **84 reviews describing research partnerships**
- **166 principles extracted**
 - 17 overarching principles
 - E.g. Partners are flexible and creative in their collaborative research activities.
- **116 strategies**
 - 11 overarching strategies
 - E.g. Use a variety of methods to facilitate communication (e.g. email, discussion, surveys, photovoice).



Knowledge Creation

Knowledge Inquiry & Synthesis

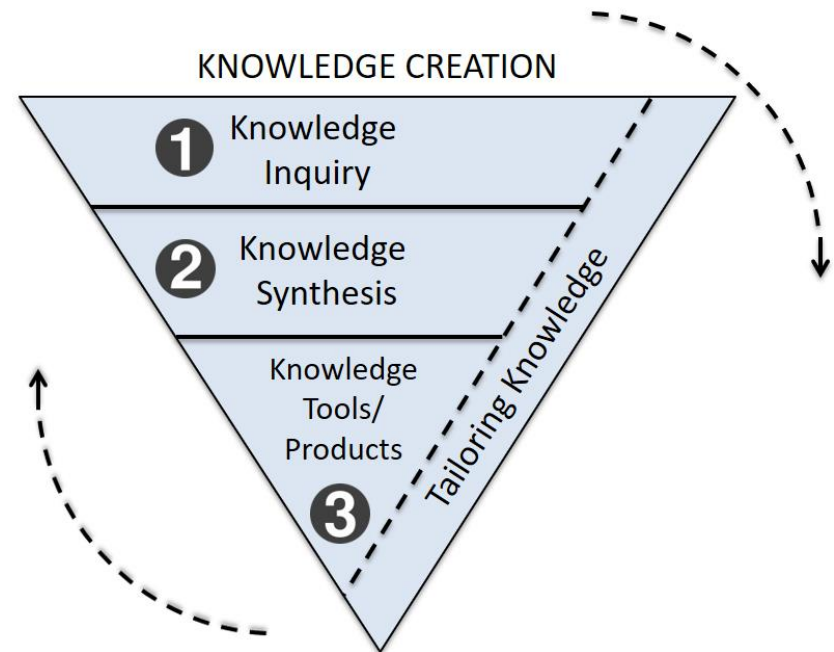
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Knowledge Creation

Knowledge Inquiry & Synthesis

- Review of Reviews
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- **Delphi Consensus Methods**



Advancing Consensus Methods

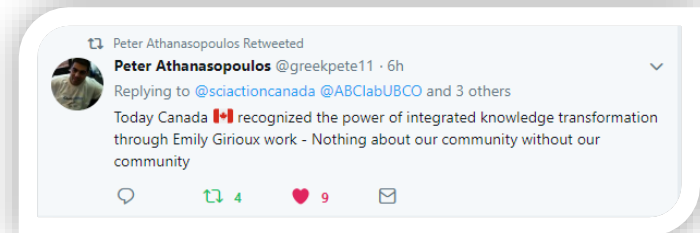
- Community-based Delphi with SCI peer mentors
- Compare Consensus Methods in IKT (BC Support Unit)
 - PI: Nelly Okele; Cols: Banner-Lukaris, Plamondon, Sibley
- Large Scale Community-Based Delphi Methods with the SCI Community
 - >2500 people in the SCI community



Mitacs

Advancing Consensus Methods

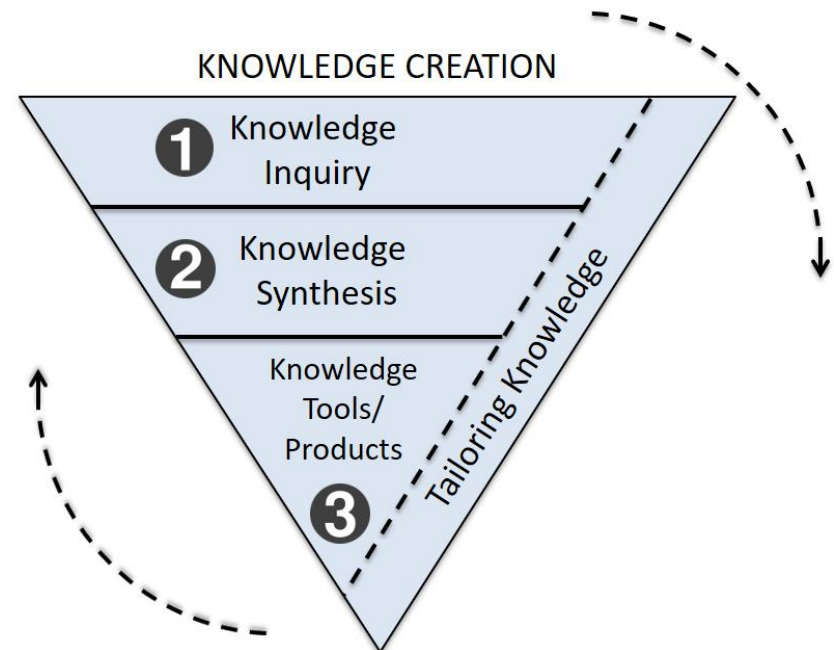
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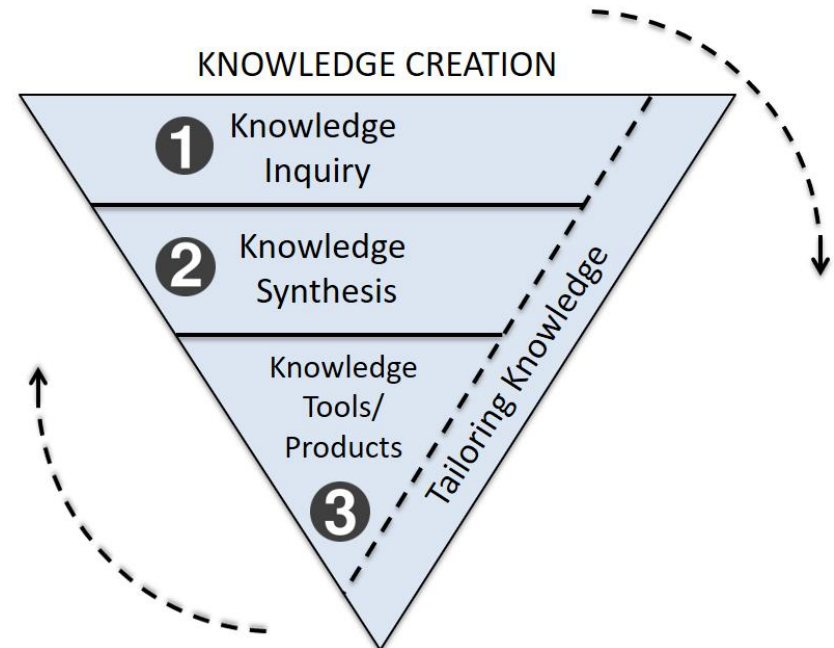
Knowledge Creation

3 Knowledge Product

- AGREE II Guiding Principle Meeting

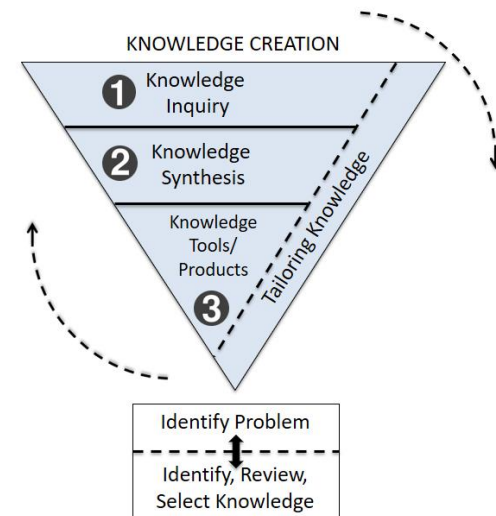


Leadership Panel



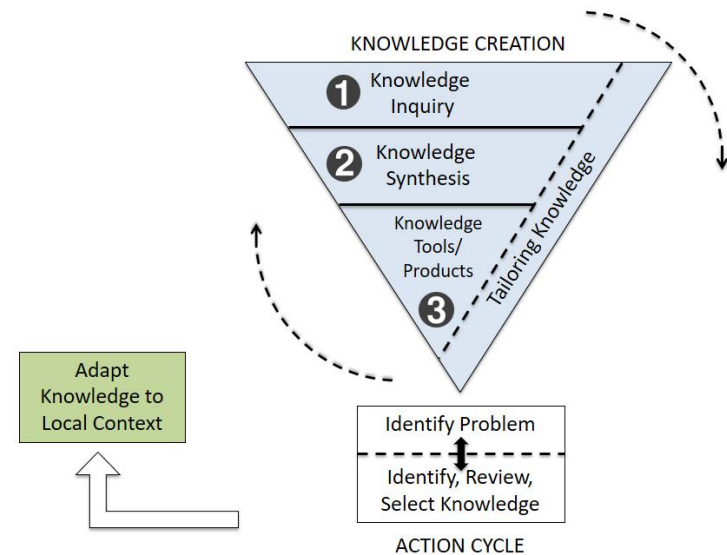
Action Cycle

- Implement and Evaluate the Guiding Principles
- Three Target Audiences:
 1. Researchers
 2. SCI Stakeholders
 3. Funders



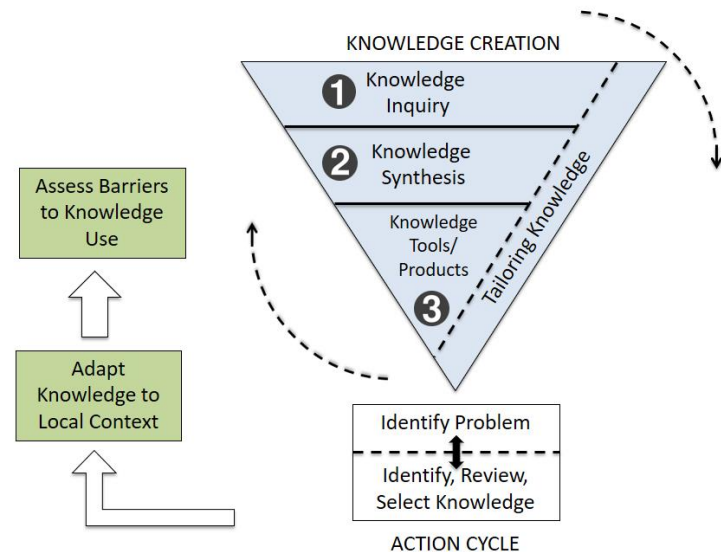
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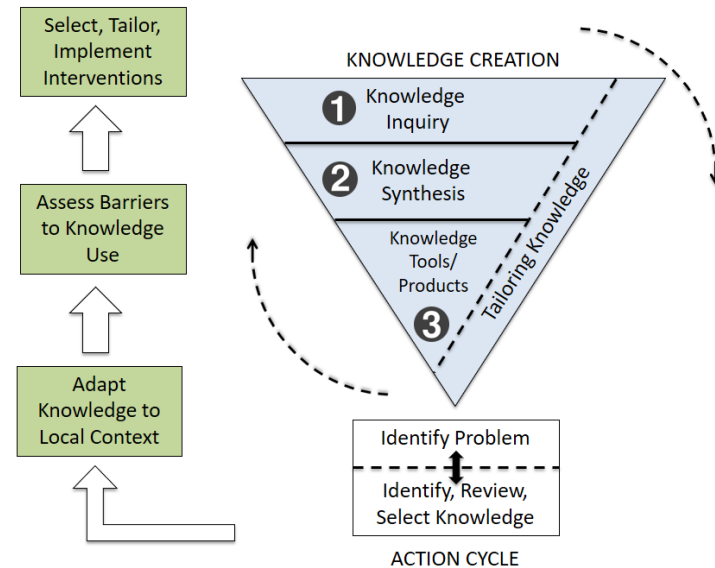


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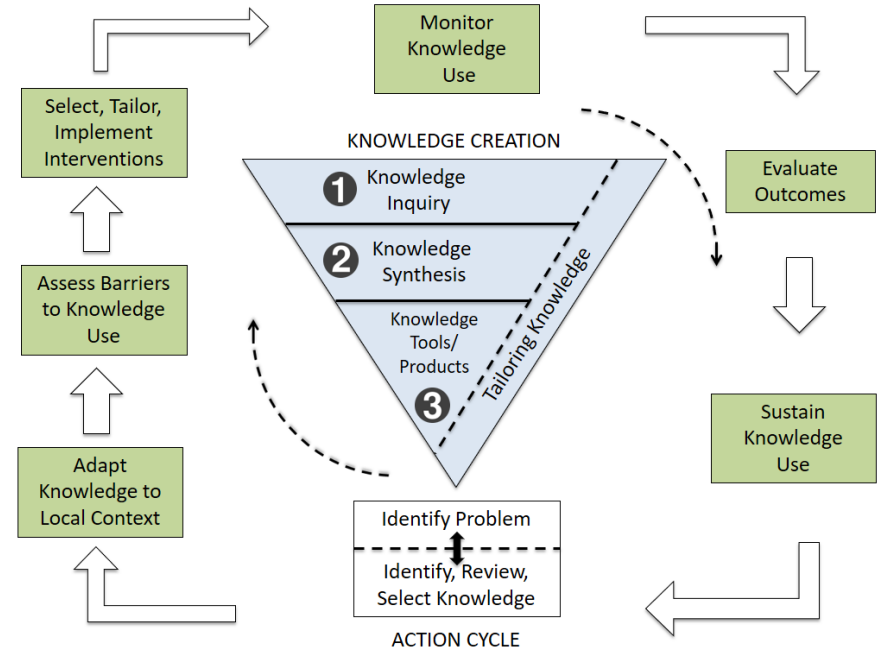
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Action Cycle

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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.



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Rising The Tide

1. Provide an overview of IKT concepts and frameworks
2. Discuss the emerging science examining IKT research partnerships
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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

Knowledge Translation



Commitment Issues: Part 2

Posted on January 25, 2017

Knowledge Translation



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

Commitment Issues: Part 1

Posted on January 17, 2017

Knowledge Translation



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

Commitment Issues: Part 2

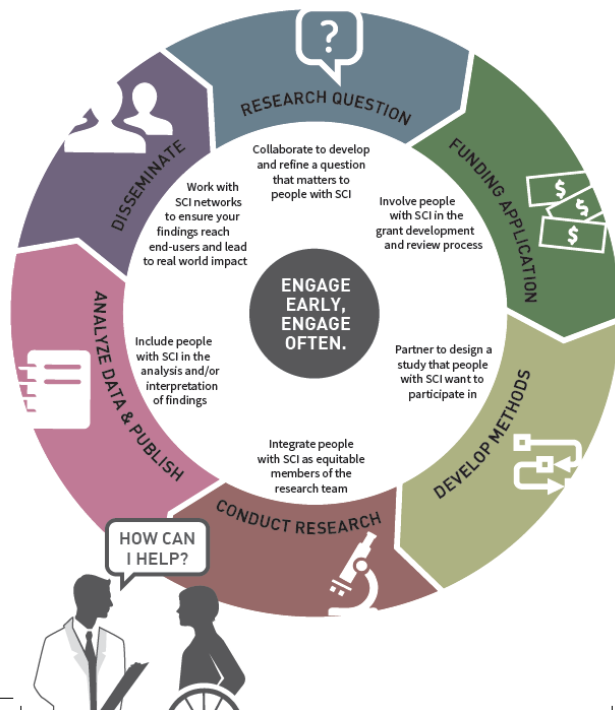
Posted on January 25, 2017

Knowledge Translation



Engage Early, Engage Often

HOW TO ENGAGE PEOPLE WITH LIVED EXPERIENCE IN SCI RESEARCH



DOs AND DON'Ts: OUR RECOMMENDATIONS

- **Engage broadly** — “If you’ve met one person with SCI, you’ve met 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
- **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

ONLINE RESOURCES

- RHI Consumer Program Roadmap — rickhanseninstitute.org
- IKT Guiding Principles — osf.io/9mq24
- NASCIC — nasciconsortium.org
- IAP2 Spectrum of Engagement — iap2.org
- Engage 2020 Action Catalogue — actioncatalogue.eu
- George and Fay Yee Public & Patient Engagement Mapping Tool — chimb.ca

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Rising The Tide





Acknowledgements

Research Collaborators

- Dr. Amy Latimer-Cheung
- Dr. Ben Mortenson
- Dr. Chris West
- Dr. Hugh Anton
- Dr. Ian Graham
- Dr. Kathleen Martin Ginis
- Dr. Kathryn Sibley
- Dr. Kim Anderson
- Dr. Lee Schaefer
- Dr. Mary Jung
- Dr. Shane Sweet
- Dr. Susan Forwell
- Dr. Paul van Donkelaar
- Dr. Wolfe Tetzlaff

Partner Collaborators

- International Collaboration on Repair Discoveries
- Kelowna Women's Shelter
- Michael Smith Foundation for Health Research
- North American Spinal Cord Injury Consortium
- Ontario Neurotrauma Foundation
- Rick Hansen Institute
- SCI Ontario, SCI BC, SCI Alberta, SCI Canada
- Peter Athanasopoulos, Sheila Casemore, Jocelyn Chernesky, Teren Clarke, Jocelyn Maffin, Karen Mason Dr. Chris McBride, Dr. Lowell McPhail

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- Emily Giroux
- Dr. Femke Hoekstra
- Rhyann McKay
- Blake Nicol
- Kelsey Wuerstl

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Thank You

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