

Commitment issues: How to get my community organization to say yes to an integrated KT project



*Helping people with spinal cord injury and their families
adjust, adapt and thrive*

Learning Objectives

- Appreciate the important role community organizations (research users) can play in integrated knowledge translation (iKT)
- Understand what often prevents community organizations from engaging in iKT projects
- Understand what it takes for a community organization to commit to an iKT partnership

Overview

Part 1: Taking time to get to know me - A bit of background on SCI BC & me

Part 2: Barriers to successful engagement

Part 3: Getting to yes

Part 4: Examples, Good and Bad

Poll Question 1

Have you been involved in an academic-community organization research and/or KT partnership?

YES

NO

Poll Question 2

What is my favourite question from potential research partners?

- ☐ Can you help me recruit participants for my study?
- ☐ Can you feature my research in your magazine?
- ☐ How can I help?
- ☐ Can I put your name on my grant application?
- ☐ Would you like to be an author this project's paper?

The answer is:

☑ How can I help?

This is an actual quote from the first time I met iKT expert and research partner extraordinaire, Dr. Heather Gainforth of the ABC Lab at UBC Okanagan

As with many modern day relationships, Heather and I met online

(For the record, it was via Twitter & it was about research...)



Her “how can I help” question has led to a very productive and mutually beneficial research partnership we both remain totally committed to.

Let's start by taking a little time to get to know SCI BC & me

(spoiler alert – this is the first step to getting me to yes...)

(a) What the heck is SCI BC* all about?

* Acronym warning!

SCI = spinal cord injury

SCI BC = Spinal Cord Injury Organization of BC



SCI BC's Members Best Describe what we do



How SCI BC Helps People with Spinal Cord Injuries

https://www.youtube.com/watch?v=x3_Ez4OJtII

<https://www.youtube.com/watch?v=-A19K9YDitc>



“SCI BC is the go-to place for information and support from people who really know what you’re going through and how to help you get back into real living.”

Why

Help people with SCI and their families adjust, adapt and thrive as they deal with a new injury or struggle with the ongoing challenges of living and aging with a physical disability

What

PEER SERVICES

Members helping members through shared & community experiences

How

Peer events, group and individual connections, webinars & other education sessions

Who

Peer Coordinators (paid/volunteer), Peer Support Specialists, Peer Mentors (volunteer), Peer participants, Staff

COMMUNICATIONS

Content delivery, information sharing & community building

Websites, Spin Magazine, social media, video content, partnerships, collaboration platforms

Management/staff, Working Groups led by Executive Office

RESOURCE CENTRE

Resource Centre providing answers & information resources

InfoLine, SCI Information Database, Swap 'N Shop, Website, Online Resources, AccessibleHousingBC, AccessibleEmploymentBC

Information Services Agents, Information & Resource Specialist, Communications Specialist

Serving BC



- **Total Staff: 30**
- **Total FTE: 20.6**
- **Staff with SCI/Disability: 17**
- **Resource Centres in**
 - GF Strong Rehab Centre
 - Prince George
 - Victoria

BC SCI Resource Centre



- InfoLine
- Physical Resource Centres
- BC SCI Information Database
- Accessible Housing BC
- Accessible Employment BC
- Employment Headstart
- Swap N Shop
- CSIL Manuals
- Spin Magazine

(b) What the heck am I all about (when it comes to KT)?









Start PhD in Neuroscience, UBC: neuroprotection	Managing Director ICORD	Co-Leader Disability Health Research Network	Managing Director SCI Solutions Network/RHI	Director, Translation Research Program, Rick Hansen Institute	Executive Director SCI BC
1992	2002	2008	2008	2010	2010

SCI BC Partnerships Overview

Why does SCI BC value partnership? Why do we engage in partnerships?

- We are on a mission to help people with SCI and their families adjust, adapt and thrive as they deal with a new injury or struggle with the ongoing challenges of living and aging with a physical disability.
- We can't do this alone – we *NEED* partnerships.

What type of partnerships?

- Formal partnerships
- Collaborations
- Sponsorships and other funding relationships

Key Partnerships

What sectors are we partnering with?

- Other disability-focused community service providers
- The private sector
- Health authorities
- Research institutions



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WORKING TO MAKE A DIFFERENCE



Inspiring Innovation and Discovery





BC Spinal Cord Injury Community Services Network



Research & Academic Institutions

ICORD (UBC & Vancouver Coastal Health Research Institute)

- Resource Centre and Fitness Centre in Blusson Spinal Cord Centre
- Scholarships and Bursaries
- Research projects (as co-applicant and/or a community partner)
- Knowledge Translation, including Café Scientifiques, which we help promote, host and webcast
- Research participation



UBC Okanagan (SCI Action Canada, Kathleen Martin-Ginis | ABC Lab, Heather Gainforth)

- Research projects (as co-applicant and/or a community partner)
- Knowledge Translation



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**So, if SCI BC needs partnerships,
why is it so hard to get us to
commit them?**

Like an unsuccessful first date,
here are some common turnoffs to
committing to a relationship:

- **False assumptions** (the overly optimistic date)
- **Expecting something for nothing** (the cheap date)
- **One-sided engagement** (the self-centred date)
- **Tokenism** (the arrogant date)

Partnership Commitment Turnoff 1: **False Assumptions**

Researchers are understandably passionate about their work and ideas, but too often assume I will be eager to help because the study is going to be of great interest and benefit to my organization and its members.

While often of academic interest, the studies are rarely as interesting or valuable to my organization and members as the researcher thinks they will be.

Partnership Commitment Turnoff 2:

Expecting something for nothing

Researchers usually assume I will be more than willing to dedicate human resources and infrastructure to help with their project needs for free.

I rarely am.

Like most nonprofits, Spinal Cord Injury BC can't afford to be a cheap date.

Partnership Commitment Turnoff 3:

One-sided engagement

When the balance of power is almost entirely held by the researcher and the scope offered for my participation is too trivial, I'm out.

With no ability for my organization to help shape the project, its methods and findings are less likely to be relevant and the overall project is more likely fail.

Partnership Commitment Turnoff 4:

Tokenism

This is where the role of the community organization is diminished to the point of triviality, such as merely being a passive conduit for recruitment notices or a newsletter story about a research project.

It often arises because researchers need to check off the "community partnership" and "knowledge translation plan" requirements of most granting agencies these days.

When all that is sought is a rubber stamp of approval or a checkbox tick, it demeans the value of the organization.

So, how do we get to YES?

Here are 6 tips on getting SCI BC to commit to a iKT partnership:

- 1. Arrive early and get to know me and my organization**
- 2. Listen carefully**
- 3. Speak the same language**
- 4. Be relevant**
- 5. Bring value**
- 6. Be respectful**

Getting to YES Tip 1:

Arrive early and get to know us

The most successful research-community partnerships happen when engagement starts at the planning stage of a research project, preferably before grants are written.

Unfortunately, most requests I receive to "partner" with researchers come way too late — like five days before a grant deadline, or worse, when project plans have been funded and ethics approvals have been granted. Basically, the researcher is coming to the table with a 'take it or leave it offer'.

In these cases, with little or no opportunity to ensure tips two to six are employed, the response is usually 'leave it'.

Getting to YES Tip 2:

Listen carefully

Early engagement allows iKT partners to share what the important questions about the general area of interest are, what is most relevant, and what is feasible.

By listening carefully to the community organization, researchers can develop a menu of valuable options for specific research questions that are of direct interest to the organization and its members.

By listening carefully to the researchers, community partners can co-develop research plans that can achieve success through feasible design and shared motivation.

Getting to YES Tip 3:

Speak the same language

Academics and community organizations often use different languages to describe the same things, so specific attention paid to ensuring all partners are using a common lexicon is vital to the success of iKT partnerships.

It's not a matter of academic partners "dumbing" things down: community organization staff members are smart people, they often just use different words to describe things.

Getting to YES Tip 4:

Be relevant

This is where early engagement, listening and using the right language really pay off.

Taking time upfront to understand what the community organization does and what its (and/or its members') priorities are will help ensure:

- the research questions and approach align with the organization's vision and mission
- the project can align with and/or enhance operational capacity
- the potential to enhance outcomes through services provided is realized

Getting to YES - Tip 5:

Bring value

All parties must understand the value proposition relating to their investment in the partnership.

I run a nonprofit = I run a business. Like most businesses, we can't afford to do things for free. But, this doesn't always mean you need to bring your wallet* - iKT projects can bring value in many ways:

- like increasing staff competencies
- enhancing the outcomes and impact of our services
- supporting operational sustainability
- providing direct and tangible benefits to those who engage in our organization's services (ie, members/participants)

* *Don't get me wrong - money helps...*

Getting to YES - Tip 6:

Be respectful

Respecting and valuing the unique strengths each partner brings to the partnership and the challenges and barriers they face in doing so is essential for the success of the project, as is ensuring co-responsibility for project development and decision-making (coproduction).

When combined with the other tips, it is the antidote to tokenism.

Examples

Some NO Some YES



I said NO

✗ timing ✗ / ✓ relevance ✗ listening ✗ value ✗ respect

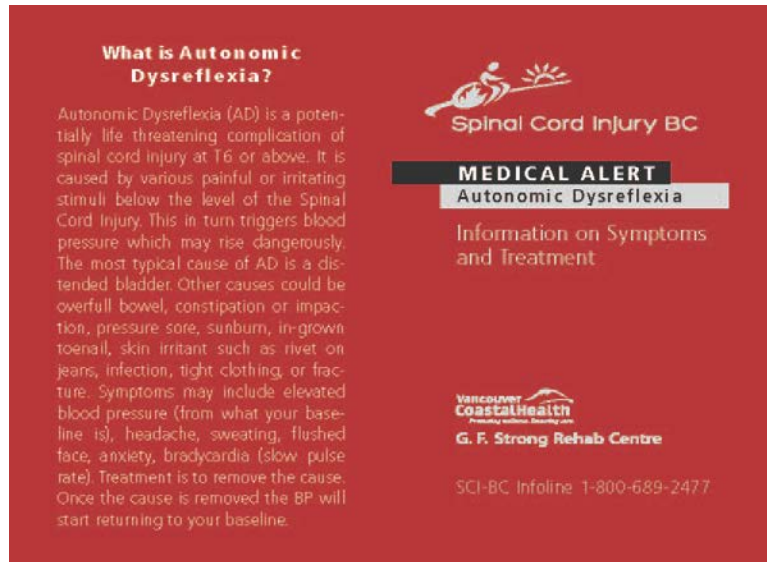


Sounds pretty awesome, right?! Who wouldn't want to support this? SCI BC, that's who. Why?

- No involvement in the development of the document or project (no coproduction)
- Our proposed role? Dissemination
- KT/advocacy piece to improve health service for 3 conditions that are not all top priorities for our members
- No value, no respect. Reputational risk and our role in the change it describes diminishes SCI BC
- Commitment? No. #Backfire

I said YES!

✓ timing ✓ listening ✓ relevance ✓ language ✓ value ✓ respect



- This wallet card was developed in partnership with researchers, clinicians and SCI BC
- Early engagement: We helped ensure the language is appropriate for our members
- Clinicians ensured the validity of the information and that the language is appropriate for physicians
- We helped with the design and delivery
- The card is carried by people with SCI – it could help them save their lives

I said YES again!

✓ timing ✓ listening ✓ relevance ✓ language ✓ value ✓ respect

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RESEARCH HIGHLIGHTS:

- Community partnerships at heart of \$3.3M from SSHRC
- \$13.6M for Discovery research from NSERC
- Steadie Prize Award
- McMaster-Fraunhofer BEAM receives 14M
- CFR funds 6 research projects
- Early Researcher Awards

Tackling community challenges across Canada

McMaster has been awarded more than \$3.3M from SSHRC for collaborations that will impact the health and welfare of all Canadians.

McMaster University will be at the helm of five multidisciplinary, cross-sectoral partnerships that have attracted more than \$3.3-million in funding from the Social Sciences and Humanities Research Council (SSHRC).

The community-based projects will better the lives of Canadians with physical disabilities, harness digital technologies to enhance participation and the quality of governance for First Nation communities, improve employment outcomes for homeless youth with intellectual and developmental disabilities, provide a publicly accessible, user-friendly community planning and visualization system for the City of Hamilton, and examine the challenges and opportunities facing Canada's oceans and the coastal communities that depend on them.

Kathleen Martin Ginis is leading a 7-year project that will enhance the quantity and quality of community participation among Canadians living with a physical disability. More than 50 partners – ranging from community-based disability-related service groups to government organizations at every level, and from university researchers to non-profits and national charities – are committed to developing and implementing evidence-based tools and services to assist Canadians with disabilities to achieve full community participation.

"Canadians with physical disabilities do not fully enjoy the UN-protected basic right to 'full and effective participation and inclusion in society,'" says Martin Ginis. "Canadians with disabilities consistently identify three areas where they feel the most restrictions, and where they'd most like to participate – in the workplace, in sports and recreation, and simply being able to move about their communities independently and with dignity."

Martin Ginis' project *Enhancing Community Participation in Canadians with Physical Disabilities: Development, Implementation and Evaluation of a Partnered Strategy* has been awarded \$2,643,997 and was one of only fourteen chosen by SSHRC in the Canada-wide Partnership Grants competition. McMaster co-applicants Catherine Connolly, Canada Research Chair in Organizational Behaviour and associate professor in the DeGroote School of Business, will lead the Employment (both employment-seeking and retention) team, and Steven Bray, professor of kinesiology, will be part of the Sport (both recreational and competitive leisure time physical activities) team.

"Our partnership is poised to generate new knowledge that can be turned into products, tools and services that will

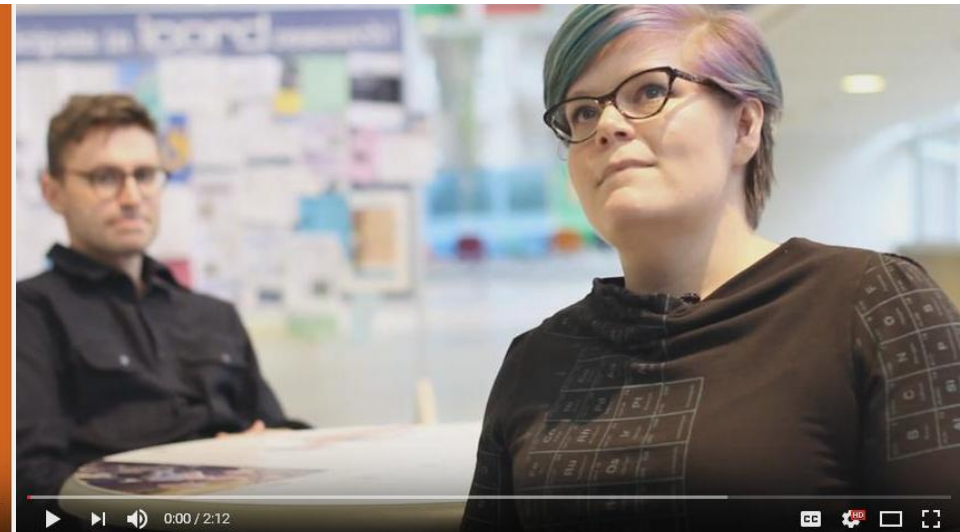
Kathleen Martin Ginis is leading a \$2.6M partnership to improve the lives of Canadians living with physical disabilities.

- Early engagement in project's conceptual development phase
- A lot of time was spent ensuring common language was used
- Research partner ensured the priorities of the community and community partner were understood and included
- Project was designed to take advantage of existing services (based upon what SCI BC already does), minimizing impact of participation
- Thoughtful remuneration for involvement

Another YES: SCI BC + ICORD

Check out our Stopwatch session videos

<https://www.youtube.com/watch?v=mr84W296vL8>



But, is it worth the bother to partner with a community organization when a patient/consumer representative could be involved, instead?

There is value in having partnerships involving both individuals & organizations

Patient/Consumer Rep	Community Organization
Power of personal impact and stories	Perspectives reflecting the diverse experiences and priorities of large memberships
Risk of attrition during the research/KT process	A pool of representatives ensures continuity
Limited ability to amplify KT-related communication	Large contact lists and communications channels that can amplify KT-related communication
Fewer bureaucratic channels to navigate	Higher “transaction costs”

Spinal Cord Injury Perinatal Interest Group:

A partnership including patients/consumers & a community organization



- Individuals with spinal cord injury provided compelling, personal impact stories and context
- Spinal Cord Injury BC provided broader perspective on issues and priorities of its membership
- Clinicians, researchers, and KT experts provided their experiences and knowledge to a process that led to the collaborative development of consensus on care in Canada & info resources for people with SCI and clinicians

Further reading and viewing

- **Commitment Issues Part 1** (Chris McBride): How to get my organization to say yes to an integrated KT project <http://www.msfhr.org/news/blog-posts/commitment-issues-part-1>
- **Commitment Issues Part 2** (Heather Gainforth): How to foster long-term collaborations with community organizations – a researcher's perspective <http://www.msfhr.org/news/blog-posts/commitment-issues-part-2>
- **Applied Behaviour Change (ABC) Lab** <http://ok-abc.sites.olt.ubc.ca/>
- **Canadian Disability Participation Project** (an alliance of university, public, private and government sector partners working together to enhance community participation among Canadians with physical disabilities) <http://cdpp.ca/>
- **Video – Why Spinal Cord Injury Research Needs You** <https://www.youtube.com/watch?v=T5XB9ysI4cl&t=161s>
- **Videos – Stopwatch series** (ICORD research participation promo) https://www.youtube.com/watch?v=mr84W296vL8&list=PLbl_Crr_ahpaRAIul1ycp-iGrrcnmNYja&index=9
- **Video - How SCI BC Helps People with Spinal Cord Injuries** <https://www.youtube.com/watch?v=-A19K9YDitc>
- **Video – SCI BC in 2016: Little Things Big Impact** https://www.youtube.com/watch?v=x3_Ez4OJtll&t=83s
- **The Spin magazine** <http://sci-bc.ca/stories/spin-magazine/>
- **Spinal Cord Injury Sexual Health website:** <http://scisexualhealth.ca/>

Questions?