



ICORD PARTNERSHIP WORKSHOP: SUMMARY AND NEXT STEPS



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GLOSSARY OF TERMS

- **Integrated knowledge translation (IKT).** Meaningful engagement of the right research users at the right time throughout the SCI research process.
- **Meaningful engagement.** Contributing to and influencing a personal and socially meaningful research, dissemination, and/or implementation goal and feeling a sense of responsibility to others (e.g. the research team, organizations, people with lived experience of SCI, etc.).
- **Partners or partnership.** Researchers and research users meaningfully engaging throughout the research process.
- **Principles.** Fundamental norms, rules, or beliefs that represent what is desirable and positive for a person, group, organization, or community, and help it in determining the rightfulness or wrongfulness of its actions. Principles are more basic than policy and objectives and are meant to govern both.
- **Research.** The systematic study of a topic to understand and/or discover information about the topic.
- **Research process.** Multiple phases in a research project. Phases include but are not limited to planning, conducting, disseminating, and applying the research.
- **Research users.** Individuals or groups that will use or benefit from the research. These groups are different than research participants and include but are not limited to persons with lived experience of SCI, policymakers, health and/or service providers, other researchers, professional organizations, funders, and industry partners. The partnership should carefully consider who the right research user(s) is/are for its project.
- **Researcher.** A person whose job it is to carry out research activities.
- **Tokenism.** The practice of making only a minimum or symbolic effort to do a particular thing, especially by recruiting a small number of people from under-represented groups in order to give the appearance of equality. Tokenism happens when a partner is asked to endorse, and therefore legitimize, research programs over which they have little real influence or control.

EVENT DESCRIPTION

Why was this report developed?

Research partnerships are essential for ensuring that spinal cord injury (SCI) research is relevant, useful, and used. Meaningful engagement with research users, particularly people with lived experience of SCI, helps ensure diverse perspectives shape the research process. ICORD is committed to improving the quality and quantity of SCI research partnerships by providing targeted support and fostering a culture of meaningful engagement.

How was this report developed?

To advance ICORD's goals, a two-day in-person workshop was held in Kelowna, BC, in October 2024. The event brought together a diverse group of participants from across the SCI research system, including 14 ICORD researchers, 20 trainees, 8 staff, 18 members of SCI community organizations, 17 individuals living with an SCI, 6 caregivers, and 8 healthcare providers.

The workshop aimed to:

1. Foster inter-campus collaborations between UBC Okanagan and UBC Vancouver
2. Explore equity, diversity, and inclusion and Integrated Knowledge Translation principles for SCI research partnerships
3. Identify strategies to support research partnerships within ICORD and broader SCI communities
4. Inform priorities for ICORD's Meaningful Engagement Committee

EVENT DESCRIPTION

How the findings were collected and summarized:

Over the course of two days, attendees participated in a range of interactive sessions, including presentations, panel discussions, small-group conversations, and open table discussions. During each discussion session, structured brainstorming activities took place, with facilitators or participants actively taking notes at each table to capture key ideas and insights. Attendees were encouraged to share both barriers and facilitators to engagement in research, as well as practical ideas for change to support meaningful partnership.

Following the event, detailed notes from each session were consolidated and reviewed by the organizing team. Ideas were grouped into themes and organized into actionable categories. These themes informed the development of a long list of suggested next steps, which are summarized in this report.

The findings presented here reflect the voices and contributions of a wide range of individuals involved in SCI research and care. They are intended to guide ICORD in strengthening its culture of meaningful partnership and in supporting the Meaningful Engagement Committee as they move these priorities forward.

1. Clarifying Scope and Role of the Meaningful Engagement Committee

- **Scope Management:** The MEC should initially focus on realistic, achievable goals and remain grounded in operational support rather than high-level strategic guidance, ensuring that efforts are feasible and impactful.
- **Operational Focus:** As an operational body, the MEC should concentrate on structural and logistical aspects of partnerships, facilitating clear, practical steps to support engagement.
- **Engagement of Trainees:** Define how trainees (from undergrad to post-doc levels) will participate in partnerships, creating pathways for them to become meaningfully involved in engagement initiatives.



2. Strengthening Connections Between Researchers, Research Users, and Partners

- **Formal and Informal Engagement:** Mix informal events (e.g., coffee groups, BBQs, sports activities) with formal gatherings (annual MEC meetings, research fairs, ARM events) to balance relationship-building and structured engagement opportunities.
- **Local and Rural Community Inclusion:** Expand reach by engaging rural communities and smaller disability organizations, such as Prince George Adaptive Sport, to ensure broader representation.
- **Annual In-Person and Online Accessibility:** Hold at least one in-person MEC meeting yearly to sustain momentum and accommodate diverse participation through virtual options.

3. Enhancing Engagement Initiatives for Meaningful Partnerships

- **Mentorship and Training Programs:** Establish mentorship and training modules tailored to researchers, trainees, and community partners. Include training on lived ableism, lay language communication, emotional safety, and partnership dynamics.
- **Community Knowledge-Sharing Initiatives:** Set up biannual or annual meetings for intentional co-development and review of engagement practices. Use these meetings to reinforce the value of community contributions in research planning.
- **Joint Community Activities:** Organize activities (e.g., camping, sports) that allow researchers and community members to connect and build trust through shared experiences.
- **Building Online Community Spaces:** Develop an online platform for continuous knowledge exchange and community interaction, such as a social media or open-source information space.



4. Increasing Presence of Persons with Lived Experience (PLEX) in ICORD Labs

- **Normalizing Inclusion:** Position the involvement of people with lived experience as a standard practice in research teams, not as an exception, to foster inclusivity and representation.
- **Trainee Opportunities:** Introduce high school and undergraduate trainees to working with PLEX early in their training to establish inclusive research norms.
- **Financial Initiatives:** Develop financial support specifically for people with SCI participating in research roles, either as PLEX or research team members, to reduce economic barriers to engagement.

5. Knowledge Dissemination to Broader Communities

- **Mentorship and Training Programs:** Establish mentorship and training modules tailored to researchers, trainees, and community partners. Include training on lived ableism, lay language communication, emotional safety, and partnership dynamics.
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6. Evaluating Engagement and Partnership Quality

- **Focus on Quality Over Quantity:** Develop metrics to evaluate partnership quality over sheer numbers, with social network analysis as a tool to track network growth, identify champions, and pinpoint areas needing support.
- **Cultural Safety and Disability Training:** Track researchers' completion of cultural safety and disability awareness training, ensuring team readiness for inclusive engagement.
- **Inclusivity Metrics:** Monitor the proportion of research teams with PLEX involvement and track the presence of people with disabilities among PIs, trainees, and researchers to identify representation gaps.
- **Engagement Metrics on Digital Platforms:** Implement website analytics to track the effectiveness of online resources and gather user feedback to refine digital engagement tools.

9. Clear Communication and Transparency

- **Robust Communication Channels:** Address communication barriers due to jargon or logistical issues by establishing a centralized online portal for partnership resources and updates. Use training sessions to build a shared language across partners.
- **Accessible Documentation:** Regularly update and maintain documents that outline partnership goals, progress, and contributions from all parties to ensure transparency and inclusivity.

10. Partner Onboarding and Orientation

- **Structured Onboarding:** Develop clear orientation sessions for all partners, including expectations around roles, responsibilities, and partnership goals. Consider using checklists for initial and ongoing onboarding processes.
- **Role Clarity and Expectations:** Standardize partnership agreements that define roles and expected contributions, particularly for newcomers to ICORD partnerships.

11. Emotional Support and Burnout Prevention

- **Mental Health and Emotional Safety:** Recognize the emotional demands of partnerships for both researchers and community members, providing mental health resources and debriefing opportunities to prevent burnout.
- **Regular Check-Ins:** Encourage periodic check-ins and informal conversations to support emotional well-being, enabling partners to voice concerns and maintain a sustainable partnership pace.

12. Measuring Outcomes and Impact

- **Define Partnership Success Metrics:** While emphasizing quality, develop both short- and long-term metrics to measure partnership outcomes. Metrics should include impacts on research quality, relevance, and the direct contributions of partnership initiatives.
- **Feedback Mechanisms:** Set up structured feedback loops, such as annual surveys and post-project evaluations, to continuously improve partnership practices and ensure that community voices are heard.



13. Leveraging Knowledge Brokers and Liaisons

- **Knowledge Broker Roles:** Appoint knowledge brokers or liaisons who can bridge knowledge gaps, facilitate communications, and support consistent application of partnership principles across projects.
- **Encouraging Continuous Learning:** Use these roles to promote continuous learning, guiding researchers and community members through effective engagement strategies and partnership management.

14. Expanding Network and Outreach Efforts

- **Formalize Networking Opportunities:** Create formal systems, such as a partnership registry or directory, to connect ICORD researchers with potential partners and share resources for expanding networks, especially in rural areas.
- **Inclusive Outreach:** Build partnerships with diverse organizations, including disability groups and organizations in rural and remote areas, to broaden the reach and inclusivity of ICORD's initiatives.

WHAT'S NEXT: MOBILIZING FOR ACTION

Building On What's Already Happening

This workshop was not the beginning. It built on a strong foundation of partnership work already happening at ICORD. It brought people together to reflect, share ideas, and set priorities for deepening meaningful engagement in spinal cord injury research.

The Role of the MEC

The Meaningful Engagement Committee (MEC) is now taking the lead on next steps. This group includes people with lived experience of SCI, researchers, trainees, and representatives from community and research-supporting organizations. They are prioritizing initiatives, assessing feasibility, and setting timelines.

Initiatives Already Underway

Some of the identified initiatives are already in motion:

- ICORD Coffee is now running in Kelowna. It brings together community members and UBCO researchers to build relationships over coffee and conversation.
- A training program for ICORD researchers is being co-developed to build capacity for meaningful partnership.

A Shared Commitment

The MEC's mission is to foster knowledge, skills, and respect for meaningful engagement. The committee is working to support researchers and research users in building authentic and reciprocal partnerships across all stages of research.

This report is a snapshot of one moment in a much longer journey. The work ahead reflects a collective commitment to embedding meaningful engagement into how research is done, shared, and sustained across ICORD.

WOKSHOP PARTNERS



Dr. Alanna Shwed; UBC Okanagan, ICORD

Dr. Sarah Lawrason; UBC Okanagan, College of Nurses of Ontario

Dr. Nancy Thorogood; ICORD

Dr. Kathleen Martin Ginis; UBC Okanagan, ICORD

Dr. Christopher McBride, SCI British Columbia

Dr. Kaela Cranston; UBC Okanagan

Dr. Cameron Gee; UBC, ICORD

Dr. Emily Giroux; UBC Okanagan, ICORD

James Hektner, Praxis; Accessible Okanagan

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Dr. Rhonda Willms; GF Strong, UBC, ICORD

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Contact Information

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**THANK
YOU.**



THE UNIVERSITY OF BRITISH COLUMBIA
Centre for Chronic Disease Prevention and Management
Faculty of Medicine



THE UNIVERSITY OF BRITISH COLUMBIA
Centre for Health Behaviour Change



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APENDIX: WORKSHOP AGENDA

SCI PARTNERSHIP WORKSHOP SCHEDULE

Monday October 28 th , 2024		
Rotary Centre for the Arts (Atrium) – 421 Cawston Ave, Kelowna, BC V1Y 6Z1		
Time	Activity/Topic	Details
11:15am	Shuttle Service	Shuttle available from 4-Points hotel to Rotary Centre for the Arts. <i>Service:</i> Driving Miss Daisy and Kelowna Concierge
12:00pm	Session 1: Sign-in & Lunch	Informal lunch and connection time.
1:00pm	Welcome & Land Acknowledgement	Welcome attendees, acknowledge the traditional territory, and introduce guiding principles and respect for the workshop. <i>Speaker:</i> Dr. Mary Jung
1:10pm	Workshop Overview & Goals	Overview of the workshop, how we got here, day-1 objectives, agenda, and plans. <i>Speakers:</i> Dr. Sarah Lawrason, Alanna <u>Shwed</u>
1:20pm	Session 2: ICORD & Partnership Values	ICORD's value of research partnership and meaningful engagement. Difference between a partner and participant in SCI research. <i>Speakers:</i> Dr. Nancy Thorogood & Dr. Brian Kwon

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1:30pm	Session 3: IDEAs in Research	Importance of inclusive, diverse, equitable, accessible, and social justice (IDEAS) principles within research partnership work. <i>Speaker:</i> Dr. Kaela Cranston
2:00pm	Session 4: IKT Guiding Principles	Overview of IKT Guiding Principles, their relevance, and importance in fostering meaningful research partnerships. <i>Speaker:</i> Dr. Heather Gainforth
2:45pm	Refreshment Break	Short break to refresh and regroup. Riddle challenges with prizes to win.
3:00pm	Session 5: Partnership in Practice Panel	Partnering Beyond Researchers—Involving Educators, Clinicians, and the SCI Community Speakers: Dr. Kathleen Martin Ginis, James Hektner, John Chernesky, Dr. Chris McBride, Dr. Chris West <i>Facilitators:</i> Dr. Sarah Lawrason, Alanna <u>Shwed</u>
4:00pm	Session 6: Table Discussions	Panel members join tables and have open discussion about further questions, strategies, concerns, etc. Sharing of partnership experiences by workshop attendees.
4:30pm	Summary, Reflections, & Questions	Summary and key takeaways, and reminders for the remainder of the day. <i>Facilitators:</i> Dr. Sarah Lawrason, Alanna <u>Shwed</u>
4:45pm	Break & Re-Energize	Individual time to regroup, explore downtown, etc.
5:30pm	Shuttle Service	Shuttle available from Rotary Centre for the Arts to The Office Brewery. <i>Service:</i> Driving Miss Daisy and Kelowna Concierge

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6:00pm	Session 7: Dinner & Social	Time to connect socially, ask more questions, and hang out. Location: The Office Brewery (890 Clement Ave #301, Kelowna, BC, V1Y 7E4)
9:00pm 10:00pm	Shuttle Service	Shuttle available from The Office Brewery to 4-Points hotel. Service: Driving Miss Daisy and Kelowna Concierge
Tuesday October 29th, 2024 Four Points Hotel Meeting Room – 5505 Airport Way, Kelowna, BC V1V 3C3		
Time	Activity/Topic	Details
9:00am	Coffee & Breakfast	Light refreshments and coffee/tea to start the day.
9:40am	Welcome Back & Land Acknowledgment	Welcome back and Land Acknowledgement. Overview of day 2 workshop objectives, agenda, and plans for the day. <i>Speakers:</i> Dr. Sarah Lawrason, Alanna Shwed
9:50am	ICORD Meaningful Engagement Committee	Introduction to ICORD's new Meaningful Engagement Committee (MEC) and their goals. <i>Speakers:</i> Dr. Heather Gainforth, Dr. Brian Kwon, Dr. Nancy Thorogood
10:00am	Session 8: Partnership in SCI and ICORD Activity *Food and drinks provided at this time	World-Café Roundtable Discussions <i>Facilitators:</i> Alanna Shwed, Dr. Sarah Lawrason
12:00pm	Summary & Closing	Summarize key insights, outline next steps, and highlight

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	Remarks	importance for continued collaboration between ICORD-O and ICORD-V. <i>Speakers:</i> Dr. Sarah Lawrason, Alanna <u>Shwed</u>
12:30pm	MEC Lunch	If you are interested in joining the ICORD Meaningful Engagement Committee meeting and lunch and/or want more information about this meeting, please email Dr. Heather Gainforth (heather.gainforth@ubc.ca)
1:30pm	Welcome and Land Acknowledgement	Welcome to the MEC <i>Speakers:</i> Dr. Heather Gainforth, Dr. Nancy Thorogood
1:40pm	Overview of MEC	Overview of the meaningful engagement committee: Scope & Objectives <i>Speakers:</i> Dr. Heather Gainforth, Dr. Nancy Thorogood
1:50pm	Co-Defining our Priorities	MEC Initiatives Roundtable Discussions <i>Facilitators:</i> Dr. Heather Gainforth, Dr. Nancy Thorogood
2:30pm	Supporting & Managing the MEC	Management Supports Roundtable Discussions <i>Facilitators:</i> Dr. Heather Gainforth, Dr. Nancy Thorogood
2:50pm	Closing and Next Steps	Summarize key insights and highlight next steps. <i>Speakers:</i> Dr. Heather Gainforth, Dr. Nancy Thorogood
3:00pm	Shuttle to CHBC	Shuttle available for those interested in a tour of the Centre for Health Behaviour Change
3:30pm	Tour of CHBC	Tour of ABC Lab and SCI Action Canada Lab
4:30pm	Shuttle to Hotel	Shuttle available for anyone staying at 4-Points back to hotel