Developed through consultation with key stakeholders, including the RHI Consumer Program Advisory Committee.
Consumer engagement is founded on the understanding that those affected by a decision have a right to be a part of the decision-making process and that their input will influence that decision.¹

Spinal cord injury (SCI) consumers are individuals with lived experiences, including people with SCI, their family and friends, as well as consumer-focused community organizations and advocacy groups. Engagement occurs when consumers have a meaningful and active role in decision-making, setting priorities, conducting research, and translating research knowledge for the benefit of its intended users. Consumer engagement in research has been proven to increase study enrollment rates, aid in securing funding, and improve study design, protocols and choice of relevant outcome measures.² Consumer engagement is most effective when there is an environment of inclusivity where consumers are provided the supports needed to contribute fully and are part of mutually respectful teams from the outset of projects.³

¹ http://www.iap2.org/?page=A4
³ http://www.cihr-irsc.gc.ca/e/48413.html
Consumer Engagement in SCI Research

Consumer engagement in research is an emerging field that is developing rapidly. Funders, research organizations and health care providers recognize that engaging consumers in their work improves health outcomes and reduces costs. Increasingly, funders acknowledge that it is critical for consumers to be part of research teams. This helps ensure research is relevant and facilitates uptake of the results.

Consumer Engagement at RHI

The Rick Hansen Institute (RHI) is a Canadian non-profit organization that drives innovation in spinal cord injury research and care. In support of its vision and mission, RHI’s Strategic Plan identifies eight organizational goals, one of which is to inform, empower and engage people with SCI to seek opportunities to participate in research and their own health decision-making. To this end, RHI established a Consumer Program (CP).

Overseen by RHI’s Consumer Engagement Lead, the CP is guided and informed by a Consumer Program Advisory Committee (CPAC). The committee is representative of the consumer population, including individuals with a variety of experiential backgrounds in SCI. The CP partners with community organizations around the world to facilitate collaboration between consumers, researchers, funders, policy-makers, care providers and industry.

Objective of RHI’s Consumer Program

To increase consumer involvement in a multi-disciplinary collaborative partnership between researchers, care providers and industry for maximum impact on health and quality of life of those living with SCI.

Areas of Focus and Current Activities

Research Involvement – develop educational materials to encourage consumers to participate in clinical studies and to be integrated as members of research teams.

- Provide educational sessions to newly-injured persons about the current state of SCI research and the importance of participating in research;
- Support consumer-focused conferences, meetings, training and education;
- Encourage the recruitment of participants in research studies through collaboration with research, community and consumer organizations;
- Create training programs for consumers to develop the skills needed to work with research teams as integrated research partners;

Self-management of health – provide self-management tools and resources to people with SCI to minimize the incidence and severity of secondary complications and improve overall quality of life.

- Support the development of evidence-based resources on SCI treatments and self-management for consumers;
- Support the development of products, devices and therapies to provide more and better options for people living with SCI.

Advocacy – foster collaborations with individuals and organizations to advocate for funding and changes in practice that will improve quality of life for SCI consumers.

- Include SCI consumers in RHI priority-setting, project review and strategic planning;
- Support the development of an international SCI consumer consortium to advocate for SCI research and programs to support SCI care
Partnerships

Effective consumer engagement involves collaborations across countries, stakeholders, and organizations. RHI will continue to nurture existing and develop new relationships with agencies and organizations such as:

- Consumer groups
- National and international SCI-related foundations
- National or regional SCI research institutions and networks
- National and international universities and hospitals
- Accreditation organizations
- Professional and work safety organizations
- Private industry (or private sector organizations)
- Non-SCI entities that have synergy with RHI’s objectives

Consumer Program Advisory Committee Members

Keiko Honda (Chair)
Consumer and Public Health Research Scientist

Peter Athanasopoulos
Consumer and Manager, Public Policy and Government Relations, Spinal Cord Injury Ontario

Mary-Jo Fetterly
Consumer

Chris McBride
Executive Director, Spinal Cord Injury BC

Ian Rigby
Consumer and Emergency Room Physician, Foothills Medical Centre

Barb Schober
Consumer

Consumer Engagement Lead

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In 1985, Rick Hansen embarked on a journey that would change the world for people living with spinal cord injury and other disabilities. More than thirty years later, the legacy of the Man In Motion World Tour continues to inspire the SCI community to carry on Rick's legacy. It is Rick's vision that motivates us to inform, empower and include people with SCI to be champions and active participants in our collective efforts to create a world without paralysis after SCI.

RHI's Vision
A world without paralysis after spinal cord injury.

RHI's Mission
To lead collaboration across the global spinal cord injury community by providing resources, infrastructure and knowledge; and to identify, develop, validate and accelerate the translation of evidence and best practices to reduce the incidence and severity of paralysis after SCI, improve health care outcomes, reduce long-term costs, and improve the quality of life for those living with SCI.

RHI’s Organizational Goals
1. Further our understanding of biology and physiology of SCI
2. Support the development of promising therapies for neuro-restoration in acute and chronic SCI.
3. Achieve evidence-informed equitable care for Canadians sustaining a SCI in Canada and address gaps in knowledge that will advance SCI care and facilitate future SCI cure(s).
4. Bring a greater number of innovations to market that will directly benefit people with SCI.
5. Inform, empower and engage people with SCI to seek opportunities to participate in clinical research and their own health decision-making.
6. Continue to nurture and expand RHI’s network locally and internationally and to include consumers, investors, industry and policy makers.
7. Demonstrate value and return on investment to RHI funders.
8. Ensure sustainability of RHI operations and programs.

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