



PRAXIS SPINAL CORD INSTITUTE CONSUMER PROGRAM

# ENGAGING PEOPLE WITH SPINAL CORD INJURY

This document is a roadmap that describes the Praxis Spinal Cord Institute's Consumer Program, its objectives and activities. It was developed based on recommendations provided by the Praxis Consumer Program Advisory Committee in 2017.

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.<sup>1</sup>

Spinal cord injury (SCI) consumers are individuals with lived experience, 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 shown to increase study enrollment rates, aid in securing funding, and improve study design, protocols and choice of relevant outcome measures.<sup>2</sup> 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.<sup>3</sup>

## 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.<sup>4</sup> 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.

<sup>1</sup> [https://cdn.ymaws.com/www.iap2.org/resource/resmgr/Communications/A3\\_P2\\_Pillars\\_brochure.pdf](https://cdn.ymaws.com/www.iap2.org/resource/resmgr/Communications/A3_P2_Pillars_brochure.pdf)

<sup>2</sup> <http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-14-89>

<sup>3</sup> <http://www.cjhr-irsc.gc.ca/e/48413.html>

<sup>4</sup> <http://www.nejm.org/doi/full/10.1056/NEJMp1209500#t=article>

## OUR VISION & MISSION

VISION: A world without paralysis after spinal cord injury.

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.

## CONSUMER ENGAGEMENT AT PRAXIS

The Praxis Spinal Cord Institute is a Canadian non-profit organization that drives innovation in spinal cord injury research and care. In support of its vision and mission, Praxis' 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, Praxis established its Consumer Program.

The Program, which now includes five individuals living with SCI, was created to engage the SCI community to become more involved in research, healthcare and advocacy. Following an Integrated Knowledge Translation (IKT) model, the Program engages persons with lived experience of SCI to inform and support not only the activities within Praxis, but also to work with researchers, healthcare teams, and decision-makers around the world.<sup>5</sup>

It is known that traumatic injury affects Canada's Indigenous populations at a higher rate than average, and often health outcomes are less than optimal. To help understand these significant inequities for indigenous persons living with SCI, we recently created the new Indigenous Peoples Liaison position within the Consumer Engagement Program. It is hoped that by better understanding the unique challenges these individuals face, we can work with all stakeholders to improve health outcomes for Canada's first people.

## OBJECTIVE OF PRAXIS' 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

**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 within 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;
- Accelerate the commercialization 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 priority-setting, project review and strategic planning;
- Facilitate networking opportunities between SCI stakeholders;
- Support the development of international SCI consumer consortiums to advocate for SCI research and programs to support SCI care;
- Support persons with SCI to attend scientific meetings and conferences to increase their understanding of the latest developments in research;
- Present on best practices in engagement and IKT at conferences and meetings around the world to provide advice and guidance on how to successfully undertake engaged research.

<sup>5</sup> <https://cihr-irsc.gc.ca/e/45321.html#a3>

## PARTNERSHIPS

Effective consumer engagement involves collaborations across countries, stakeholders, and organizations. Praxis 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 Praxis' objectives

## PRAXIS ADVISORY COMMITTEE

In 2015, a Consumer Program Advisory Committee (CPAC) was formed to provide on-going advice on Praxis activities. CPAC membership was drawn from the consumer population, including individuals with a variety of experiential backgrounds in SCI, and community service organizations. In 2020, CPAC transitioned to the Praxis Advisory Committee (PAC). The purpose of the PAC is to provide strategic direction to the Board on the integration of its programmatic activities.

## MOVING FORWARD

Please refer to the [Praxis website](#) for more information.

## CONSUMER PROGRAM PRAXIS CONTACT

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Praxis Spinal Cord Institute is proudly accredited by Imagine Canada.

## PRAXIS ADVISORY COMMITTEE (PAC)

The Committee advises Praxis on our strategic direction, including the integration of the activities of the Cure, Care, Consumer and Commercialization programs, to achieve our vision, mission and operational and fundraising goals.

### PAC MEMBERS

#### Michael Beattie (Chair)\*

Professor of Neurological Surgery & Co-Director, Brain and Spinal Injury Center, University of California

#### Kristine Cowley\*

Assistant Professor, Physiology & Pathophysiology, University of Manitoba

#### Graham Creasey

Paralyzed Veterans of America Professor of Spinal Cord Injury Medicine Emeritus, Stanford University

#### Richdeep Gill\*

Minimally Invasive Upper Gastrointestinal & Bariatric Surgeon, Assistant Professor of Surgery, University of Calgary, Peter Lougheed Hospital

#### Hans Keirstead

Chairman & CEO, AIVITA Biomedical Inc.

#### Katie Lafferty

CEO, Heart & Stroke Foundation Canadian Partnerships for Stroke Recovery

#### Ian Rigby\*

Emergency Room Physician, Foothills Medical Centre Chair, Praxis Board of Directors

#### Christine Sang\*

Director, Translational Pain Research, Brigham and Women's Hospital

#### Simon Sutcliffe

Former President, BC Cancer Agency Vice Chairman, Omnitura Therapeutics

#### Rob Wudlick

Treasurer & Co-Founder, Get Up Stand Up Associate Professor, Harvard Medical School

\*Member of the Praxis Board of Directors