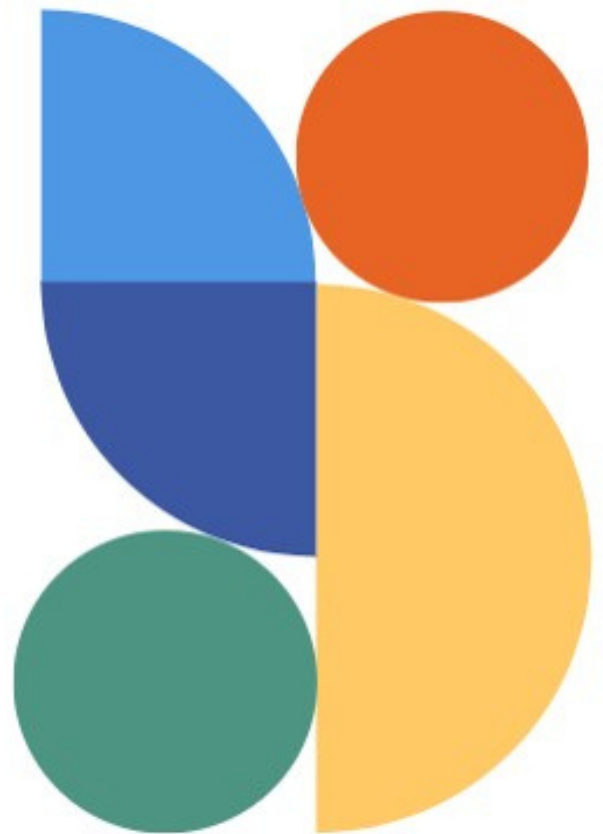


ACTION REPORT

Pressure Injury in People with Lived Experience of Spinal Cord Injury



MAY 2023

ACKNOWLEDGEMENTS

Our Team

We are an interdisciplinary team of people with lived experience of spinal cord injury, health researchers, healthcare providers, and others with an interest in patient/persons with lived experience engagement in research.

This project was funded by

The Canadian Institutes of Health Research.

Thank you

To all of our participants and partners.

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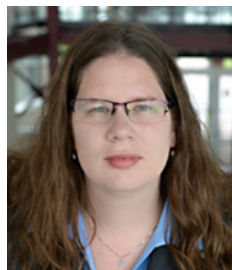
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STUDY OVERVIEW

BACKGROUND

- Funded by a Canadian Institutes of Health Research (CIHR) Catalyst grant for Patient-Oriented research (POR)
- The goal of the study is to contribute diverse perspectives of pressure injury (PI) in adults with traumatic spinal cord injury (SCI) and to generate patient-driven* and patient-oriented* priorities to catalyze future research that optimizes the health of Canadians with SCI

IMPORTANT NOTE

The term "**patient**" is used here as an umbrella term defined by the CIHR Strategy for Patient-Oriented Research (SPOR). The term "patient" may include individuals with personal lived experience of a health issue, informal caregivers, family, friends, and community members.

Through our collaboration with our study team and participants we learned that not everyone with a SCI identifies as a "patient". For this reason we choose to use "**PLEX**", "persons with lived experience" in our work.

Specifically, this work has **two** principal objectives:

- 1) To examine the experiences of pressure injury in adults with traumatic SCI
- 2) To develop PLEX-driven priorities to catalyze and inform future actionable PLEX-oriented research

OUR BEGINNINGS

This research came about in response to study co-lead Spring's own lived experience of pressure injury. In August 2016, Spring noticed a small red mark on her right iliotibial band, a strong thick band of tissue that runs down the outside of the thigh. After it persisted for a week, she had it assessed by a community nurse and was advised to treat it with a simple, wound dressing. By November, the wound had grown considerably, and Spring was losing weight and in severe pain. She was diagnosed with osteomyelitis (an infection in the bone) and admitted to hospital for six weeks where she received intravenous antibiotics.

After this, Spring returned home on complete bed rest. This resulted in 10 consecutive months of bed rest. Spring recalled that during the time, her life was on hold as she endured extended bed rest without any end time in sight. She recalled:

"My healthcare team seemed satisfied with the state of care and there was no sense of urgency to resolve the wound."

After repeated requests to be referred to a plastic surgeon, Spring had successful flap surgery with bone reduction followed by another six weeks of recovery in hospital. Spring noted:

"From start to resolution, my journey with pressure injury lasted 20 months with well over 300 medical appointments. It was due to self-advocacy that it ended when it did."

When John Chernesky, Lead of Consumer Engagement for Praxis Spinal Cord Institute, heard Spring's story, he knew he wanted to explore this important issue, particularly as he also lives with a SCI and has experienced pressure injury. He connected with Davina at the BC SUPPORT Unit conference and Nicola at a SCI event, seeing an opportunity to bring together stakeholders from across British Columbia. The group connected and began to meet to explore a potential partnership. Team members each came with different expertise, but together provided an ideal group to begin to explore this issue.

There was a desire to ensure that the voice of those with lived experience of SCI was at the heart of the work and a commitment to contribute actionable and impactful evidence that could improve the health and wellbeing of those living with SCI. As Spring commented:

"Pressure injury is a leading cause of death for those living with spinal cord injury, but spinal cord injury research that is not patient-led often focuses on less crucial things, like walking, because non-disabled people make research decisions based on erroneous assumptions about what is important to people with spinal cord injury."

During our initial meetings, our team purposefully spent time getting to know each other and establishing collective goals and expectations. We then began to co-develop a research plan and grant application.

Our team was awarded a Canadian Institutes of Health Research Catalyst Grant for Patient-Oriented Research in 2020. Taking the time to develop an engagement plan built on relationship, trust, and authentic partnership was essential if the team was to achieve the goal of contributing diverse perspectives of pressure injury in adults with research that optimizes the health of Canadians with SCI.

This engagement plan addressed team members lived experience and strengths, detailed timelines and scope of work, and a dedicated budget for compensation of patient partners. Spring explains:

"Research partnerships are about more than time and money, it's about the human face and the involvement of the end user, or patient. Patient partnered research like our project has the potential to bridge the gap in understanding the priorities of the SCI community."

Integral to this work was the development of a safe research ecosystem that is continually reflected upon and strengthened. The below relational practices were instrumental in partnering in a safe and inclusive way:

- ✓ **Respecting personal and professional boundaries**
- ✓ **Actively working to mitigate power imbalances**
- ✓ **Sensitivity around ableism and equity**
- ✓ **Recognizing the emotional work of sharing experiences**
- ✓ **Considering privacy**
- ✓ **Challenging assumptions and unconscious biases**
- ✓ **Cultivating open communication and feedback**

As spring explains:

"Honoring and respecting that peoples' experiences can be traumatic and sharing those experiences with people can also be a pretty emotional and so giving space to recognize that and to honor that and give people the support that they need to feel safe in sharing those stories."

From the very start, this work has remained PLEX-driven and PLEX-led, providing a vehicle through which to tackle this complex health issue. As a team, we remain deeply committed to advancing the health of Canadians living with SCI through advocacy and the creation and mobilization of impactful, relevant, and timely evidence.

"Safety lies in the power relationship between healthcare providers and researchers and patients, it can often be unequal. Our partnership space was always a safe place in that we paid attention to the power dynamics and feeling valued for the importance of lived experience." -Spring

OVERVIEW OF PRESSURE INJURY IN SPINAL CORD INJURY

- A pressure injury (PI) is defined as localized damage to the skin and tissues, commonly occurring as a result of intense and/or prolonged pressure or shear¹
- PI in persons with lived experience of SCI are common, with approximately 95% of individuals experiencing at least one PI in their lifetime²
- While PIs occur in those without SCI, PI in those with a SCI can be catastrophic and give rise to enormous healthcare costs and significant morbidity and mortality³⁻⁶

Persons with SCI experience a higher risk of PI due to restrictions in mobility and sensory impairment that may leave the person unable to feel pain or temperature changes. These factors mean that a pressure injury may occur rapidly and without the person's awareness.³⁻⁶

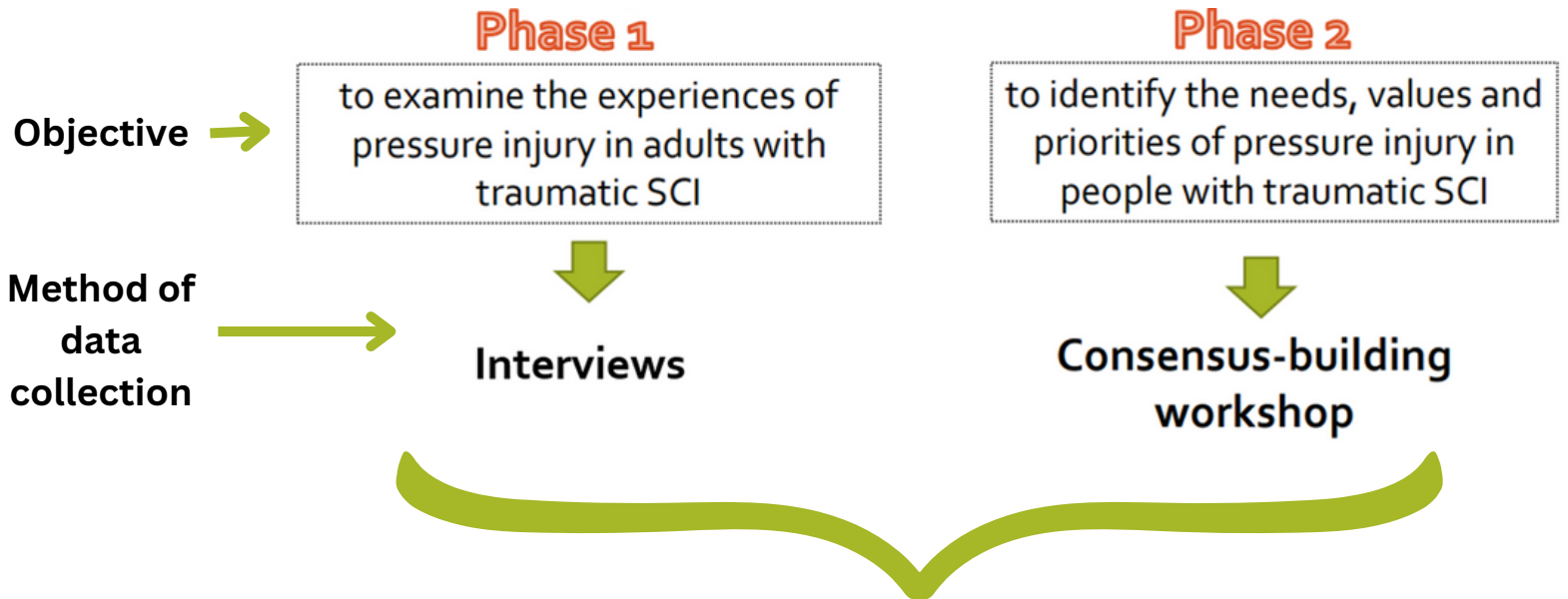
While public awareness of the challenges associated with PI in SCI has risen in recent years, there has been limited attention given to PI, particularly from the perspective of those living with SCI.



**GAPS IN
KNOWLEDGE &
CARE**

STUDY METHODS

To achieve our goal of contributing diverse perspectives of PI in adults with traumatic SCI and to generate PLEX-driven and PLEX-oriented priorities to catalyze future research that optimizes the health of Canadians with SCI, we designed a two-phased study:



STUDY OUTCOMES

- 1) A comprehensive study of experiences related to PI in adults with SCI in BC. This will advance our theoretical knowledge by studying the experiences of patients with SCI as they work to prevent and manage pressure injury and their experiences of interacting with the healthcare system.
- 2) Develop a PLEX-oriented research plan to document the priorities of persons with lived experience of PI and SCI and to inform future pan-Canadian research in PI and SCI.

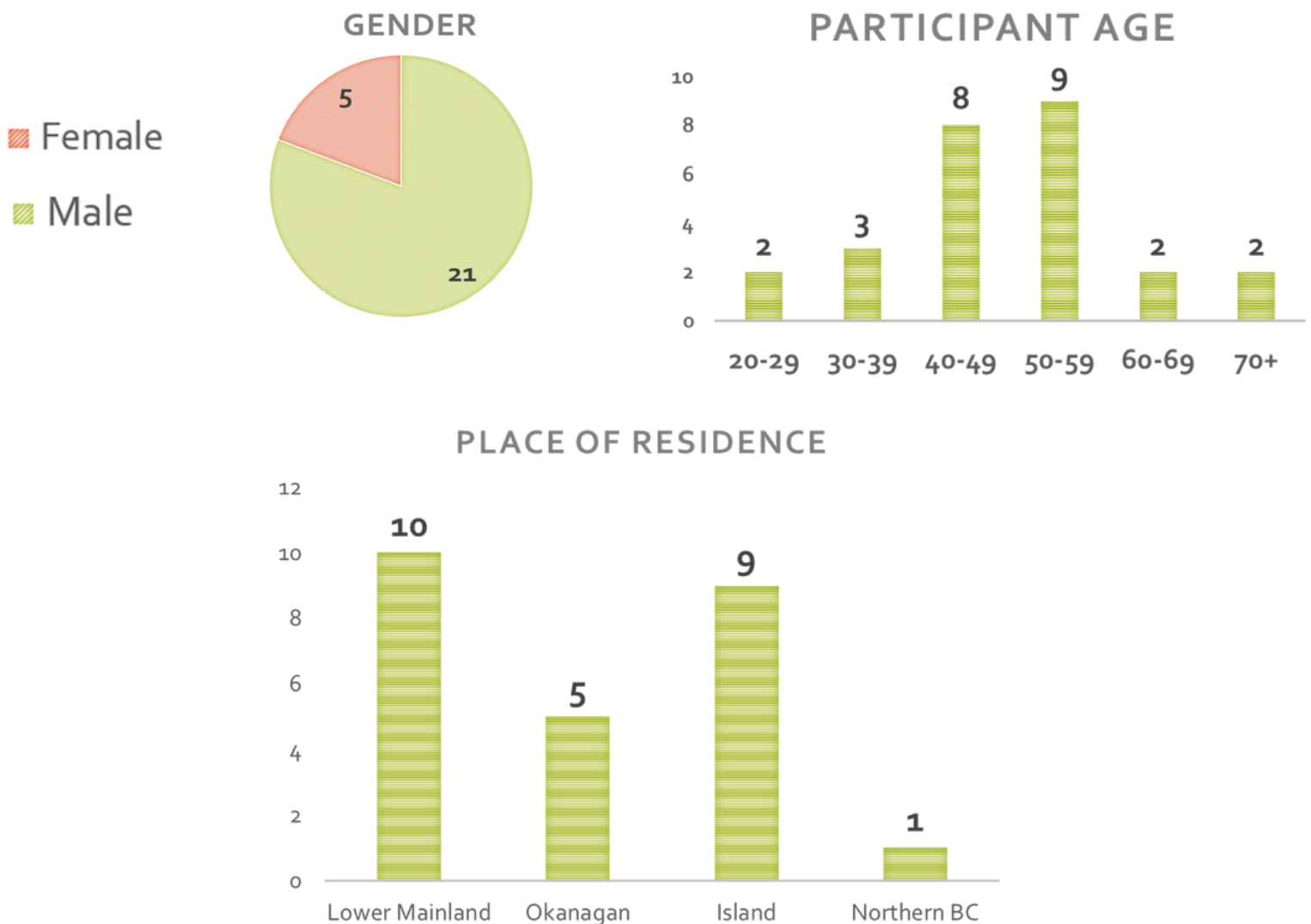
contributing to

**IMPROVEMENTS IN HEALTHCARE DELIVERY AND
HEALTH OUTCOMES**

OVERVIEW OF PHASE 1: INTERVIEWS

- The interviews examined the experiences of adults with lived experience of SCI, the work involved in preventing and managing PI, and interactions with the healthcare system.
- Participants were recruited through existing relationships and interactions as well as advertising with organizations such as Praxis, Spinal Cord Injury BC, and iCORD.
- **26** interviews were conducted over zoom between December 2020 and May 2021 and ranged in length from 45 minutes- 1.5 hours.

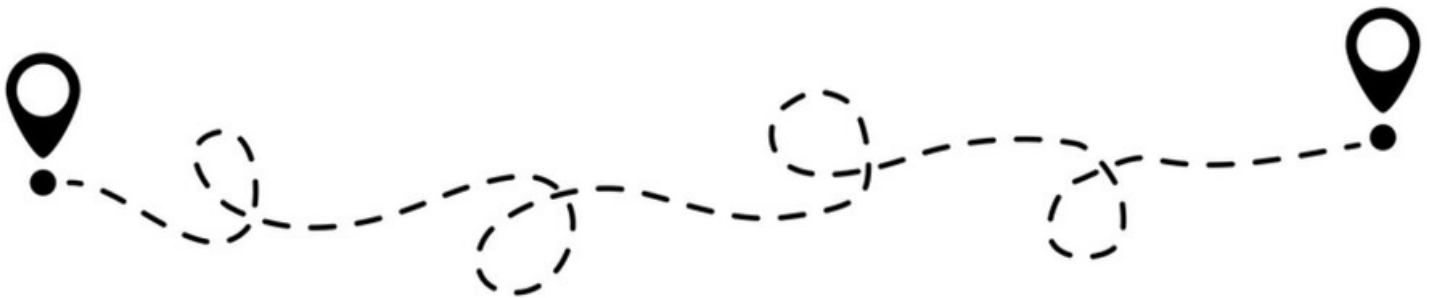
PARTICIPANT-REPORTED DEMOGRAPHICS



FROM DATA COLLECTION TO ANALYSIS...

Data analysis is the process by which data (in this case, interviews) is transformed into new credible and meaningful knowledge.

- The 26 interviews were recorded and then transcribed by a professional transcriptionist.
- Members of the study analysis team read through all of the transcripts to get a sense of the data as a whole.
- Several meetings were held to discuss the content of the interviews, guided by the research objectives.
- Interview data was organized into themes to convey the perspectives and experiences of interview participants.



WHAT WE FOUND...

The experiences of pressure injury in adults with spinal cord injury can be conceptualized as a journey. The journey begins with coming to learn about the existence and significance of pressure injury. This learning is facilitated through rehabilitative care and interactions with peers. From here, an immense amount of work is involved in preventing and managing pressure injury. Throughout this journey, a constant interplay of trial and error and self-advocacy is required by the individual.

PARTICIPANTS SHARED....

The knowledge of PI in SCI

"The nurse struck the fear of God into me, she asked the other patient if it would be okay to share history with me ... I never got to see his face cause he was rolled onto his side and the smell of rotting flesh was more than enough to terrify me. And so, that fear has been instilled before my [pressure] injury. Before my pressure sore."

"So I probably only heard the language once I started hanging around other people with spinal cord injuries to be honest, yeah. A very limited, as I learned almost everything else, you know. Just by talking to other spinal cord injuries, I don't remember it coming from a nurse or a healthcare professional."

The work of preventing PIs

"Prevention, prevention, prevention. I say it on the form. I say it to caregivers. I say it to my friends. Cause once you break that skin, it never heals quite the same and it's hard to come back from and I've seen first-hand the weeks and months [referring to how long it takes for pressure injuries to heal]."

"... if you ask a person with a spinal cord injury, what are the three greatest challenges that you face and I don't think anybody really jumps to mobility, it's bladder, sexual, and skin health. [Skin health] has always been a priority. "

"I check my skin every single day. I'll grab a mirror and make sure I check the most critical areas, so your ITs, I mean that's typically what you're setting on all the time. Make sure you check your hips, your feet, from when you're sleeping."

"Like, I'm sure everybody's skin reacts different to different products, some things will work for other people and not for others. I've had to trial a few things and they thought this would work and it just definitely was not working and had to go another route."

"If you have the right equipment, I mean, I can't stress enough how important equipment is and one thing that I typically, I say to people you're as good as your equipment."

"One of the things I found, especially out here in [name of rural city], ... when you go to the skin or the wound clinic, everybody has a different idea or different solution to what should be applied. There's so many different bandages and ointments ... I found that there wasn't necessarily a consensus across the board and every time you'd go in there, ... it didn't seem to be a protocol ... so I would say that that would be a critical area that we need to improve on, ... it's not that they're doing a bad job, it's just that everybody' got a different idea as far as what needs to be done."

OVERVIEW OF PHASE 2: CONSENSUS BUILDING WORKSHOP

To identify the needs, values and priorities of PI in people with SCI, we facilitated two consensus-building workshops (also called deliberative dialogues) to generate a PLEX-driven and PLEX-oriented research plan.

These 2-hour online workshops included members of the research study team, PLEX of SCI and PI, and healthcare providers working in the SCI community.

BEFORE THE MEETING...

As well as receiving an evidence brief, participants were asked to review the participant information sheet provided and contact us with any questions. Written and/or verbal consent was also obtained from all participants. Additionally, we provided a video that offered an easy-to-understand explanation of the priority-setting process and a brief summary of findings. Two consensus building workshops were held at separate times on April 28th, 2023, one in the afternoon and one in the evening, to accommodate the greatest number of participants.

DURING THE MEETING...

Plain language was used throughout. Members of our team aided meeting facilitation, technological support, support for participants, and note-taking. Participants were invited to reach out at any time if additional support was needed.

Our meeting began with some introductions, followed by a review of the process and findings to date. In the first workshop, we then broke out into smaller groups to discuss each of the themes before coming back together. In the second workshop, we held an open group discussion due to the smaller number of participants. Following these discussions in both workshops, we identified priorities and voted on those that we felt were the most important or timely.

WHAT HAPPENS NOW?

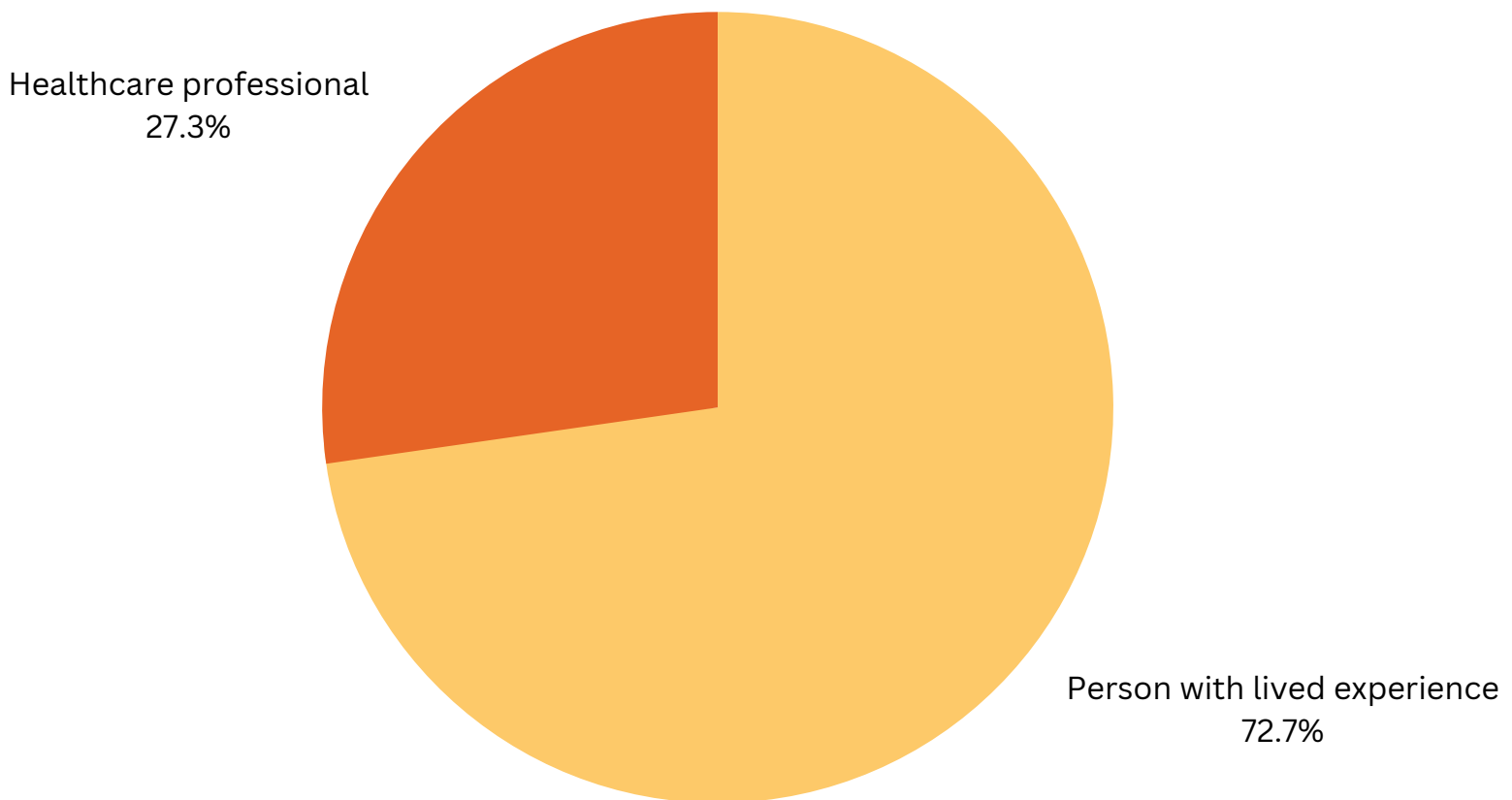
Our team has summarized these discussions and priorities in this Action Report and are looking forward to reviews and feedback from participants. Once we have a finalized document, we will complete our report and share it with the ** community.

**

THE PARTICIPANTS

We invited a diverse range of stakeholders. Our workshops had a total of 11* participants including persons with lived experience (PWLE) of SCI and/or PI, and healthcare professionals, including occupational therapists, who work with persons with SCI. The roles of the participants are summarized below. All participants provided informed consent before data collection.

The participants who identified as PWLE have all been living with an SCI for a minimum of 16 years, and the majority have been living with an SCI for more than 20 years.



OVERVIEW OF THE DISCUSSIONS

After reporting the key highlights from the documents provided (including the Evidence Report), we began with a roundtable discussion where we first asked participants to introduce themselves and their role in this workshop (e.g., person with lived experience of SCI, healthcare provider, etc.) and a fun fact about themselves. As well, we facilitated an ice-breaker activity which helped to build connections, mitigate power relationships, and familiarize participants with the ranking and voting process.

Our discussions in each workshop began with a brief roundtable discussion focusing on participant reflections on the Evidence Report and early interview findings. Overall, participants were pleased with the report, describing it as "honest" and "personal."

In the afternoon session, participants were split into two 'breakout groups' to discuss different prompts. Due to the smaller number of participants in the evening session, the group was not split into breakout groups and instead continued with a group discussion of the same prompts. After these discussions, the afternoon group was brought back together to share the main points of their discussions with everyone. These group discussions developed specific action points which were then ranked by participants.

THE DISCUSSIONS

In both deliberative dialogue sessions, our guiding questions were:

- What are the top research priorities for PLEX of PI?
- What populations or contexts do we need to focus on? (ie: unplanned admissions)
- Are there perspectives missing?
- How do we involve a more diverse group of PLEX of SCI in research?

In the first session, we ranked our action priorities:

Timely and rapid access to knowledgeable and experienced clinicians to implement immediate and responsive strategies.

1ST

Need for immediate protocols, assessments, and supports for PWLE accessing healthcare system, particularly during unplanned visit.

2ND

Need for innovation in equipment that is accessible and affordable - Expensive and time consuming set up of equipment.

5TH

Models of care that increase access to skilled professionals.

3RD

Need to identify and respond to gaps in engagement, including focusing on Indigenous and rural populations.

4TH

Optimize secure technology, including virtual, access to experienced providers, sharing data to support rapid management and prevention.

6TH

Conducting research that spans PWLE, healthcare provider, health system, and ministry of health levels.

7TH

"Our health authority has probably invested \$300,000 in my ass. We're not even gonna talk about the 3 years of my life, that's invaluable."

In the session, we ranked our action priorities:

Healthcare provider attitudes and knowledge about PI in SCI.

1ST

Timely and rapid access to knowledgeable and experienced, coordinated, multidisciplinary care to implement immediate and responsive strategies.

2ND

Need to identify and respond to gaps in engagement, including focusing on Indigenous populations, rural, areas, and industry.

3RD

Teaching and learning about SCI. When and how is it optimal to learn about PI?
How do we empower PLEX?

4TH

Conducting research that spans PWLE, healthcare providers, the health system, and the ministry of health levels.

5TH

Optimize secure technology, including virtual, access to experienced providers, sharing data to support rapid management and prevention.

6TH

"A waitlist for a flap surgery or a ... skin graft ... can be up to a year, year and a half long. And if that's the case, what happens to that wound in that year and a half?"

BLUE SKY THINKING



What do you hope comes out of this project?

We heard:

- Resources to effectively manage PIs - could include enhanced access to plastic surgery and more advanced therapy to be quicker, more effective, and have better outcomes
- Need for the right information and education at the right time for people with SCI to access support for PIs - education must be targeted and tailored
- Research that can show the reasons for PI as well as the other granular impacts (hospital stays, quality of life, etc.)

When thinking of PI in SCI, what impacts would we like to see in 5 and 10 years?

We heard:

- In 10 years, we hope that PIs are not even talked about because they don't happen anymore
- Overall health system change - increased capacity to support people with SCI to prevent PIs

NEXT STEPS



Step 1 - Action Report

We have created an action report that outlines tangible solutions. We are now asking for feedback from participants which will be used to finalize the report.

We have created an action report that outlines the priorities generated in our priority-setting workshop. Our goal was to identify priorities that are actionable and specific enough to provide direction to researchers and patient partners.

We are now seeking reviews and feedback from participants to ensure that we captured the priorities. This action report will **

YOUR FEEDBACK MATTERS!

- Does this report reflect the content and messaging from the workshop?
- What about these results resonates strongly with you?
- What do you think is missing?
- Who do you think needs to hear these results and recommendations?
- What do you think should happen with these results?

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References

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