



Gathering Perspective

Reshaping Rehabilitation & Recovery of Stroke,
Brain Injury, and Spinal Cord Injury in BC through
community engagement

Table of Contents

05	Acknowledgment
07	Executive Summary
09	Project Description & Goal
12	Key Terms
18	Community Engagement Series Overview
19	Project Timeline
20	Summary of Key Insights
22	Current Experiences of Rehab + Recovery in BC
50	Future Ideas & Considerations
66	Reference
68	Appendix A: Participant Demographics
70	Appendix B: Detailed Workshop Summary
77	Workshop Activity Breakdown

PROJECT STEERING COMMITTEE:

Emily Carr University of Art + Design Health Design Lab

Caylee Raber, Director

Nadia Beyzaei, Manager

Yutaan Lin, Research Assistant

Blair Muxiang Yu, Research Assistant

Heart & Stroke

Jeff Sommers, Director, Health Policy
and Systems, BC + Yukon

Spinal Cord Injury BC

Chris McBride, Executive Director

After Stroke BC/March of Dimes Canada

Brent Page, Executive Director

BC Brain Injury Association

Geoff Sing, President

BC Brain Wellness Program

Sally-Ann Stelling, Team Lead,
Exercise Programs & Education

GF Strong Rehabilitation Centre

Jennifer Yao, MD, FRCPC Physical Med &
Rehab, UBC Clinical Associate Professor

Person With Lived Experience

Jennifer Monaghan, Patient Partner

Workshop Facilitators

Carol Paetkau, Fraser Valley Brain
Injury Association

Janelle Breese Biagioni, CGB Centre
for Traumatic Life Losses

Jenna Beaumont, Stroke Services BC

Katie White, Stroke Services BC

Kix Citton, Nanaimo Brain Injury Society

Sacha Arsenaault, Stroke Services BC

Tori Dach, Cridge Centre for the Family

For more information, please contact:

Jeff Sommers at: jeff.sommers@heartandstroke.ca

Acknowledgments

The development of this report took place in Vancouver, British Columbia, located within the unceded lands of the Musqueam, Skwxwú7mesh-ulh Úxwumixw (Squamish) and Tsleil-Waututh peoples. The workshops that informed this report took place virtually across British Columbia but were hosted by project team members also located on these lands. We practice these land acknowledgments not only as acts of recognition, but also as a reminder to attune ourselves to the real, and lived impacts of colonial systemic forces, as we work towards engaging in processes that look to better support people who have experienced a stroke, spinal cord injury and/or brain injury.

This report is the outcome of the valuable contributions of people with lived experience, as well as health care professionals and researchers through a community engagement series. Around 50 participants and 16 facilitators were engaged in 12 virtual workshops, with over 4,600 individual notes collected and synthesized, informing this report. We would like to thank the people with lived experience, healthcare professionals and researchers who shared their views to support this work and recognize the value of their lived experiences.

The Project Steering Committee, made up of nine British Columbia-based health and community organizations, co-developed the workshop engagement and recruitment plan for the community engagement series. The Emily Carr University Health Design Lab team synthesized the information gathered through the workshops, a core writing group from the Project Steering Committee drafted and edited this report, and the full Project Steering Committee reviewed this report before publishing.

This initiative is supported by funding through a systems-change grant from the Vancouver Foundation.

Executive Summary

This report presents the findings from twelve virtual workshops that were held in April/May 2022 with health care professionals and people with lived experience of stroke, spinal cord injury, and brain injury.

The goal of the workshops was to understand the experience of – and learn from - people who both work and live with British Columbia’s current system of rehabilitation and recovery for these three diagnoses as well as elicit their ideas about how to improve that system.

Workshop participants identified five key sets of challenges commonly faced by those who work in the system and/or people with lived experience, each of which operates along several dimensions. These include:

- The impact on consistency of care generated by personnel challenges within the system.
- The impact of limited financial support on people’s experience and ability to cope and live with their injuries.

- The impact on the quality of care created by geographical disparities in access to services.
- The absence of support over the life-long recovery journey.
- Declining availability of services as people age and the complexity of their diagnoses increases.

Participants also talked about avenues for system improvements in four main areas, based on their experiences and knowledge of current gaps and barriers, including:

- Enhancing provincial networks for professional learning and support.
- Increasing long-term support over the life span by investing in community-based programming and support.
- Enhancing coordination of information and services across the continuum of care and geographical regions.
- Formally integrating roles for people with lived experience throughout the recovery journey.

Project Description & Goals

Every year in British Columbia, thousands of people experience a stroke, brain injury, or spinal cord injury — adding to the many thousands more who are already living with these diagnoses.

All three are chronic conditions that can have a direct effect on the functioning of the brain and/or spinal cord, and thus have the potential (in almost all cases) to be life-altering in one way or another. For many people, their physical and/or cognitive functioning will be changed for the rest of their lives. While it is possible for people to regain at least some of that functioning or adapt to the new circumstances, the current system of rehabilitation and recovery is far from ideal. In many cases, the system can result in barriers or delays that negatively impact an individual's recovery trajectory.

In 2007, a group known as the Physicians' Working Group on Rehabilitation Services wrote that "there has been no recognition provincially or regionally of the key role that rehabilitation plays in the care of the elderly

and those with chronic disease" while "rehabilitation services are currently delivered through a fragmented patchwork and access is often based on availability of third-party funding or geography¹." Little has changed in this regard over the past fifteen years. Specifically, three key obstacles stand in the way of change:

- Political/policy inertia
- Administrative fragmentation
- A clinical focus that privileges emergency response and acute/hyperacute conditions

The Ministry of Health and Health Authorities have yet to prioritize post-hospital rehabilitation and recovery. However, there is a deeply committed community dedicated to improving the lives of people living with these conditions. Health care professionals — from system administrators, specialists, and family physicians to nurses, therapists, counsellors, and community workers — often struggle to deliver services within the systemic gaps and challenges faced by people living

with stroke, spinal cord injury, and brain injury. the latter and their families live with these limitations every day for the rest of their lives, after discharge from hospital, resulting in not only physiological and cognitive changes, but at a social impact cost as well. To start this change, we brought representatives from all these groups together:

This project, The BC Rehabilitation and Recovery (R+R) Strategy and Advocacy Plan, is a collaboration between nine health & community organizations engaged on a Project Steering Committee, as well as people with lived experience, that aims to:

- Build the case for a client-centred, systematic, integrated, and organized province-wide approach to rehabilitation and recovery services.
- Diligently highlight and share the case to all levels of relevant decision-makers in the province over the next two years and beyond.

The BC R+R Strategy and Advocacy Plan, of which this document is part of, will work closely with these constituents to facilitate dialogue and translate their daily experiences into concrete policy recommendations. The BC R+R Community Engagement Series of workshops is the first step in that process. The project team will work to advocate for these recommendations with key decision-makers provincially, regionally, and locally, and the Project Steering

Committee will work closely to ensure peoples' concerns are heard as we work toward a client-centred, systematic, integrated, and province-wide approach to rehabilitation and recovery services.

THIS REPORT

The purpose of this report is to convey what we heard during a series of twelve virtual workshops that were organized in the Spring of 2022. This BC R+R Community Engagement Series brought together People with Lived Experience (PWLE), and Rehabilitation and Recovery Professionals and Researchers (RRPR). The workshops were clustered by diagnosis (i.e., stroke, spinal cord injury, and brain injury) and perspective (i.e., PWLE or RRPR). Each group participated in two sessions — the first focused on the current state of rehab and recovery services, while the second looked at what a future, more integrated system could look like.

The goal of the BC R+R Community Engagement Series has been to:

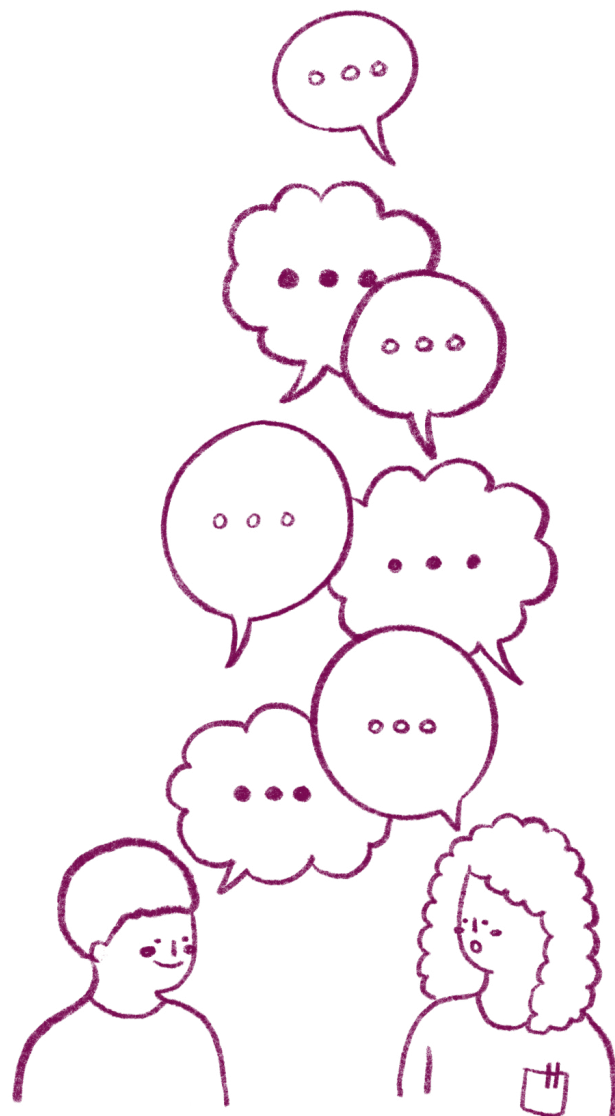
- Understand and map out the experiences of people who are directly involved in the current rehabilitation and recovery system in BC.
- Identify the challenges and obstacles encountered by both professionals and people with lived experience throughout the recovery journey.
- Determine some of the key elements, based on the experience of participants, that could make up a province-wide, comprehensive, and

integrated system of post-hospital neurorehabilitation and recovery that is inclusive of many different diagnoses and circumstances.

A final plenary session of the BC R+R Community Engagement Series was held on September 29, 2022, which brought workshop participants together to give feedback to the main themes generated through the knowledge gathering and synthesis process.

It is important to emphasize that the workshops were designed to specifically focus on the current and potential future states of rehabilitation and recovery in BC, from the lens of participants' experiences and knowledge. Although there are clearly relationships between the challenges that were identified in the current state and the solutions proposed for a possible future state, there is not necessarily a one-to-one relationship between challenges and proposed solutions.

The BC R+R Community Engagement Series is a crucial element informing the development of the BC R+R Strategy and Action Plan. However, there are also additional pieces of work that are currently ongoing that will help shape the recommendations, including an environmental scan of current services offerings in BC. These include an inventory of rehab and recovery services in BC for people living with stroke, spinal cord injury, and brain injury, and research using administrative databases into patient pathways through the BC stroke system. We will be supplementing this work in the future with economic analyses and best practices reviews.



Key Terms

THE FOLLOWING LIST CONTAINS A LIST OF TERMS USED IN THIS REPORT, AND THEIR DEFINITIONS.

Activities of Daily Living (ADL):

Activities of daily living refers to different kinds of tasks that are a necessary part of taking care of someone's basic needs in their daily lives. These can include but are not limited to mobility (such as getting up from sitting down); eating; personal hygiene; dressing; locomotion (like walking and taking stairs); or bowel and bladder control².

Acute care (In-patient care)

A period in which a patient receives intensive and typically short-term treatment or rehabilitation in a hospital, for a severe injury or urgent medical condition³.

Aphasia

Aphasia is a communication problem that masks a person's inherent competence. It is usually the lasting result of a stroke or brain injury. It may also be caused by other neurological conditions such as dementia or brain tumours. Aphasia is not well known or understood and may be classified as an 'invisible' disability. People with aphasia may have a language problem. This means that talking and understanding can be difficult; the ability to communicate opinions, feelings, thoughts, and emotions can also be impaired⁴.

Brain Injury

A brain injury refers to any damage done to the brain, that may result in partial to extensive impairment of someone's body functions. In this report, brain injury is defined as both:

- An Acquired Brain Injury (ABI), which is any damage to the brain that occurs after birth and is not congenital, degenerative, or is induced from birth⁵.
- Or a Traumatic Brain injury (TBI), which is any damage caused to the brain through external injuries such as a blow, bump, falls or any accidents causing blunt-force trauma to the head⁵.

Client

Someone who has been discharged from in-patient care and is receiving post-discharge care or rehabilitation in some form.

Community organization

In this report, community organizations refer to non-profits, NGOs, or informal groups predominantly set up and run by people with lived experience, with the intention of helping or providing services to other people with lived experience from outside of the provincialized health care system. Examples of such groups are After Stroke BC, the Young Stroke Survivors Support Group, or the Victoria Brain Injury Society.

Choice in Supports for Independent Living (CSIL)

A provincial funding option to support home support services. It is self-managed; CSIL clients receive funds directly from their local health authority to purchase their own home support services. Clients become employers who manage all aspects of their home support, from hiring and supervising staff to overseeing how CSIL funds are spent⁶.

Family Physician (FP)

Also known as Primary Care Providers or General Practitioners (GPs), FPs are physicians who provide primary-care, meaning they are usually people's first main point of contact when someone is seeking medical help⁷.

Home care

Home care includes a range of services — such as home support — that help clients remain independent and in their own home as long as possible. Home support services are provided by community health workers to clients who require personal assistance with activities of daily living⁸.

The Insurance Corporation of British Columbia (ICBC)

ICBC is the provider of mandatory insurance coverage for owning and driving a vehicle in the province of BC. ICBC provides, amongst other services, funds to pay for medical bills and treatment⁹⁻¹⁰.

Occupational therapist (OT)

OTs help people whose everyday capabilities (eating, moving, attending school/work & social activities) have been impaired by illness, injury, developmental disorders, emotional or psychological disorders, or the aging process¹¹.

Patient

Someone who is receiving formalized health care within a hospital setting, before being discharged.

People with Lived Experience (PWLE)

In this context, PWLE refers to people who have experience with stroke, spinal cord injury, or brain injury. It also includes their care partners and may include other family members and/or friends.

Physiatrist

Physiatrists are physicians who specialize in physical medicine and rehabilitation, evaluating and treating patients or clients whose functional abilities have been impaired due to an injury¹².

Physiotherapist

Physiotherapists are licensed health care professionals who work autonomously and collaboratively alongside physicians and health care teams. With a patient-centred approach, physiotherapists use evidence-informed knowledge of rehabilitation sciences, anatomy, kinesiology and physiology to assess, treat, and manage pain, injuries, movement dysfunction, and chronic conditions. The goal of physiotherapy is to empower, promote independence, and improve the quality of life for British Columbians across all ages and abilities¹³.

Professionals/Rehabilitation and Recovery Professionals and Researchers (RRPR)

In this context, professionals or RRPR refers to people with specialized training who work with people living with stroke, spinal cord injury, and/or brain injury in a health system or community setting. This includes medical personnel (i.e., physicians, and nurses) as well as allied professionals such as physio- and occupational therapists. It can also include social workers, counselors, or other related occupations.

Recovery

Recovery refers to the process in which a person experiencing an injury or diagnosis receives general care or treatment, to improve their condition. This can include both in-patient and out-patient care, and for some people may extend to be a lifelong process¹⁴.

Rehabilitation

Rehabilitation, also known as rehab, is a period in someone's recovery where their formal health care is focused on regaining or partially regaining the functionality and skills they may have lost as a result of an injury. The patient or client may work with a professional specialist or groups of specialists to perform this rehab and is not exclusively limited to being done within a hospital setting¹⁵.

Speech Language Pathologist (SLP)

SLPs assess and treat many kinds of communication and swallowing problems. They work with adults following a stroke, brain injury, and in some cases, with individuals with spinal cord injury.

Spinal Cord Injury (SCI)

A spinal cord injury is an injury that occurs when someone receives damage to any part of the spinal cord or nerves at the end of the spinal canal. This often causes permanent changes in strength, sensation, and other body functions below the site of the injury, and the recipient of the injury might feel the effects of the injury mentally, emotionally, and socially¹⁶.

Stroke

A stroke is an injury that occurs when there is a blood blockage or bleed in any part of the brain, resulting in brain cells being damaged and possible loss of some body functions. The effects that someone experiences due to a stroke depend on the part of the brain that was damaged, and the amount of damage done. Strokes are usually classified by differing levels of severity¹⁷.

Sub-acute care (Out-patient care)

Sub-acute care is a period in which a patient receives care that is less intensive and longer term than acute care, when they are no longer required to be admitted to hospital full-time for treatment. This level of care is done typically if someone's condition requires further attention and rehabilitation than could be given during acute care¹⁸.

Transitioning back to home/community

Sometimes referred to as post sub-acute care in the report, this is the period of someone's recovery journey when they have completed acute care and sub-acute care (meaning they have completed most of their intensive rehabilitation) and are now moving back to a living situation like that of prior to being admitted to hospital for their injury.

WorkSafeBC

WorkSafeBC is a statutory insurance system that also partners with workers and employers to prevent injury, disease and disability. The service provides compensation for work-related injuries to support people in their recovery, rehabilitation, and return to work. WorkSafeBC is partly funded by insurance premiums paid by employers¹⁹.

Community Engagement Series Overview

This BC R+R Community Engagement Series consisted of twelve virtual workshops over Zoom, between April and May 2022, and were intended to create a platform for PWLE of stroke, spinal cord injury, and brain injury — as well as RRPR — to share their experiences and feedback on the current health care system, in the context of rehabilitation and recovery services and systems for these three conditions.

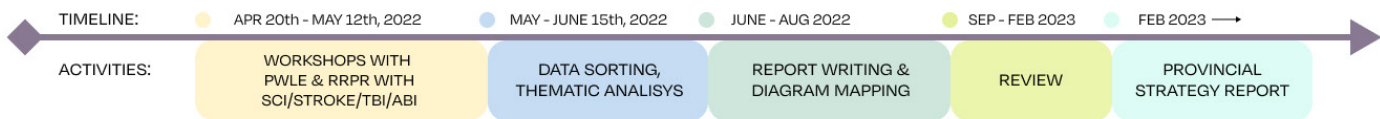
Workshops were separated by the three diagnosis types (i.e., stroke, spinal cord injury, and brain injury) and perspective (i.e., PWLE and RRPR) to create safe spaces of discussion amongst participants to allow for people to connect with their peers without underlying power hierarchies informing the direction of conversations in the sessions. For a description of the participants of these workshops, please

see **APPENDIX A**. For detailed methods, including timeline and activities, please see **APPENDIX B**.

People from across British Columbia were present at the workshops, from different health authorities. Sessions were co-facilitated by members of the Health Design Lab team and experts from the Project Steering Committee who represented a specific diagnostic group.

Using digital software designed for collaborative exercises, facilitators co-led activities with PWLE and RRPR to hear and document their experiences of the rehab and recovery system. The first session asked participants about their current experiences in the health care system. The second session shifted focus to what participants wanted in a future health care system or felt was needed to achieve this future vision.

PROJECT TIMELINE



Workshops were set up to be as accessible as possible for people who may have difficulty using technology or attending virtual meetings.

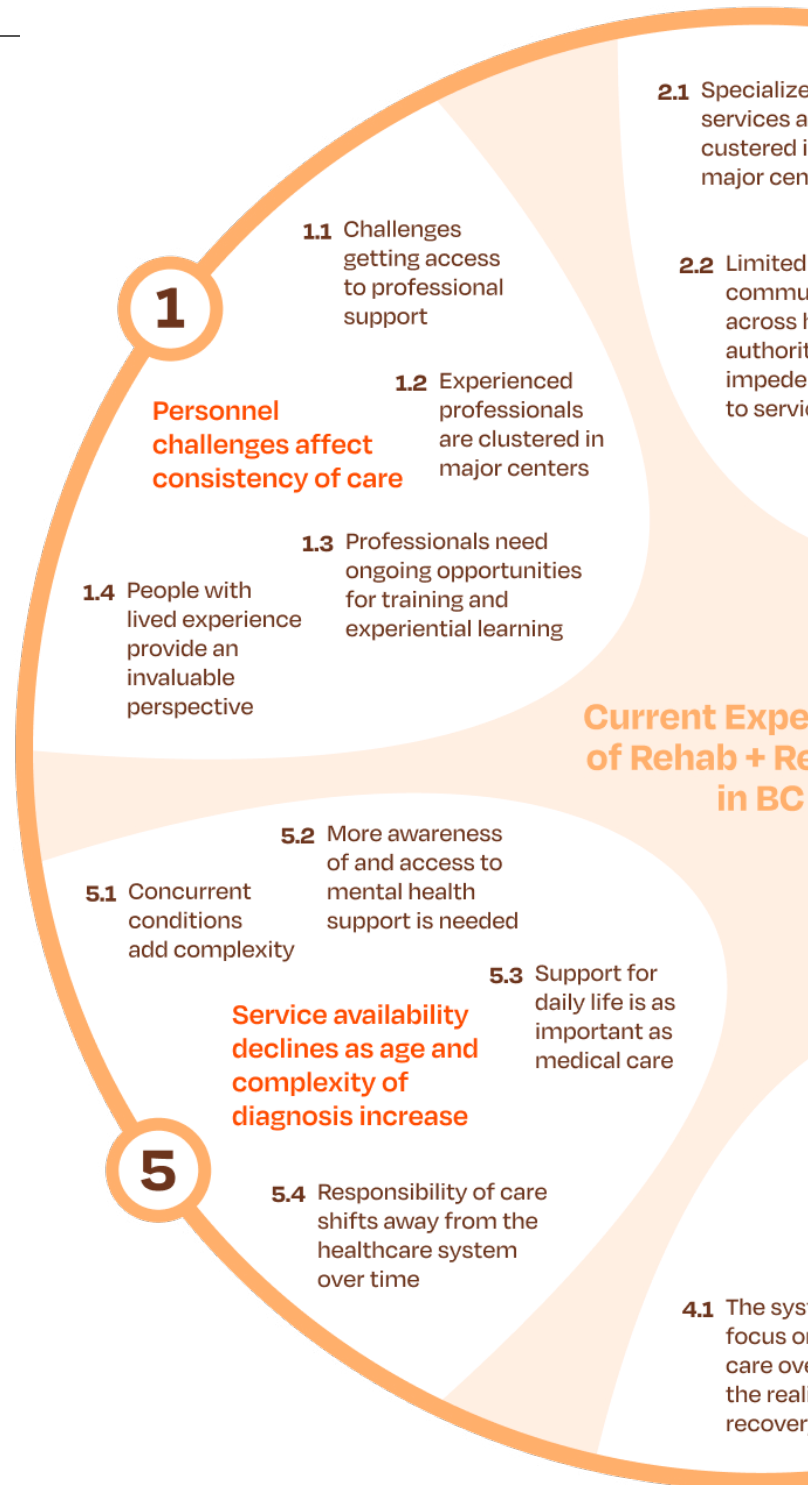
Once the workshop series concluded, the Health Design Lab team took all the notes and documentation captured in the sessions to synthesize. These notes were sorted and analysed, through many iterations of synthesis, to create the themes and statements for this report.

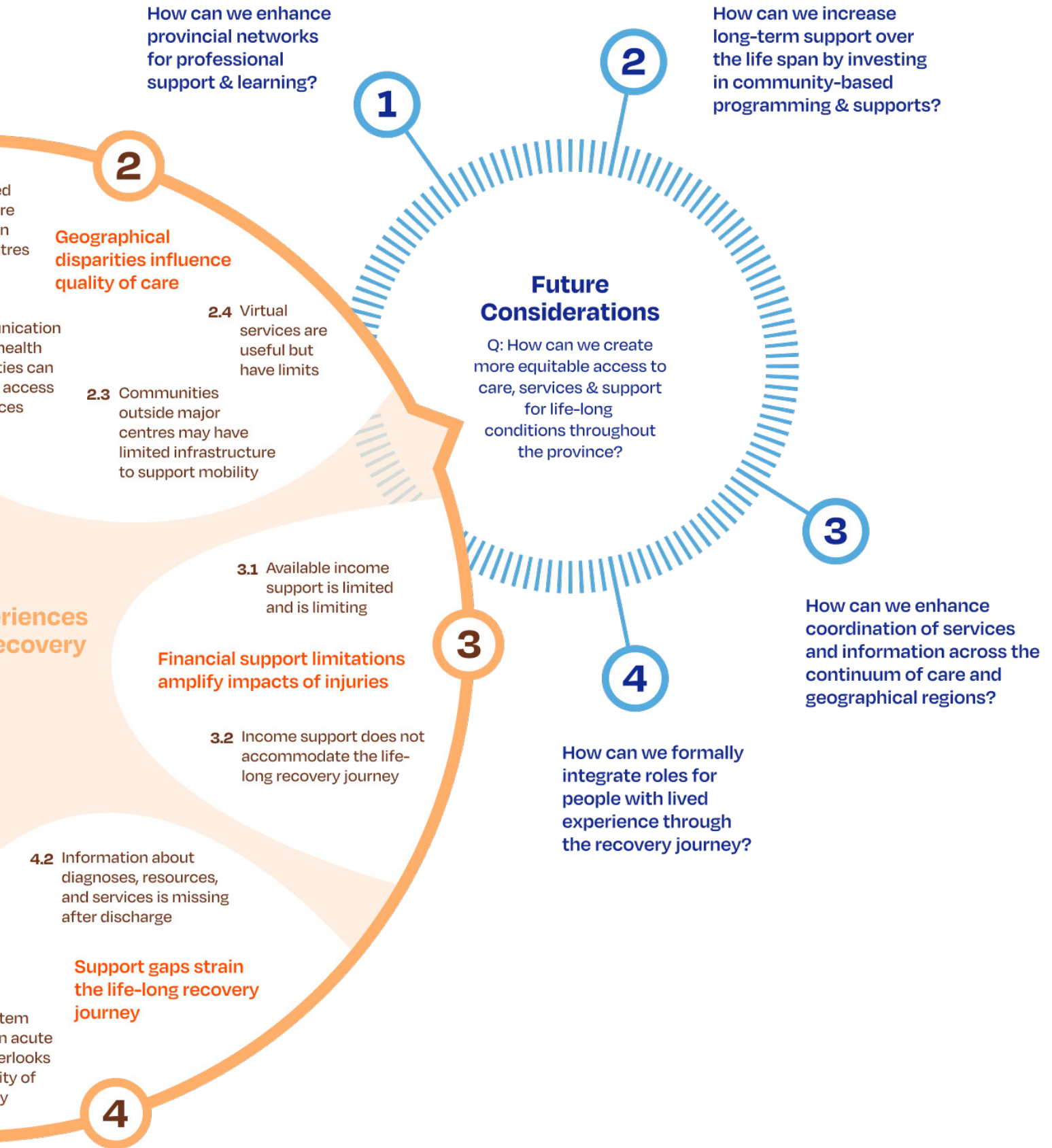
The statements and questions derived from the synthesis process, have been laid out in this report linearly for ease of reading. This linear nature, however, does not reflect the way the feedback and perspectives were given in the workshops, which were far more interconnected and related than could be efficiently honoured in this document.

Summary of Key Insights

The diagram below is an at-a-glance visualization of the feedback heard in workshops with PWLE and RRPR, and the major points that arose from those conversations. The diagram highlights **current experiences of post-hospital rehab + recovery in BC** — that were generated from both PWLE and RRPR — and four future considerations that can be envisioned for an improved system.

This diagram is an at-a-glance visualization of the insights gathered in the workshops with PWLE and RRPR, and the major themes that arose from those conversations. The diagram highlights current experiences of Rehab + Recovery in BC that emerged. These are linked to four future considerations that can be envisioned as part of a future experience of the health care system.





Current Experience of rehab + recovery in BC

1. Personnel challenges affect consistency of care	pg. 24
2. Geographical disparities influence quality of care	pg. 30
3. Financial support limitations amplify impacts of injuries	pg. 34
4. Support gaps strain the life-long recovery journey	pg. 38
5. Service availability declines as age and complexity of diagnoses increase	pg. 42

The information presented here is a summary of commonly identified issues captured from the personal experiences of workshop participants. Whilst important and valuable insights were shared, these themes are representative of the perspectives of only the individuals who participated. They are not representative of the entire B.C. population, nor the full current state of the rehab and recovery system at large.



1

Personnel challenges affect consistency of care

Workshop participants pointed out several challenges related to personnel access, distribution and training in the current system. People with lived experience (PWLE) spoke about difficulties getting access to the kind of specialized professionals required to support their highly specialized conditions. Professionals outside the major centres talked about the difficulties of gaining the necessary clinical experience and training to provide that specialized support. These challenges are driven, at least in part, by the uneven distribution of professionals and services across the province, resulting in disparities in access to expertise and support. Participants asked for more consistent access to services and support as well as availability of that support across their lifespan.

1.1 CHALLENGES GETTING ACCESS TO PROFESSIONAL SUPPORT

PWLE talked about their difficulties in getting access to professional expertise and support as a problem across two dimensions. First, they articulated their access challenges as organizational and coordination related, especially in how referrals are set up and made available in a

“If people don’t have primary care providers, you don’t have ongoing care, and you can’t access the specialist care you need.”

— RRPR with expertise in SCI

timely and useful manner. This was often perceived as a problem of limited numbers of personnel in the system. Second, PWLE expressed significant frustration with what they perceive to be a general lack of professionals who are educated and experienced in working with people who are living with a stroke, spinal cord injury and/or brain injury.

- **ACCESS TO REFERRALS:** PWLE often commented that access to knowledgeable professionals — ranging from Family Physicians (FPs), occupational therapists (OTs), speech-language pathologists (SLPs), physiotherapists (PTs) and physiatrists — should be available to everyone. However, in practice this is difficult for many. First, FPs serve as key points of reference to specialist physicians, and other specialist professionals in allied health, but many people don’t have a family doctor. “If people don’t have primary care providers, you don’t have ongoing care, and you can’t access the specialist care you need.”

Second, having a referral to a specialist professional doesn’t always mean reasonable access. As one person living with stroke told us: “fifteen months later in the referral for occupational therapists and I’m still waiting. Referral for SLP still waiting nine months. I was waiting on a cardio follow-up, and I never got the call. Everything fell apart post-discharge that was supposed to be lined up.”

- **DIAGNOSIS-SPECIFIC EXPERTISE OF PROFESSIONALS:** Getting access to professionals is not the only daunting challenge for PWLE. Finding care providers with the combination of specialized expertise and experience who can help them understand their diagnosis and what it means is another layer of difficulty that PWLE contend with.

Some people spoke about having to deal with professionals and care providers who aren’t familiar with their needs and diagnosis, thus requiring them to do self-advocacy

to educate the professionals who are part of their care team. “I’ve had GPs who don’t know anything [about my condition] and pretend they do, and that’s dangerous”.

One professional noted that they advise patients to: “assume [their] home care workers haven’t seen anyone with SCI before and assume it’s on [the client] to explain things to [the health care provider]”. Such experiences can contribute to a sense of isolation or promote distrust and doubt in the efficacy of the health system to help people.



1.2 EXPERIENCED PROFESSIONALS ARE CLUSTERED IN MAJOR CENTRES

The range and quality of available rehabilitation and recovery services is also dependent on their location. Participants noted that professionals with expertise in the relevant conditions are usually clustered major centres, where the established rehab programs are based, such as GF Strong, Holy Family, Queen’s Park or other large urban areas. This seems to be a particular problem for communities outside the major centres. If professionals do not get exposure to people with complex needs, they may lack the experience that helps build expertise in specialized conditions. As a result, we heard from PWLE that their support needs often go unmet due to this knowledge gap that exists for many professionals working outside the major centres.

1.3 PROFESSIONALS NEED ONGOING OPPORTUNITIES FOR TRAINING AND EXPERIENTIAL LEARNING

Participants highlighted the need for much more understanding, education, and awareness about the multi-faceted effects of stroke, spinal cord injury, and brain injury, as well as associated recovery needs beyond the basic introductions offered in professional training programs (i.e., MD, PT, OT, SLP etc.).

PWLE pointed out that professionals should understand not just their diagnoses but also the

context of their needs. In other words, rehab and recovery should be about more than just providing treatment. It should also be concerned with providing encouragement and support in appropriate ways. “In rehab, I heard about more things that I couldn’t do, instead of things I could do. I became identified by my disability. My sexuality as a woman was set aside, and I was identified as a quadriplegic. I felt like the person that I was before, died”.

However, professionals noted that it can be difficult to access expertise and mentorship when they work outside the major population centres, having limited exposure to (and thus experience with) certain diagnoses. “Up north, we don’t have physical therapists who have been working in the field for a long time to be mentors. We are the ‘experts’ and we’ve only done this a few years through a few courses. Being able to advance our education to provide evidence-based practice is difficult.” This limited knowledge and experience in particular areas means that professionals may be less familiar with available or appropriate resources for PWLE.

“In rehab, I heard about more things that I couldn’t do, instead of things I could do. I became identified by my disability. My sexuality as a woman was set aside, and I was identified as a quadriplegic. I felt like the person that I was before, died”.

— PWLE with SCI

1.4 PEOPLE WITH LIVED EXPERIENCE PROVIDE AN INVALUABLE PERSPECTIVE

Workshop participants shared that having access to networks of people with lived experience fosters encouragement and offers crucial emotional support. The valuable experience that PWLE offer can help to create a smoother journey for patients and their caregivers in navigating the health care system, and their knowledge and experience should be recognized and appreciated.

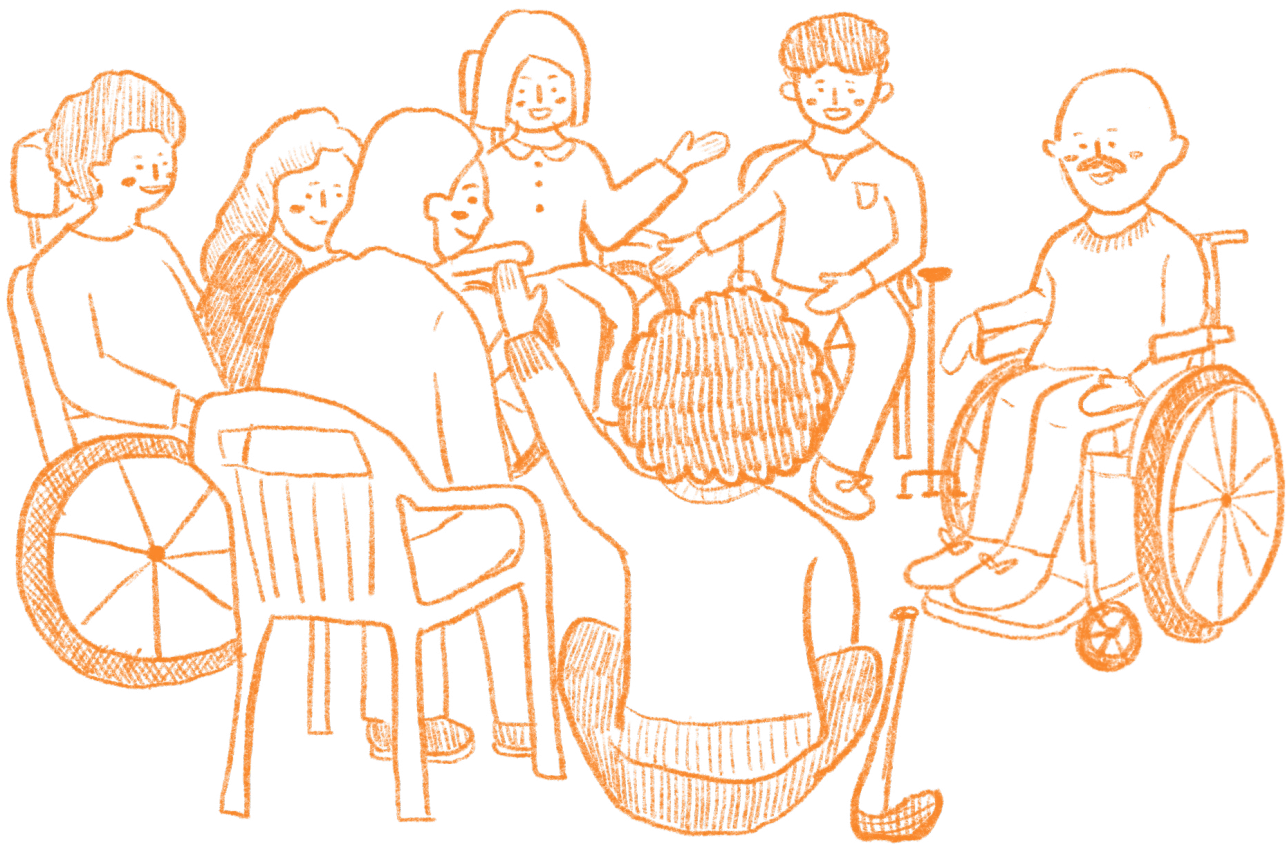
This kind of experience is helpful to PWLE both in the kind of guidance and mental safety net it provides, but also as a level of insight that professionals who do not have these lived experiences can learn from. Professionals can build better dynamics of trust and comradery with their patients by understanding their patient's care through the lens of lived experience. The impact that PWLE made on the recovery of their peers was evident across all three diagnostic groups. One participant from the stroke workshop stated that: “[He’s] never giving them up, [and that] they have been absolutely key to [him],” when sharing about his experience with connecting to peer networks.

“Only these people can understand what I’m going through, even though all strokes are different. [They are the] people who have walked that same journey, they can empathize, they can understand, that’s critical!” The connections

“Only these people can understand what I’m going through, even though all strokes are different. [They are the] people who have walked that same journey, they can empathize, they can understand, that’s critical!”

— PWLE with Stroke

established between PWLE are not just about understanding each other. Their experiences provide comforting guidance, helping others to connect to helpful services and resolve uncertainties, by sharing their personal experiences on living with and recovering from their diagnoses.



2

Geographical disparities influence quality of care



Geography has a major impact on access to high quality services and professional expertise. Services, programs, physicians, and allied health professionals with the right training and expertise tend to be concentrated in large urban centers; mostly in the Lower Mainland. This is compounded by what participants see as an insufficient degree of coordination between Health Authorities, so that people who live outside Metro Vancouver may experience difficulties accessing appropriate services and are often under-served. Insufficient transportation infrastructure in smaller communities also limits access to services. People who cannot travel say that virtual service offerings are helpful, but do not replicate in-person care.

“If you live and work in a rural area, access to services is always the biggest issue.”

— RRPR with expertise in Stroke

2.1 SPECIALIZED SERVICES ARE CLUSTERED IN MAJOR CENTRES

Both PWLE and professional participants highlighted the uneven distribution of services around the province. The established, specialized, high-quality health care centres and programs that specifically work with people living with stroke, spinal cord injury, and brain injury, together with the physicians and allied professionals who staff or work closely with them, are based mainly in the major centers. As a result, people who live outside of the major city centers, and particularly in the north, are often unable to access services that adequately meet their needs close to where they live. One professional from the north explained that: “If you live and work in a rural area, access to services is always the biggest issue.”

Access to services is crucial for people living with chronic injuries and their absence can make a huge difference in the trajectory of recovery. A spinal cord injury professional remarked that

they notice huge gaps in care when clients are not afforded the opportunity to receive in-patient rehab: “In an ideal situation, anyone with moderate to severe injuries would see rehab to better understand their injuries. It’s inhumane to not be educated about your injury and be discharged into a community with limited resources. Everyone should come through some sort of rehab with some sort of education.”

2.2 LIMITED COMMUNICATION ACROSS HEALTH AUTHORITIES CAN IMPEDE ACCESS TO SERVICES

Participants noted that coordination and information flow between Health Authorities can be cumbersome to the point that some participants, including professionals, highlighted experiencing issues with referrals. As one professional told us, “an inequity that exists in BC is that there’s no referral across health authorities”. If a person needs to seek services or support in a different region, the transfer of health and referral information

between the different Health Authorities can be slow and difficult. This combined with the concentration of services in the southwest part of the province, leads to what both PWLE and professionals see as bottlenecks in services, with long waiting periods and short durations of service.

This is compounded — or perhaps caused — by the fact that different Health Authorities use different information systems. Another professional noted that, “all health authorities use different electronic health records [that] don’t communicate to each other.” This seems to present a potential barrier to information flow between health professionals, that can lead to people experiencing major disconnections in the kinds of care they receive if and when they move from one jurisdiction to another.

2.3 COMMUNITIES OUTSIDE THE URBAN CENTRES MAY HAVE LIMITED INFRASTRUCTURE TO SUPPORT MOBILITY

Participants living outside the province’s urban centres told us that they have to deal with lengthy and difficult travel, disruptions related to their recovery needs, and increased living costs in their daily lives. One participant living with spinal cord injury told us he had to move from Gibson’s Landing to Vancouver, due to a lack of wheelchair accessible transit. The more rural a place is, the harder it is to find adequate transportation services, and proper mobility or support equipment.

“A simple thing for independence is expanding the mandate of HandyDarts. Right now, you must book it two weeks in advance, no sooner. If you don’t do it that day, it’ll be full by then for a scheduled appointment.”

— PWLE with Stroke

The absence of transportation can serve as a barrier in people’s recovery journeys as it is often required to help people access services and live independently in their communities. Some participants noted that HandyDart, which is operated by Translink and BC Transit as an accessible shuttle service, is

not consistently available. A stroke PWLE workshop participant noted that: “A simple thing for independence is expanding the mandate of HandyDarts because, okay, you need to get groceries, right now. You must book it two weeks in advance, no sooner. If you don’t do it that day, it’ll be full by then for a scheduled appointment.”

2.4 VIRTUAL SERVICES ARE USEFUL BUT HAVE LIMITS

Telemedicine or virtual/remote health is a key emerging avenue of rehab and recovery system support for people who live farther away from the centres of rehab and recovery services. When talking about how these services have benefited them, a participant from the PWLE workshops told us: “I don’t live in a place with public transit, I couldn’t drive. I wouldn’t have been able to participate in anything without it [being online]. We meet online, from all over the country, and we bonded. With the right facilitation and support virtual can work. It opened access to connections I wouldn’t have had. We need both [Virtual and in-person] systems.”

However, some people also feel that virtual technology is not a fully suitable substitute for in-person services. Participants said that these services can be very useful, but that their experience was dependent on technological literacy, access to the right technology, and whether their injury permitted its use. Professionals

insisted in the workshops that we shouldn’t

completely rely on virtual services as a substitute for in-person approaches — one PWLE of stroke also highlighted that whilst “it seems like stroke recovery has transitioned to virtual meetings during Covid-19, in [their] opinion it does not work for everyone. Especially for people that have had a brain injury, connecting with peers or professionals on a screen [may be difficult].”





3

Financial support limitations amplify impacts of injuries

Income support is limited for people living with Stroke, Spinal Cord Injury, and Brain Injury who are not able to maintain employment. Both provincial support (Disability Assistance) and federal support (Canada Pension Disability) require assessments and have constraints that can be extremely challenging for people dealing with life-long recovery journeys.

3.1 AVAILABLE INCOME SUPPORT IS LIMITED AND LIMITING

An evident challenge that exists for PWLE is that the financial supports available for rehab and recovery related costs often end up not being completely adequate to compensate people for those financial needs. This creates a situation where it would be difficult even for people not facing life-long diagnoses to make an adequate living in most parts of BC. Younger stroke survivors, as well as those who experience secondary or concurrent conditions, were clear that their needs are not adequately reflected in the eligibility criteria of funding programs. “I lost my career because of my stroke. And so that means I lost my benefits. I lost my income I lost financially everything. None of these things are available to me. And you know, I’ve gone broke trying to fund my own recovery,

“I lost my career because of my stroke. And so that means I lost my benefits. I lost my income, I lost financially everything. None of these things are available to me.”

— PWLE with Stroke

which is the biggest thing, and you lose your career because your company won't stand behind you after an injury like this. You've got an entire industry that now looks at you as damaged goods.”

After having a stroke at a young age, one participant told us that she hesitated at applying for Disability Assistance when she was required to officially declare that she was “incapable of work:” “And I'm not incapable of work. I'm very capable. I just need somebody to give me a chance. And you know I could have signed that document and gotten some financial support. It wouldn't have paid the mortgage or anything, but it certainly would have paid a few bills. But I couldn't do that to myself.”

Important aspects of returning home and gaining independence like adaptive housing, bowel control support, occupational therapy, or in-home support are not readily available to many people who need it; suitable equipment such as wheelchairs can also be prohibitively expensive. Financial support plans

generally are not built to consider PWLE's lifestyles and needs once they have returned to community, and therefore aren't well suited to helping someone navigate the life-long impacts of their injuries at home.



3.2 INCOME SUPPORT DOES NOT ACCOMMODATE THE LIFE-LONG RECOVERY JOURNEY

Static eligibility criteria and minimal funding levels make for income supports that don't recognize the dynamic and long-term nature of stroke, spinal cord injury and brain injuries. These supports often do not meet the changing needs of those who live with these conditions.

Despite their designation as 'disability' support, participants felt that these forms of financial support are not designed to adequately maintain or enhance a person's quality of life post-acute care, to assist them in navigating an entirely new way of life in their community, nor are they sufficient to support evolving needs over a lifetime recovery journey. "The only financial support available is if you're considered low income. So, if you're above that level, you're responsible for covering any home renovations, vehicle modifications, specialized recreational equipment, etc. These items likely aren't covered by insurance plans."

The challenge of adequate housing and related support services can be especially vexing. On the one hand, the province provides Choices in Supports for Independent Living (CSIL) — funding that is administered by the Health Authorities — that enables people to buy their own home support services. However, this funding also has criteria that limits the types and duration of services that can be used. Participants described how this can limit key aspects of a person's life, like going back to

"The only financial support available is if you're considered low income. So, if you're above that level, you're responsible for covering any home renovations, vehicle modifications, specialized recreational equipment, etc. These items likely aren't covered by insurance plans."

— PWLE with SCI

work or school, or personal hygiene. One participant talked about missing showers for two weeks because their caregiver was unable to provide support due to the combination of funded support services being limited by the program and a staffing shortage. In addition, guidelines vary across Health Authorities; as one participant with lived experience of stroke who shared their perspective about using CSIL said: “CSIL is really different depending on health authority, and I would really like to see it be a little more flexible, more focused on quality of life, and also a little bit more consistent.” On the other hand, the lack of funding for housing modifications can be a major barrier to returning home. Going home after the hospital is not simply a question of a physical relocation but is also about a person’s ability to navigate and practice daily activities in their own space. This was emphasized by a PWLE who told us that, “For me, I live in an accessible home, and the need for me to have someone to help me is reduced. Prioritization of accessible housing is important. If you live in an inaccessible home, you need a lot of help because of the physical environment you live in.”

The lack of resources to support home renovation can thus have major implications for one’s life trajectory far beyond the injury itself. A professional pointed out that “If they do not have an accessibility-enabled home, or cannot renovate a house to make it accessible, they may have to transition to a long-term care facility before they can find other appropriate housing.”



WorkSafeBC and ICBC

Both PWLE and professional participants talked about the difference between funds derived from WorkSafe and ICBC and the standard income and service support programs. A few PWLE had income and program support from these two agencies because of the circumstances in which their injuries were sustained. From their perspective, this kind of support was financially liberating for them, their families, and partners, and made a huge difference to their recovery journey. Some professionals noted that WorkSafe funding offered a model for the ideal post-hospital rehab and recovery system.



4 Support gaps strain the life-long recovery journey

Despite the often life-long path required for the recovery journey, the system is not designed to co-ordinate and/or provide life-long support. PWLE said that they were often not adequately informed about their injuries in ways that built a strong foundation for their recovery, and frequently felt that their movement across different phases in their journeys were disconnected and inconsistent. The workshops highlighted gaps and obstacles to the flow of information, knowledge, transitions, and connections. As the existing system may be complicated to navigate, these kinds of barriers make it appear even more opaque to PWLE, care partners and sometimes even to professionals.

4.1 THE SYSTEM FOCUS ON ACUTE CARE OVERLOOKS THE REALITY OF RECOVERY

Older participants who had been living with Stroke, Spinal Cord Injury, or Brain Injury for many years talked about feeling unsupported after returning home, without much follow-up or guidance on how to navigate their new circumstances. This affected people's ability to find specialists to monitor their injuries, or to find support at home. They attributed this to health system focus on acute care delivery, in which information, resources, and services are 'front-loaded' during the early stages of the recovery path rather than being available along the whole

“We need help. We need that follow-up. We need somebody that’s in our corner. That’s going to go ‘I haven’t heard from you in a couple of months. You’re doing, okay? Anything that you need?’”

— PWLE with Brain injury

journey. “This is a life-long thing,” one person told us, saying that support should be about “not just treat[ing] it once but follow[ing] up with us and get[ting] us through the long-term.” Additionally, we heard that it can be difficult for people to process, understand and retain important information when it is delivered in the acute phase of care.

Participants highlighted the way that support diminishes the longer a person is away from the formal health care setting. As one professional noted: “The health care system is set up to address the acute phase; in-patient rehab is not well-funded as a requirement. Services drop off as you get further away from the acute phase.” Resources and services tend to be delivered during and immediately after people leave acute care. Some professionals pointed out that when people are discharged from the hospital,

this front-loading of resources and attention often results in a skewed recovery experience while access to support decreases over time.

Additionally, many participants said they felt ill-equipped to leave acute care centres: “We need help. We need that follow-up. We need somebody that’s in our corner. That’s going to go ‘I haven’t heard from you in a couple of months. You’re doing, okay? Anything that you need?’” This suggests that PWLE and care partners need not only information, but proactive support after discharge. Yet, in the experience of at least one participant, that proactivity currently is a responsibility that falls solely on them or their caregivers: “I didn’t get any follow-up post-recovery until close to the two-year mark when I somehow realized, hey, you don’t have help.”



4.2 INFORMATION ABOUT DIAGNOSES, RESOURCES, AND SERVICES IS MISSING AFTER DISCHARGE

We consistently heard that PWLE had difficulties identifying the information, resources, and services they need at the same time they are returning home and only beginning to understand the long-term impact of their injury. This is especially the case when there is no follow-up in the community. Many people have heard of what a stroke, a spinal cord injury, or a brain injury is —yet, without having undergone the recovery journey themselves, few are aware of the future implications, nor do they recognize in advance what their needs will be. This lack of awareness and understanding can be detrimental to downstream recovery. As one professional noted, “Some patients leave acute care walking but don’t realize they actually have a spinal cord injury.”

Participants who were care partners and loved ones of people with injuries, also wanted better guidance and information. “It’s really, really, strange, you know, that you are out on your own. I would love to tell you and say [that] I got three handouts or three little, you know, brochures or two handouts. The [health care services] really didn’t do a lot [for information], [and] you’re not given a whole lot.”

At the very least, they asked to be pointed in the direction of such information in order to find ways to provide better support. Key pieces of information here included helping people to navigate

their recovery journey (case management or social and emotional support), learning more about the relevant injuries and their effects, connecting with peer caregivers with similar experiences, and how to find professional mental health support.

However, even when people receive information they find useful, it sometimes proves to be out of date: “I’m just looking at three handouts I was given when my husband was released from rehab. And even when I contacted the information for the stroke recovery group, it was outdated. I made calls over the summer and everything. It was just, there was nothing, it was difficult, really difficult.”

“I contacted the information for the stroke recovery group, it was outdated. I made calls over the summer and everything. It was just, there was nothing.”

— PWLE with Brain injury



5

Service availability declines as age and complexity of diagnoses increase

Building on the discussion in the previous section about stroke, SPINAL CORD INJURY, and brain injury as life-long recovery journeys, participants talked about their experiences with complications and secondary, or concurrent, conditions. However, in its current state, the post-hospital system has difficulty handling increasingly complex situations. This includes not only physical health but also mental health, which is a theme that ran throughout the workshops among all participants. PWLE told us that they dreamed of a system that can provide care beyond their immediate needs from their initial injuries and involves other aspects of recovery — like activities of daily living or mental health support — that are important for a healthy recovery experience as they shift away from the health care system over time.

5.1 CONCURRENT CONDITIONS ADD COMPLEXITY

Secondary conditions can develop as a result of, or be exacerbated, by stroke, spinal cord injury, and brain injury. These may include heart disease, arthritis, bowel conditions, or diabetes, all of which

can create needs that involve additional services and support beyond the original injury. Such needs can increase with age, requiring more individualized support. However, the services available are often limited in their capacity to provide support for a wide range of individualized needs. People living with spinal cord injury in particular (but not only) talked about how they may require constant attention and/or have equipment that needs to be periodically changed or upgraded. All this was in addition to mental health support needs, or services that facilitate community participation. These issues can persist—or initially emerge—even after people have lived at home for years.

Aphasia, as a result of stroke or brain injury, brings communication challenges that can make it very hard for people to advocate for themselves. In the absence of a strong circle of support, people living with aphasia often have difficulties getting access to resources and making the connections they need for social support. A participant from the stroke workshop told us about experiencing feelings of isolation and disconnectedness due to difficulties with communication which, in turn, make it hard to navigate in the community and health system. **“I had full aphasia; an inability to speak and write, which has recovered quite well. Still, as soon as I get tired, I lose all fluency.”**

“I had full aphasia; an inability to speak and write, which has recovered quite well. Still, as soon as I get tired I lose all fluency.”

— PWLE with Stroke

5.2 MORE AWARENESS OF AND ACCESS TO MENTAL HEALTH SUPPORT IS NEEDED

Mental health support as part of recovery featured prominently in our discussions with PWLE, mainly in terms of the relative absence of mental health services over the course of recovery, which is seen by participants as a massive gap. As one health professional noted, **“There is a lack of awareness of the value of mental health support roles. [In] our inpatient rehab that services the entire [Health Authority], there isn’t even a position. There are discrepancies across health care systems. There should be a standardized position that exists.”**

The gap in mental health services is especially critical at the community level, where resources are scarce for those who may be experiencing

“It’s great to see [other] people with a disability doing their lives. At 33, I didn’t know anyone who used a wheelchair. I had no concept of what it was like to be a disabled person at all.”

— PWLE with SCI

isolation and disconnection, and their access may be governed by the ability to pay: “In-patient and outpatient are short periods of time. [Professionals] then have to refer people to private practice to access mental health services [which are] very expensive.” However, even then, the expertise of available mental health practitioners may not be aligned with the special needs of people living with chronic injuries like stroke, spinal cord injury, or brain injury.

Navigating a new injury can be a baffling process. One professional pointed out that once discharged, people often don’t know where to go, where to get services, or how to talk to clinicians. They elaborated that, because health care workers have to treat so many patients, and because the rate of incoming patients is very high, the process of discharge may feel quite abrupt and unceremonious for some patients. This can leave them feeling lost, negatively affecting mental health and, ultimately, their recovery experience. PWLE told us that peer support organizations and communities of lived experience could play a key role here if they were better coordinated and connected, creating a more consistent experience for people. One person said that “it’s great to see [other] people with a disability

doing their lives. At 33, I didn't know anyone who used a wheelchair. I had no concept of what it was like to be a disabled person at all."

This paucity of resources and services can be experienced as marginalization, especially when people don't fit into standardized categories of service delivery. As one community worker told us, "Services are set up to serve a particular set of pre-existing qualifications. [...] It happens to us all the time where they say, 'Oh, it was a brain injury, so you don't require mental health services. You require brain injury services.' Well in fact, we do require the mental health services — the person happens to come with a pre-existing brain injury."

The experience of marginalization can be particularly felt for young people who may find that the health care system is not set up to address their concerns. "The idea that strokes only happened to older people is outdated. We've seen a shift, and we've seen a shift because there are more younger people having a stroke. But what we perhaps have not seen yet, is services adapting to that shift." Younger PWLE told us their priorities and needs were different than those of older people, especially in terms of their ability to return to work and maintaining financial independence. They

told us they are more likely to experience social dismissal and stigma, leading to isolation, marginalization, and once again poor mental health. A few people highlighted what they believe is a void — that needs to be addressed — of services that help people in their position figure out how to navigate life post-injury. One person said that: "Many of these people are back in community with very little supports - trying to learn with brain injury and need help to look at how they are making decisions. This feeds into mental health [challenges] later on in their life."



5.3 SUPPORT FOR DAILY LIFE IS AS IMPORTANT AS MEDICAL CARE

In general, both professionals and PWLE feel that there is a lack of support for many PWLE in a range of aspects of their lives in community. Key parts of daily life are sometimes ignored over the recovery journey. Things like sexual health support, accessibility-friendly recreational activities, occupational therapy, physiotherapy, speech language pathology, and more diverse transport options are important tools for helping people regain autonomy in their lives.

Sexual health support can help someone affirm their sense of sexual well-being after a life-changing physical impairment. Speech language pathology can help people to regain the ability to speak and express their needs; occupational therapy is important to helping someone figure out every day, basic activities of living such as cooking, or boiling water.

Transportation is another big factor that PWLE mentioned, as being able to access a reliable form of transport or regaining their driver's license can be extremely freeing for them. "I got my license back after a year and that is huge. So, you know, I'm pretty independent. [But] some people can't go back to driving — I was lucky that I could."

"I got my license back after a year and that is huge. So, you know, I'm pretty independent. [But] some people can't go back to driving — I was lucky that I could."

— PWLE with Stroke





5.4 RESPONSIBILITY OF CARE SHIFTS AWAY FROM THE HEALTH CARE SYSTEM OVER TIME

Once they return home, PWLE often find people in their close support circles, especially family members, taking on many of the responsibilities that people in the health care system once performed. Family members often take on the responsibility of navigating and managing care needs. One participant whose partner had experienced a stroke shared their perspective regarding the kind of information they were given upon discharge: “It is overwhelmingly difficult, and a very emotional situation for the caregivers going through this without supports put in place to help with education, navigation etc. The caregivers are often not looked after.”

These challenges can put undue stress on the family dynamics when family members step into a caregiving role. Both the PWLE and the family members may be restricted from working which can result in financial stress. PWLE also sometimes find they must educate their families about their injuries and needs, potentially facing stigma which places another burden on their recovery experience. If someone does not have a close circle of care partners, they can lose any kind of personal help whatsoever, and as a result have a higher chance of facing isolation.

“It is overwhelmingly difficult, and a very emotional situation for the caregivers going through this without supports put in place to help with education, navigation etc. The caregivers are often not looked after.”

— PWLE with Brain injury

Future


Ideas & Considerations
of rehab + recovery in BC

1. How can we enhance provincial networks for professional learning and support? pg. 54

2. How can we increase long-term support over the life span by investing in community-based programming and supports? pg. 58

3. How can we enhance coordination of services and information across the continuum of care and geographical regions? pg. 62

4. How can we formally integrate roles for people with lived experience through the recovery journey? pg. 64



“How can we create more equitable access to care, services, and support for life-long conditions throughout the province?”

The following questions are ‘how can we...’ statements that were derived from the workshops held with both people with lived experience (PWLE) and rehabilitation and recovery professionals and researchers (RRPR) in each of the diagnostic groups. These statements pose opportunities for further discussion around what a reimagined and improved system could look like and are presented here to showcase a summary of ideas from workshop participants based on their experience and knowledge of the current system. In these conversations, participants were encouraged to take-on a blue-sky thinking approach — thinking widely, broadly and without practical limitations.

It is important to note here that the participants are all people who either work in or have been through the rehabilitation and recovery system as it currently operates. The insights that are analyzed and summarized in this report are based on their experiences and knowledge, but this is a limited sample based on perspectives of a relatively small number of people rather than an overview of the entire system.

The central question that was posed to participants in both the professional and PWLE workshops was straightforward: *How can we create more equitable access to care, services, and support for life-long conditions throughout the province?*

The sections below provide a synthesis of the answers to these questions, which offer a starting point for thinking about how to improve the system in ways that will benefit people living stroke, SCI, & brain injury, the people who work with them, and the communities in which they live. Readers will notice that there is not necessarily a direct correspondence between the solutions suggested below and the challenges and gaps that were raised earlier. This, to a large extent, is because the resolution to some of those challenges (i.e., staff shortages) required a broad system overview while the solutions proposed here arise from the direct experience and knowledge of the workshop participants.





1

How can we enhance provincial networks for professional learning and support?

Throughout the workshops it was clear that there is a need to enhance provincial networks for professional learning and support, to address current staffing challenges related to geographical distribution and limited educational opportunities.

Participants suggested that an ideal system would have more coordinated networks for knowledge exchange and education available for professionals to be better informed about the specific and enduring needs of stroke, spinal cord injury, and brain injury patients. Sharing knowledge and experience across different professional & geographical communities and Health Authorities can be a way to help mitigate or address inequities and disparities in care. Enhanced professional networks for learning and support may also lead to more informed referrals to specialists and community-based programs/services.

IDEAS FROM PARTICIPANTS INCLUDED:



Workshop participant with a lived experience of Stroke

“Building relationships amongst other professionals have a significant benefit, especially when a lot of my patients have worked with other professionals before they meet with me. It would be fantastic to get to know these other practitioners, instead of just seeing their names on referral paperwork.”

- A physician consultation service, through which more experienced physicians can help guide/advise/counsel physicians in different locations, improving access to expertise for professionals in rural areas. For example, consider expanding existing programs like RACE (Rapid Access to Consultative Services) to allow General Practitioners to seek specialist advice for stroke, spinal cord injury, and brain injury patients.
- Establish mentorship programs linked to specialists to provide ongoing education and training for General Practitioners and remotely located practitioners.
- Create a committee of individuals who are experienced in providing specific services to stroke survivors, who come together three times a year within the province to share updates. These updates could then go to larger governing organization that supports the implementation of any changes or updates BC-wide.
- Create community-based infrastructure to support patients in joining virtual appointments or programs. This may include locally based telemedicine hubs that can provide internet set-up, support with virtual calls and even participation by local care team members (i.e., General Practitioner, Nurse Practitioners).
- Build a system for coordination of care across transition points—a network that could be put in place across health authorities and programs where everyone can “go to get their source of truth”.



Workshop participant with expertise in Stroke

“Virtual check-ins with professionals once a month to talk about diagnosis cases could be a great opportunity for learning. Having access to conferences once a year can also provide great and up-to-date education and mentorship.”

“We have an HR crisis – lots of PTs are going private. If we can’t find them, what else can we do to utilize funding that we do have available only to the public sector?”



Workshop participant with expertise in Stroke

- Establish a system that provides a centralized process for access to spinal cord injury-related care (telehealth, virtual care).
- Implement PODS (Patient Oriented Discharge Summary). Meetings would be helpful to review patients’ cases and identify knowledge gaps that exist in their own understanding and that of the health care system, impacting their recovery journey.
- Enhance education for culturally safe/trauma-informed practice.
- Create a platform for regular discussion among health professionals.
- Create an online resource portal to seamlessly link professionals with relevant resources and services for their patients.
- Create traveling clinics to communities that would allow local professionals to assist and learn from visiting specialists.



Workshop participant with expertise in Stroke

"In our health care system, there are specialist groups for doctors, and somewhat in nursing, but not in allied health. The system does not recognize allied health specialists. Having support to develop expertise regionally, could be helpful and beneficial."

"Physio assistants are great. There is a large network of kinesiologists - who are trained in exercise for people with pathologies. Can we tap into that resource? Work with a PT to develop a plan, but then work with more clients independently. I feel like we aren't accessing all the people we could be."



Workshop participant with expertise in Stroke



2

How can we increase long-term support over the life span by investing in community-based programming and support?

Through current state and future visioning conversations it became clear that workshop participants feel there is a need for longer-term support across the life span. These diagnoses are life-long injuries that affect a person's daily life in cumulative ways. They may require constant attention, have support and equipment costs that need to be changed or upgraded periodically, and secondary conditions or associated needs like mental health support or social and community re-integration. Once we recognize the life-long implications and support needs of people living with stroke, spinal cord injury, and brain injury (as discussed in section 4) we need to address the falloff of support that people experience after acute care. Participants further spoke about the significant value that community-based programming and support groups can have in providing that long-term support.

IDEAS FROM PARTICIPANTS INCLUDED:



Workshop participant with
a expertise in Stroke

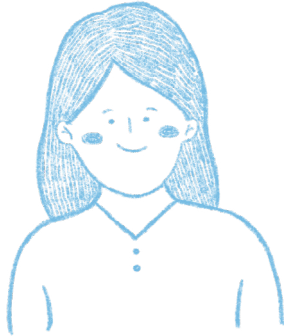
"There are opportunities for partnerships with other health agencies and organizations – we need to be doing the same work in different ways - making it stronger, not delivering it in silo."

"I have an idea of a provincial resource centre where people could tap into knowledge and apply within local communities working within."



Workshop participant with
expertise in Spinal Cord Injury

- A structurally integrated and mandated provincial role for on-going, proactive check-ins and navigation – a “navigator”. Rather than assigning an individual to fully manage someone’s case, this was envisioned by participants as a key position or role held by a team of trained professionals or through an organization, including PWLE. Core aspects suggested by participants for this role would include:
 1. A provincial system that keeps a record of all stroke, spinal cord injury, and brain injury patients provincially.
 2. Scheduled check-in calls (i.e., annually) to proactively inquire and respond to patient concerns as they shift.
 3. Informational case management to guide and refer patients in finding appropriate care, services and supports across the continuum of care.



Workshop participant with a lived experience of Stroke

“I don’t live in a place with public transit, I couldn’t drive. I wouldn’t have been able to participate in anything without it [being online]. We meet online, from all over the country, and we bonded. With the right facilitation and support, virtual can work. It opened up access to connections I wouldn’t have had. We need both systems”.

4. A social support role which could look like providing or connecting patients to emotional counsel and advice based on lived experience.
5. A support transitions across the continuum of care in terms of navigation and information services.

- Create a system to flag people with specific/ complex needs to keep track of their extended needs.
- Increased funding and stability for community-based programs and supports to run consistent programming that can therefore be

well-known and promoted. This should include in-person and virtual programming/services.

- More inclusive and proactive funding options would recognize the importance of supporting independent living by PWLE. Funders should prioritize PWLE independence — financially and through rehab support and resources for quality-of-life improvement at home so they can regain agency in their life.
- More versatile funding models that support changing needs across the life span.



Workshop participant with expertise in Stroke

"We have [partnered with] the 'community mental health association (the live life to full program)', with a trained facilitator. [They] are offering mental health support to folks in BC who have had stroke, and which we will continue to offer. That's one strategy we have used. There is a lot of work to be done in this field."

"At [the rehab centers] when you're leaving, they have a discharge plan - that's the extent of a navigator you get access to. To me, there would be a huge role for a peer navigator - someone who is a peer but is available to help you navigate beyond [the rehab center]."



Workshop participant with a lived experience of Spinal Cord Injury



3

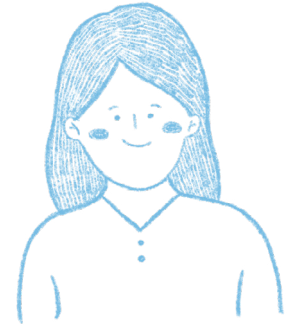
How can we enhance coordination of services and information across the continuum of care and geographical regions?

Workshop participants talked about the challenges involved with accessing timely, coordinated, and relevant information and services. A central feature of an improved future system should be enhanced coordination of services and information across the care continuum or lifespan, from acute care to rehab to community-based programming and supports.

IDEAS FROM PARTICIPANTS INCLUDED:

- Create a centralized online ‘hub’ of information that is accessible to patients, caregivers, and professionals to provide consistent, updated, and timely information relevant to stroke, spinal cord injury, and brain injury patients.
- Create and promote community-based opportunities for people without adequate home internet or who require help with internet searches to get the support they need to find information.

"That's what we need. we need one place, a one-stop-shop. We can go and see somebody and say you know what? okay, yeah, you need a little OT. Come on, let's go. let's go talk to these people out here."



Workshop participant with a lived experience of Stroke and Brain Injury



Workshop participant with a lived experience of Stroke

"Being part of the stroke recovery group in my community was more important than I even understood at the time. I am thankful I got connected. I think it happened by chance. The coordinator happened to be in the hospital, talked to me, and gave me a brochure."

- A “navigator role” (See previous section) that provides follow-up information at key points through the continuum of care and lifespan, rather than relying on all information delivery occurring during the acute phase.
- An improved Electronic Medical Record system that allows patients to have increased access to their own data to enhance patient understanding and allow patients to provide various members of their care team access to the same information.
- Enhanced formal connection between acute and rehab programs and locally based community programs and services to increase awareness and utilization. This would support information sharing across the continuum of care.



4

How can we formally integrate roles for people with lived experience through the recovery journey?

Throughout the workshops, the importance of peer connections and relationships with people who have similar lived experience was a clear and consistent message. Participants explained that having someone provide support and guidance that is informed by their own experience of recovery from a stroke, spinal cord injury, or brain injury cannot be replaced by the training and expertise of an able-bodied professional or caregiver who does not have the same lived experience. Conversely, many people spoke about the ways that taking on peer support roles, often voluntary, provided benefits to their own recovery, mental health, and well-being.



Workshop participant with
a lived experience of
Spinal cord injury

“My social worker who is the ‘expert’ in the situation, told me she might be able to arrange for me to have a shower [only] once a week in LTC. It was a very difficult, and entirely wrong, disheartening, frightening thing for me to imagine. We need people who are disabled in those roles. She had no concept of what my life could look like when I returned to my community, she didn’t know. But she was in the position of providing that advice. There are many roles in health care that people with disabilities could do. Usually [PWLE] are token roles, telling their story for free on a volunteer basis.”

IDEAS FROM PARTICIPANTS INCLUDED:

- Peer support networks (virtually and locally).
- Train PWLE to play a role in provincial ‘navigator’ position (described in the section above).
- Encouraging enrollment in health science training/education programs by PWLE.
- Increase professional opportunities for PWLE in community-based organizations, including enhanced recruitment, training, and mentorship.
- Paid positions for trained peer support workers in acute care, rehab, and home/community settings.

References

1. Physician Working Group on Rehabilitation Services. Conversation on health: improving rehabilitation services for the people of British Columbia. 2007 p. 2.
2. ADLs and IADLs: What are they? [Internet]. BCSLA. 2021 [cited 2022Oct14]. Available from: [https://www.bcsla.ca/blog/what-are-activities-of-daily-living/#:~:text=Activities%20of%20Daily%20Living%20\(ADLs,take%20care%20of%20ourselves%20independently.](https://www.bcsla.ca/blog/what-are-activities-of-daily-living/#:~:text=Activities%20of%20Daily%20Living%20(ADLs,take%20care%20of%20ourselves%20independently.)
3. Martel P. What is the Difference between acute and sub-acute care? [Internet]. Knollwood Nursing Center. 2020 [cited 2022Oct14]. Available from: <https://www.knollwoodnursingcenter.com/difference-between-acute-sub-acute-care/>
4. What is Aphasia? [Internet]. Aphasia Institute. [cited 2022Oct14]. Available from: <https://www.aphasia.ca/family-and-friends-of-people-with-aphasia/what-is-aphasia-2/>
5. Karissa. Traumatic brain injury (TBI) [Internet]. Brain Injury Canada. 2020 [cited 2022Oct14]. Available from: <https://brain-injurycanada.ca/en/traumatic-brain-injury/>
6. Ministry of Health. Choice in supports for Independent Living [Internet]. Province of British Columbia. Province of British Columbia; 2021 [cited 2022Nov7]. Available from: <https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/choice-in-supports-for-independent-living>
7. General Practitioners and Family Physicians (NOC 3112) [Internet]. WorkBC. [cited 2022Oct14]. Available from: <https://www.workbc.ca/Job-Seekers/Career-Profiles/3112>
8. Ministry of Health. Home care [Internet]. Province of British Columbia. Province of British Columbia; 2017 [cited 2022Oct14]. Available from: <https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/health-care-programs-and-services/home-care>
9. Getting medical care and treatment after a crash [Internet]. ICBC. [cited 2022Oct14]. Available from: <https://www.icbc.com/claims/injury/Pages/medical-care-treatment.aspx>

10. Basic insurance and Enhanced Care [Internet]. ICBC. [cited 2022Oct14]. Available from: <https://www.icbc.com/insurance/products-coverage/Pages/basic-insurance.aspx>
11. What is occupational therapy? [Internet]. Canadian Association of Occupational Therapists. [cited 2022Oct14]. Available from: <https://caot.ca/site/aboutot/whatisot?nav=sidebar>
12. What is a physiatrist? [Internet]. CAPM&R. [cited 2022Oct14]. Available from: <https://capmr.ca/about-us/what-is-a-physiatrist/>
13. Policy statement: Description of physical therapy [Internet]. World Physiotherapy. [cited 2022Oct14]. Available from: https://world.physio/policy/ps-descriptionPT#appendix_1
14. Stroke Quality Standard. Vancouver: BC Patient Safety & Quality Council; 2022. Available from: <https://bcpsqc.ca/wp-content/uploads/2022/09/Stroke-Quality-Standard-2022-08-25-FINAL.pdf>
15. Stroke Rehabilitation [Internet]. HealthLink BC. [cited 2022Oct14]. Available from: <https://www.healthlinkbc.ca/illnesses-conditions/heart-health-and-stroke/stroke-rehabilitation>
16. Spinal Cord Injury Basics [Internet]. SCIRE Community. 2022 [cited 2022Nov30]. Available from: <https://community.scireproject.com/topic/sci-basics/#what-is-spinal-cord-injury>
17. What is stroke? [Internet]. Heart and Stroke Foundation of Canada. [cited 2022Oct14]. Available from: <https://www.heartandstroke.ca/stroke/what-is-stroke>
18. Martel P. Difference between acute and sub-acute care [Internet]. Knollwood Nursing Center. 2020 [cited 2022Oct14]. Available from: <https://www.knollwoodnursingcenter.com/difference-between-acute-sub-acute-care/>
19. What we do [Internet]. WorkSafeBC. 2016 [cited 2022Oct14]. Available from: <https://www.worksafebc.com/en/about-us/what-we-do>
20. Braun V, Clarke V. Thematic Analysis. In: APA Handbook of Research Methods in Psychology. Sage; 2021.

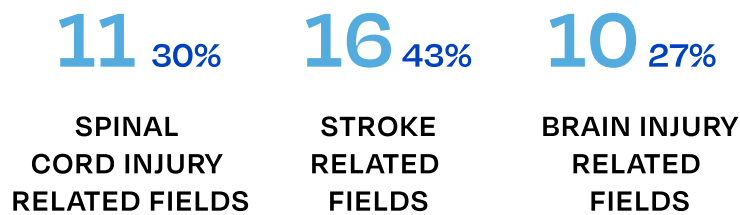
Appendix A: Participant Demographics

Workshop Participant Demographics

Rehabilitation & Recovery Professionals & Researchers

Summary of who joined*

NO. OF PEOPLE %



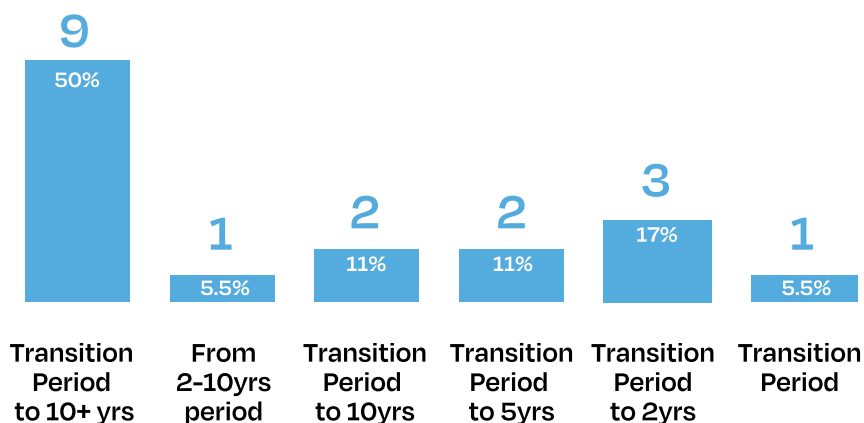
Prespective present

NO. OF PEOPLE %

Occupational Therapist	3	14%
Registered Nurse	2	9%
Physiatrist	1	4.5%
Physician	2	9%
Speech Language Pathologist	2	9%
Physio Therapist	3	14%
Program manager & Director	4	18%
Social Worker	1	4.5%
Researcher	2	9%
Other Rehabilitation Professionals	2	9%

Expertise

NO. OF RRPR WORKING IN EACH STAGE %



*Note: Some participants attended multiple workshops, as they identify as having experiences or skillsets that apply across more than one workshop.

Workshop Participant Demographics

Rehabilitation & Recovery People With Lived Experience

Summary of who joined*

NO. OF PEOPLE %



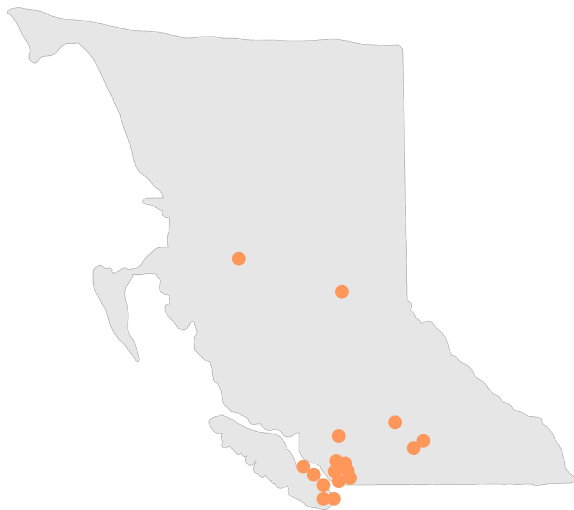
Length of the injury

NO. OF YEARS %

1-2 YRS AGO	7	31.8%
3-5 YRS AGO	4	18.2%
6-10 YRS AGO	4	18.2%
11-15 YRS AGO	5	22.7%
16-20 YRS AGO	1	4.5%
20-25 YRS AGO	1	4.5%

Geographical location

NO. OF PEOPLE %

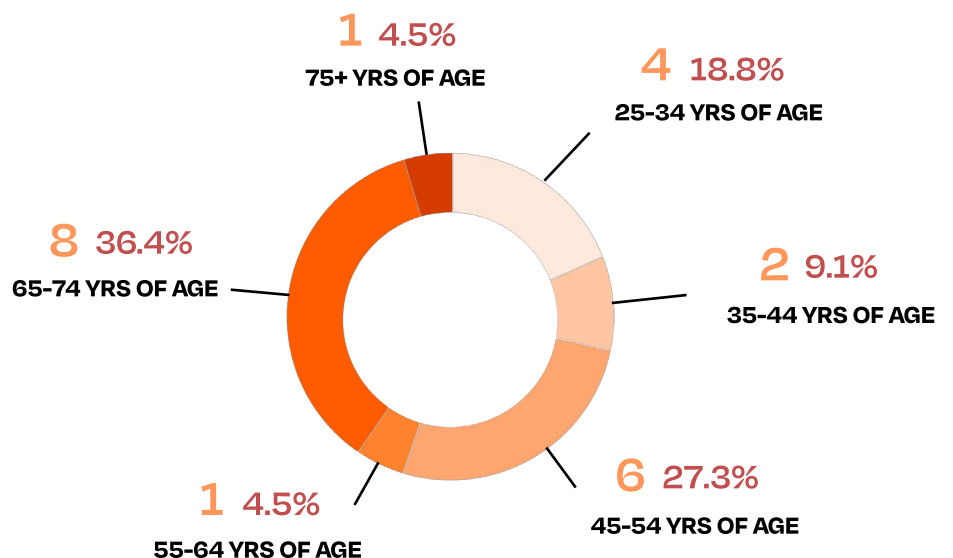


ISLAND HEALTH	8	36.4%
FRASER HEALTH	4	18.2%
INTERIOR HEALTH	4	18.2%
VANCOUVER COASTAL HEALTH	4	18.2%
NORTHERN HEALTH	2	9%

Age

NO. OF PEOPLE IN EACH AGE RANGE %

- 25-34 YRS OF AGE
- 35-44 YRS OF AGE
- 45-54 YRS OF AGE
- 55-64 YRS OF AGE
- 65-74 YRS OF AGE
- 75+ YRS OF AGE



Appendix B: Detailed workshop summary

WORKSHOP TIMELINE

The Twelve workshops were run across a period of four weeks.

APR 20th, 2022	APR 27th, 2022	MAY 3rd, 2022	May 5th, 2022	MAY 10th, 2022	MAY 12th, 2022
SPINAL CORD INJURY <i>Workshop 1: Gaps & Needs</i>	SPINAL CORD INJURY <i>Workshop 2: Vision & Improvements</i>	STROKE <i>Workshop 1: Gaps & Needs</i>	STROKE <i>Workshop 2: Vision & Improvements</i>	ACQUIRED BRAIN INJURY <i>Workshop 1: Gaps & Needs</i>	ACQUIRED BRAIN INJURY <i>Workshop 2: Vision & Improvements</i>
Recovery & rehabilitation of professionals & researchers	Recovery & rehabilitation of professionals & researchers	Recovery & rehabilitation of professionals & researchers	Recovery & rehabilitation of professionals & researchers	Recovery & rehabilitation of professionals & researchers	Recovery & rehabilitation of professionals & researchers
People with lived experience	People with lived experience	People with lived experience	People with lived experience	People with lived experience	People with lived experience

Timeline of the workshop series that was run during the months of April and May, 2022.

FULL PROJECT METHOD SUMMARY

This phase of the project focused on gathering perspectives from PWLE of stroke, spinal cord injury, and brain injury, as well as RRPR about their experiences within the current recovery and rehab system and generate ideas that respond to current challenges. To gather this information, the project team co-developed a series of virtual workshops, the Community Engagement Series. One month after the workshops concluded, participants were invited to attend a virtual recap event, where a summary of the knowledge synthesis to date was shared.

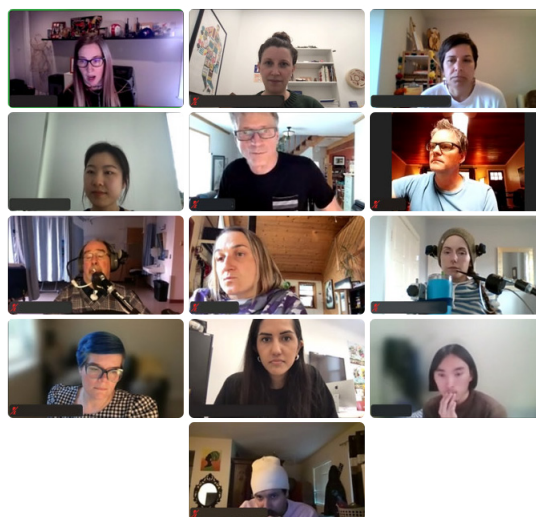
WORKSHOP FORMAT & ACCESSIBILITY

The virtual workshops were conducted remotely over Zoom, a video conferencing tool. The virtual format allowed participants from across British Columbia to gather and connect, without the added health risk of meeting in person, due to the Covid-19 pandemic. Additionally, gathering online allowed for participants from outside the Lower Mainland to participate, without the need to travel. While the virtual format allowed for a more geographically diverse group of individuals to participate, we acknowledge that the virtual format presents other barriers to participation such as access

to a computer, access to high-speed internet, and comfort with technology. With the intention of supporting accessibility, where possible, the virtual workshop space was optimized to support participant engagement, with minimal digital literacy requirements. To support both verbal and written communication and comprehension, closed captioning was enabled to allow for live transcription of conversations for participants. Facilitators also shared their computer screens to reveal text-based activity prompts that reinforced verbal instructions.

WORKSHOP RECRUITMENT

All participants, PWLE and RRPR, were recruited through individuals and organizations on the Steering Committee to form a pool of perspectives that would potentially voice their experiences in the workshop sessions. This initial group was then sent a survey drafted by the Steering Committee and Health Design Lab, which asked respondents the diagnosis they identified with having or (in the case of RRPR) diagnosis they worked with, and whether they wanted to attend the workshop series. These surveys also acted as consent forms for potential participants to give permission for the use of their image and feedback. For the purpose of these workshops, we defined PWLE as anyone with an experience having an injury or caring for someone with an injury. RRPR were defined as anyone working professionally to treat or is related to the formal provision of health care to people with injuries.



VIRTUAL WORKSHOP BREAKDOWN

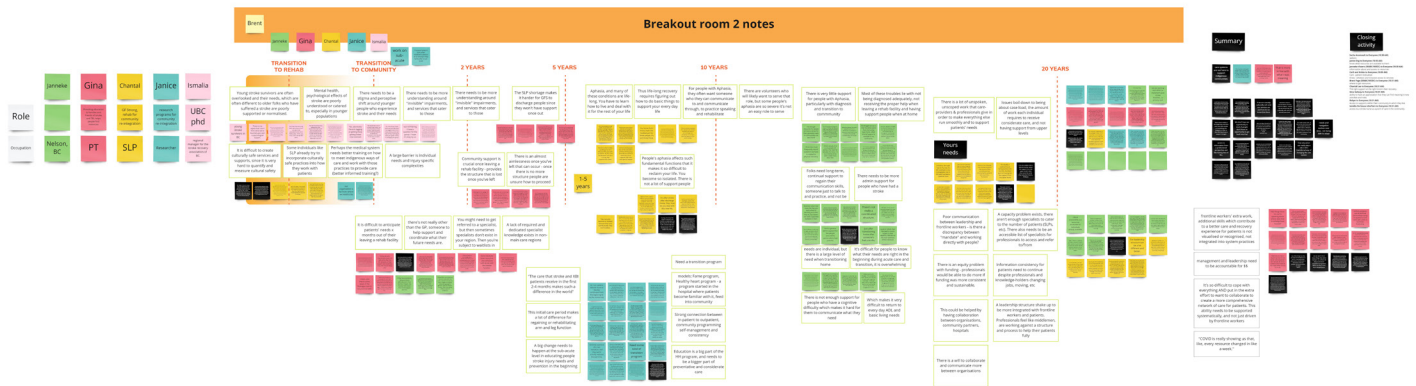
Each workshop was 1.5 hours in length. Across the 12 workshops, 23 PLWE (4-11 participants/workshop) and 23 RRPR (6-11 participants/workshop) participated.

The workshop activities were designed by the Health Design Lab team in conjunction with the Rehab + Recovery Project Steering Committee (A detailed activity breakdown is given after this summary). In total, twelve virtual workshops were conducted. The first round of workshops focusing on participants' current observations, needs and experiences within the system, including the transition from rehabilitation to community. The second round of workshops focused on patients' networks of care — circles of people they viewed as important to their recovery journey, as well as areas in the health care system that both PWLE and RRPR wanted to prioritize for improvement. For both rounds of workshops, participants were organized by diagnoses (i.e., stroke, spinal cord injury, and brain injury), and perspective (i.e., PWLE or RRPR) to facilitate a more focused and cohesive line of discussion in the sessions. For example, PWLE of a stroke were invited to attend one workshop, while RRPR who work with people who have experienced a stroke were invited to attend a separate workshop.

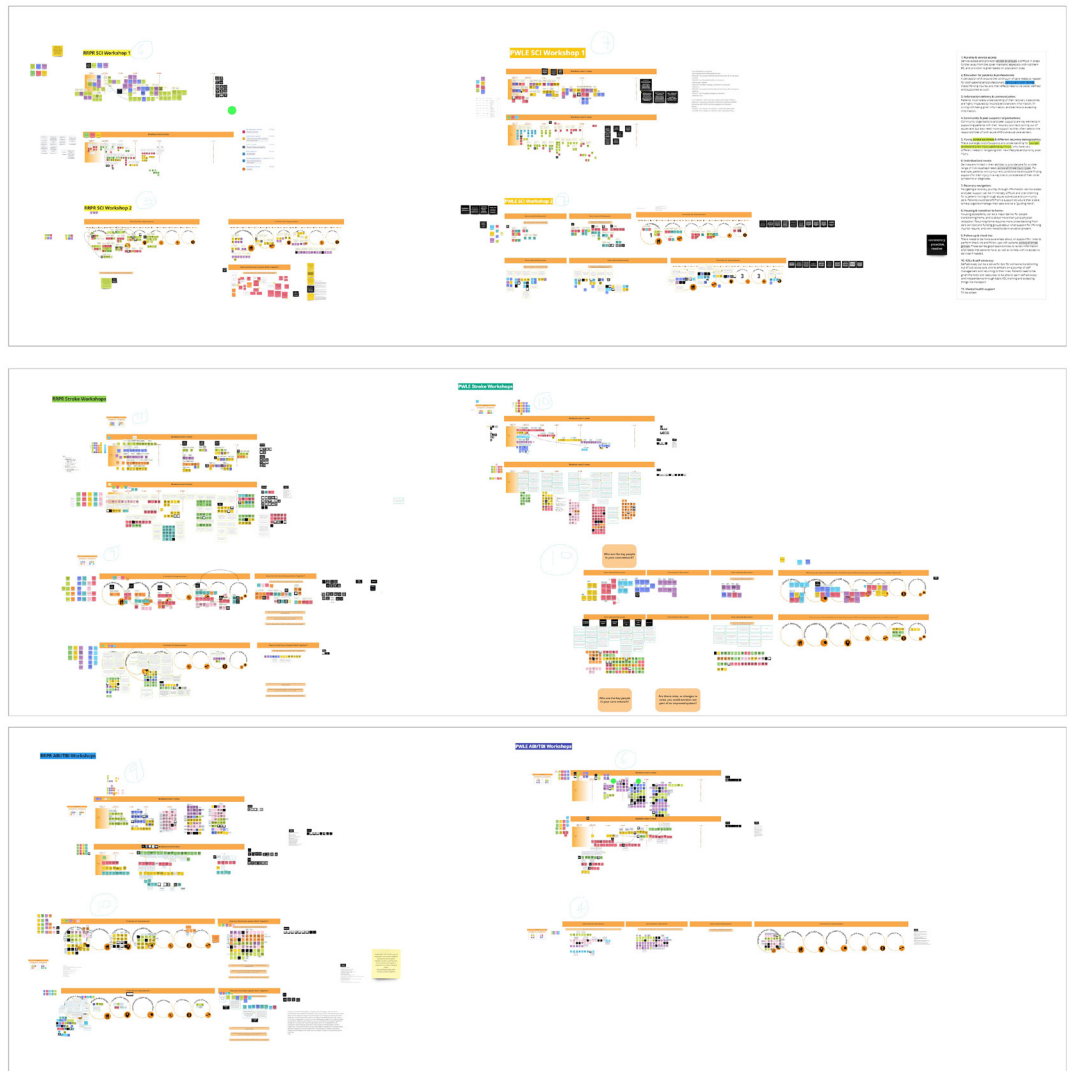
The workshops were co-facilitated by the Health Design Lab team and diagnosis-specific knowledge holders. Health Design Lab staff asked the main questions and guided the discussion and co-facilitators provided condition specific expertise to support with

follow-up questions and] conversation flow. Additional HDL staff were also present taking detailed notes of the conversation. Facilitators asked the main questions and guided the discussions, whilst notetakers took detailed notes. The inclusion of the co-facilitators was also key to helping create a safe space for participants, by creating an intersection of shared understanding. Notetakers recorded information on digital sticky notes in Miro, a digital whiteboarding tool, for later analysis. After the activities had concluded, insights and feedback voiced in the session were then summarized and shared back with the greater group. To support with documentation, the virtual workshops were video-recorded, and auto-transcribed for reference purposes only.

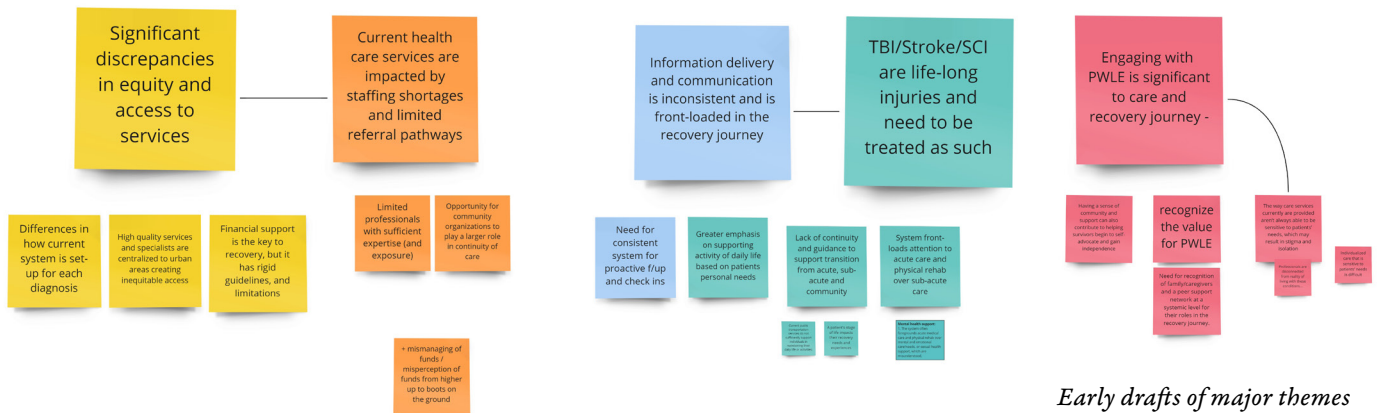
Each session started with an introduction to the larger Rehab + Recovery initiative project, and workshop participants were invited to introduce themselves through an icebreaker activity, where time permitted. To allow all participants an opportunity to engage in a fulsome way, participants were split into breakout rooms.



Screenshot from RRRP of Stroke, Breakout room 2



Overview of all workshop notes



Early drafts of major themes

WORKSHOP KNOWLEDGE SYNTHESIS

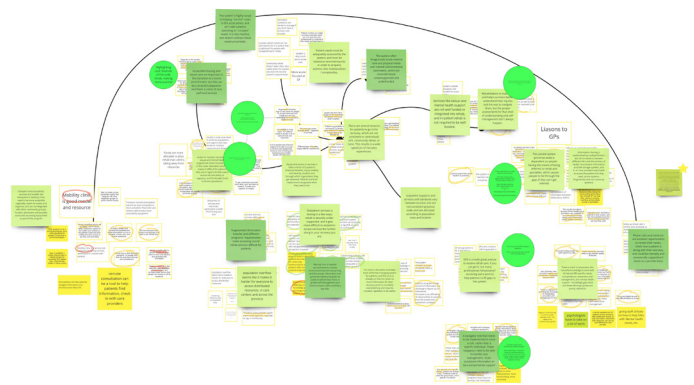
Reflexive Thematic Analysis is an easily accessible, inductive and “theoretically flexible interpretative approach to qualitative data analysis”²⁰. This method was used for synthesizing and distilling the workshop notes into themes and questions for the basis of this report. The themes and questions discussed in detail in the following report are reflective of the perspectives shared in the workshops by PWLE and RRPR.

The final themes speak to many of the major discussion points of the workshops, by PWLE and RRPR.

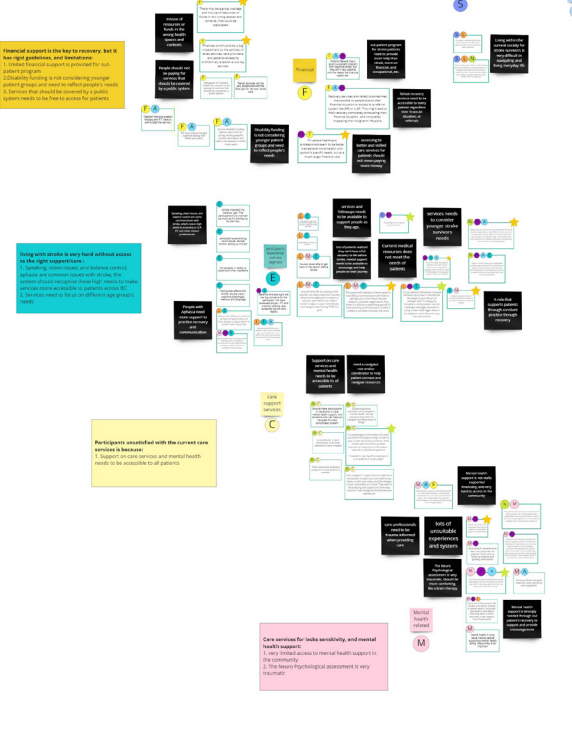
The format in which the categories are presented in the document is for ease of comprehension and is not intended to indicate prioritization.

Themes were refined over 5 rounds of revisions, culminating in the themes and definitions presented in the report.

RRPR SCI Workshop



RRPR SCI Workshop synthesis notes



Workshop activity breakdown

WORKSHOP WITH PWLE—ROUND 1:

The primary focus of the first session was to gain an understanding of people’s experiences of the rehab and recovery system as it is.

- **Icebreaker:**
Participants were asked to introduce themselves, and to share something about their week that they enjoyed.
- **Activity 1:**
In breakout rooms, participants were asked: “what are your current needs”, and “what were your needs upon returning to community.” These questions helped us get a basic snapshot of the system formed through people’s individual perspectives.
- **Closing question:**
Returning to the larger group, participants were then given a concluding question, as a prompt to think share and think about before the next session: “In your experience, what is ONE thing that you need to be successful in your recovery?”

WORKSHOP WITH PWLE—ROUND 2:

The second sessions looked at asking participants who are key people in their recovery experiences, and what kinds of improvements and changes they wished for in the system.

- **Icebreaker:**
We had a quick check in with participants, asking them to “describe how you’re feeling today in one word.”
- **Activity 1:**
The first question asked to participants in breakout rooms was: “Who are the key people in your care network”. This was to begin an overall conversation in this session about what key roles in the health care system would benefit from improvement or change. This question was then followed up by: “Are there roles, or changes to roles, you could envision are part of an improved system?”
- **Activity 2:**
The second activity in round two of the breakout rooms asked participants to describe, out

of six given areas of the health care system, how they would improve these areas. These areas were: Navigating Health Care Services & Getting Information; Physical Rehabilitation; Mental Health Support; Communication Support & Cognitive Rehab; Caregiver Support; Financial Support; Proximity of Services. These areas were chosen from a survey question asking participants to identify areas of the system that they thought needed the most improvement.

- Closing question:

In the larger group, participants were asked: “What is one word to describe your vision for an improved recovery system?”

WORKSHOP WITH RRPR—ROUND 1:

The first session with RRPR was intended to hear from professionals what kinds of challenges and needs PWLE had, when seeing these professionals at specific times of the recovery journey.

- Icebreaker:

We asked participants to introduce themselves and share something about their week that they enjoyed. Additionally, we also asked them to share what their professional role was, and at what location / organization they worked at.

- Activity 1:

In breakout rooms, participants were asked to talk about:

1. “What stage in the recovery period

do people usually see you?”

2. “What are your patients’ needs and challenges in the stage of recovery you typically see them?”

3. “What are your needs in providing care, and what are typical challenges for the people working in stroke/spinal cord injury/brain injury?”

4. “What do you wish clients knew before being discharged from the acute phase?”

Closing question:

Returning to the larger group, participants were then given a concluding question, as a prompt to think share and think about before the next session: “In your experience, what is ONE thing that you need to be successful in your recovery?”

WORKSHOP WITH RRPR—ROUND 2:

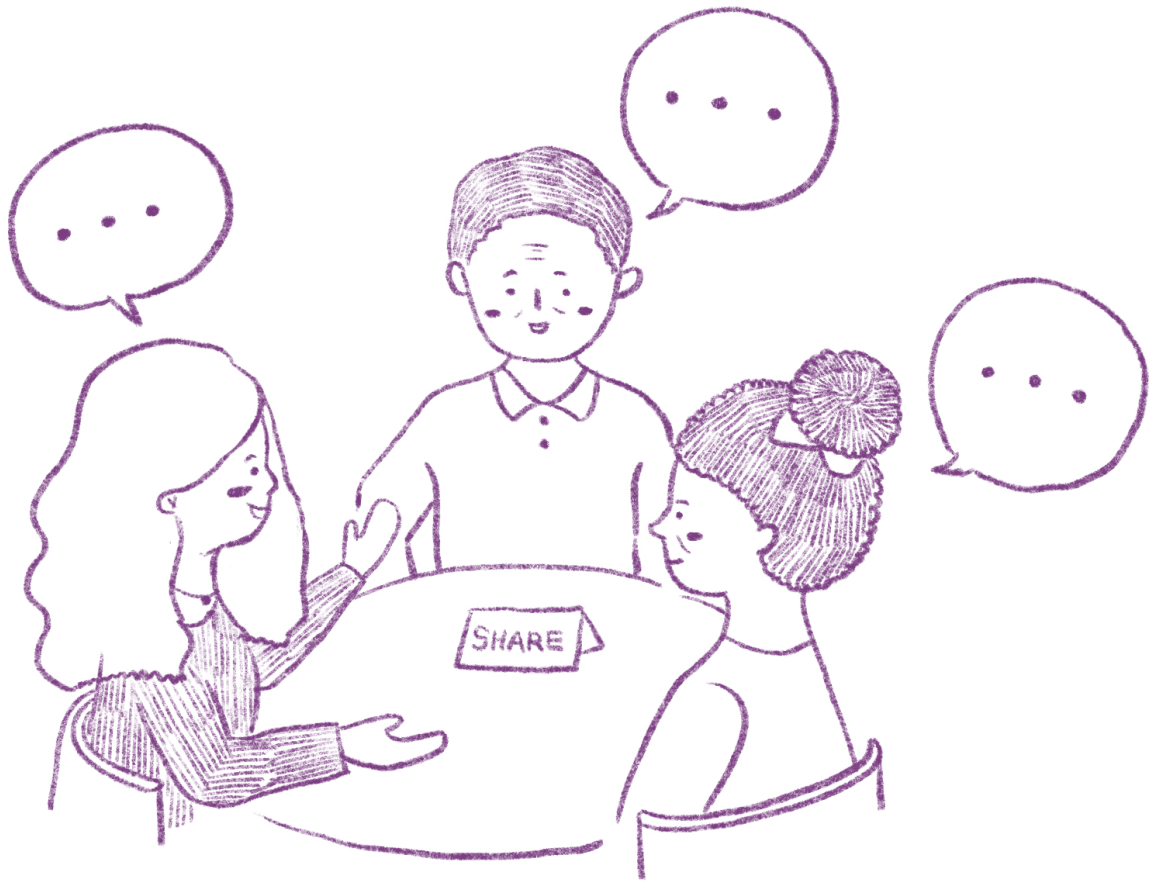
The second session held with RRPR was about brainstorming ideas for improving the system with professionals, and to discuss larger, more systemic changes that they could see needing to happen in the system.

- Icebreaker:

Having a quick check in, participants were asked to “describe how you’re feeling today in one word.”

- Activity 1:

Using the same areas as was given in the PWLE workshops, in breakout rooms participants were also asked to describe and give their ideas about how to improve these given areas.



- Activity 2:

The second activity asked participants to consider these many areas of improvement from the previous activity, and to imagine how a future system might work better together. Questions asked to participants were:

1. How can you imagine parts of an improved system working together?
2. Discuss movement between services and programs, including navigation and transitions of care.
3. How do you see various Health Authorities,

community organizations and professional working together and interacting?

4. Do you see changes in who is responsible for different types of care and support?

