

Spinal Cord Injury

Service Delivery Model for Queensland

Co-design Process and Outcomes Report



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EXECUTIVE SUMMARY

A new service delivery model (service model) for adult Queenslanders with a spinal cord injury has been developed. The service model, co-designed with people with a spinal cord injury and their families, outlines how Queensland Health will deliver high-quality spinal injury care across Queensland in the future.

Co-design is a relatively novel and contemporary approach for health service planning. Experience based co-design (EBCD) methodology guided the co-design approach. It brings together a range of stakeholders to share insights and experiences to achieve a collaborative change process focussing on key “touch points” in the healthcare journey. The Department of Health engaged and consulted extensively and iteratively with a wide range of stakeholders, over a nine-month period, enabling their ongoing involvement to progressively shape the service model.

The co-design process sought to improve healthcare quality, accessibility, experiences and outcomes, to ensure the health system truly addresses the diverse needs and preferences of people with a spinal cord injury and their families. The co-design approach thrived on the diverse knowledge, expertise, and experiences of its participants. By actively involving many different stakeholders, this approach harnessed a wide range of perspectives and insights, to design innovative solutions.

The Department of Health’s project team sought to create a safe space for individuals to share their insights about what was working well and the challenges and gaps in the system. In addition to extensive consultation, five co-design workshops were held bringing together stakeholders to exchange insights and ideas through a collaborative process to co-create a future state addressing the system challenges and gaps.

Key insights and outcomes

Appendix 1 addresses the key outputs of the co-design process which includes:

Five shared principles of care which:

- underpin spinal cord care services in Queensland, now and into the future; and
- were consulted upon during the co-design process to validate ideas and reconcile differing opinions.

High-quality care across the healthcare journey

- The key stages for high-quality care throughout the healthcare journey
- The need for standards for best practice spinal cord injury care in Queensland.

How spinal cord injury services are delivered

- Promoting sustainability and care closer to home through formalised networked service arrangements
- The identification of key enablers which need to be fostered to enhance services and ensure success of the service model.

TERMINOLOGY

Term	Acronym	Description
Brain and Spinal Cord Injury Project	BaSCI	The statewide BaSCI Project aims to improve health services and outcomes for people with acquired brain and spinal cord injuries in Queensland through timely access to specialist rehabilitation services.
Experience-based co-design	EBCD	EBCD is a methodology that involves consumers and staff and other stakeholders working together to improve healthcare services. It’s a participatory approach that focuses on using the actual experiences of users and providers to drive the design process.
Hospital and Health Service	HHS	Hospital and Health Services are providers of Queensland Health public hospital services and other health services to specific geographic areas across the state. Each Hospital and Health Service is managed by its own Board.
International Standards for Neurological Classification of Spinal Cord Injury	ISNCSCI	A standardised examination used to score the motor and sensory impairment and severity of a spinal cord injury.
Queensland Spinal Cord Injury Service	QSCIS	The Queensland Spinal Cord Injuries Service, located in Brisbane within Metro South Health, is a statewide service providing acute care, rehabilitation and ongoing management for individuals with spinal cord injury.
Spinal Injury Unit	SIU	The Spinal Injuries Unit is located at the Princess Alexandra Hospital and is the statewide specialist adult spinal injuries acute and rehabilitation unit in Queensland. SIU is part of QSCIS.

INTRODUCTION AND CONTEXT

In late 2023, the Department of Health commenced a co-design project to develop a service delivery model (service model) for Queensland adults with a spinal cord injury. The service model articulates how spinal cord injury services will evolve over the next 10 years to provide high-quality care as close to home as possible. From the project's outset, there was a commitment to take an authentic, collaborative, and transparent approach to developing a service model enabling high-quality care centred on what is important to people with a spinal cord injury and their families.

Spinal cord injuries are complex and varied, having significant and lifelong impacts on people's physical and mental health, social well-being, employment, and family. The management of spinal cord injuries requires a specialised, multidisciplinary and coordinated approach across the healthcare journey from the time of the initial injury to assessment, and diagnosis, and rehabilitation and management of complications and changes in health over an individual's lifespan.

Due to this complexity, there was recognition that the service model needed to accommodate the diverse needs and preferences of people with a spinal cord injury across Queensland. A co-design process was deemed important for gathering and understanding different consumer and provider experiences. For example, people living in different areas of Queensland who are accessing health services at various Hospital and Health Services (HHS) and the staff delivering these services. The co-design method helped empower participants with a spinal cord injury and their loved ones to provide honest and practical input, laying the foundations for the service model's development.

Co-design enabled participants to collectively co-create a service model for the future enabling equitable access to high-quality care, delivered in contemporary healthcare environments and catering for lifelong needs.

Call to action for improving spinal cord injury care across Queensland

Several factors coincided to drive the co-design of a service model:

- consumers publicly expressed concerns, through the media, regarding the quality of care and culture and the ageing physical environment of Queensland's only Spinal Injuries Unit (SIU) at the Princess Alexandra Hospital (PAH)
- in response, Queensland Health initiated rapid and extensive consultation with current and past consumers and families to find out what was working well and what could be improved in spinal cord injury care across Queensland. This re-affirmed some of the challenges that had been raised in the media
- there were implementation challenges for the Statewide Adult Spinal Cord Injury Health Service Plan 2016 – 2026, identified as coordination, leadership, buy-in, resource allocation and action. This plan was developed to address long-standing challenges within the system and increased demand
- Queensland Health released a new 10-year vision, HealthQ32, in early 2023 with a focus on optimising the delivery of safe, appropriate, timely hospital care and strengthening access to care in the community where people live so that they can return home more quickly. There were opportunities to leverage the system initiatives arising through HealthQ32 including:
 - networked service arrangements between HHSs to improve equitable access to specialist care where it is not possible to provide these services in each HHS
 - strengthening partnerships across the system, including with primary care, community-based organisations, aged and disability care and other healthcare providers and social services.

Enablers for improving spinal cord injury care across Queensland

There were several improvements underway upon commencement of the co-design process. This project sought to leverage and complement these improvements:

- The Commonwealth and State-funded Brain and Spinal Cord Injury (BaSCI) Project, commenced in July 2021 to implement key actions in the Statewide adult brain injury rehabilitation health service plan 2016-2026. The project, funded until June 2025, operates across five HHSs: Townsville HHS, Sunshine Coast HHS, Metro North HHS, Metro South HHS, and Gold Coast HHS and provides a very useful foundation upon which to advance collaboration across HHSs.
- in August 2023 the Queensland Government announced a \$20 million investment in spinal cord injury care which included immediate upgrades to the SIU at Princess Alexandra Hospital (PAH) and commencement of detailed business cases for new facilities to increase the delivery of inpatient spinal cord injury care. Following these announcements, two projects commenced:
 - the Queensland Spinal Cord Injuries Service (QSCIS) Enhancement Project, a Metro South HHS led project enhancing service provision within the statewide service.
 - a project led by the Department of Health to ensure appropriate uplift of spinal cord injury workforce and infrastructure capacity across Queensland. This included the business case development of a new and expanded SIU at PAH together with dedicated spinal cord injury inpatient rehabilitation services at Townsville University Hospital and the Surgical, Treatment and Rehabilitation Service (STARS) in Metro North HHS.

A CO-DESIGN APPROACH

Methodology

The co-design process provided a methodology for bringing together stakeholders to design solutions to challenges that are difficult to overcome using traditional engagement and consultation. Co-design applies a dynamic, iterative and collaborative approach creating an equal relationship amongst contributors.

Experience-based co-design was chosen as the preferred methodology because of the nature of the system challenges which spanned multiple aspects of the care continuum including acute management and rehabilitation in hospital, transition care between hospital and community settings, and lifelong healthcare (Dawada, P. & A; Knight, 2017).

During a nine-month period, more than 300 stakeholders were involved in the co-design and over 30 engagement sessions were held. These sessions included workshops, focus groups, meetings and one site visit. The co-design was structured with three key components:

- a collaborative governance structure including a steering committee and a consumer and clinical advisory groups
- five online co-design workshops where participants shared experiences and collaborated to shape the service model including what high-quality spinal cord injury care looks and feels like. Co-design participants were involved in making sense of information and feedback. Insights were exchanged during each workshop to generate ideas and shape the service model's components
- extensive and iterative engagement and consultation with stakeholders to understand different stakeholders' experiences and test and refine ideas and solutions.

The key components of the co-design process are shown in *Figure 1*.

A timeline comprising the key co-design steps is shown below in *Figure 2*.

Figure 1: Key elements for co-design

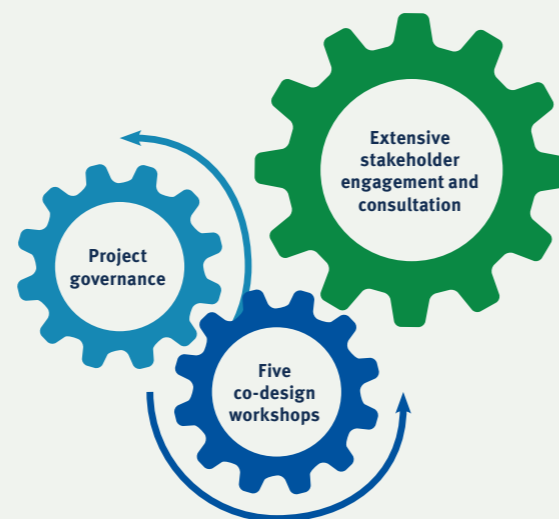


Figure 2: Timeline for the co-design process

November 2023	Engaged peak consumer body to support consumer and family engagement during co-design
December 2023	Established Consumer Advisory Group
January 2024	Established Project Governance Committee
February 2024	Established Clinical Advisory Group
February - April 2024	Fortnightly meetings of Consumer Advisory Group and additional consultation with other consumers and families
March 2024	Full day clinician workshop with clinicians across the state
April - June 2024	4x 2-hour fortnightly online co-design workshops
June - July 2024	Targeted consultation to explore and test potential solutions identified through co-design workshops
August - September 2024	Final co-design workshop and broad consultation on the draft service model

Who was involved?

THE FACILITATORS

A project team from Queensland Health's Department of Health, facilitated the co-design process and documented the co-design outputs. The project team was responsible for recording all stakeholder feedback and insights and incorporating collective ideas and suggestions into the service model. These insights were shared at regular intervals and further input was sought. The project team also gathered contextual information such as national and international best practice in spinal cord injury care and data on health service usage in Queensland. International models of best practice were shared throughout the co-design process. There were limitations in sharing health service data due to delays in accessing data and privacy issues. This is noted as a limitation of the co-design process.



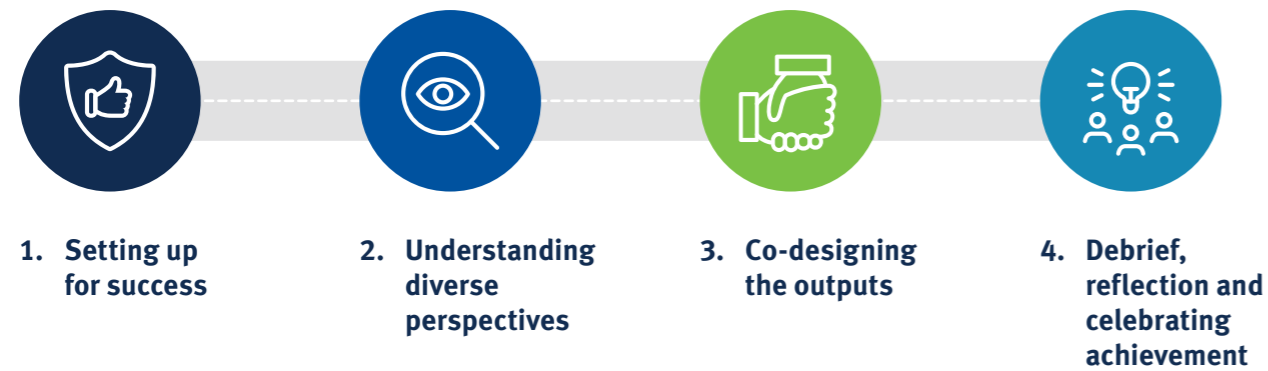
THE PARTICIPANTS

Stakeholders with a special interest or expertise in spinal cord injury care participated in the co-design process. These included:

- people with a spinal cord injury
- families and loved ones of people with a spinal cord injury
- representatives from advocacy organisations for people with spinal cord injuries and disabilities
- hospital and community-based clinicians providing health services for people with spinal cord injuries across Queensland
- Queensland clinical networks for emergency care, trauma, surgery, rehabilitation and general medicine
- Queensland Health senior leaders and representatives, including officers from the Department of Health and Hospital and Health Services' Chief Executives
- first responders including Queensland Ambulance Service
- community service providers (non-government and private) providing a range of support in the community including personal care, rehabilitation, health and wellbeing programs, peer support, education and employment support
- researchers focussed on improved outcomes for people with spinal cord injuries
- allies from other state health departments with an interest in spinal cord injury services.

What was involved?

The phases of co-design included:



1. Setting up for success

2. Understanding diverse perspectives

3. Co-designing the outputs

4. Debrief, reflection and celebrating achievement

1. SETTING UP FOR SUCCESS

From the outset, there was a commitment to authentic co-design allowing participants to contribute meaningfully and engage to the extent that they wished. The approach was underpinned by the principles of inclusion and diversity; equal participation; respect for different perspectives; trust and safety; choice; transparency and empowerment. These principles guided actions and decisions throughout the co-design process. Examples of how the principles were applied in setting up for success are described below.

1.1 Inclusive project governance

A steering committee with 11 members was established, comprising representatives from Queensland Health, including the Department of Health and HHSs, and representatives from consumer and clinical advisory groups.

The consumer advisory group was represented by people with diverse lived experience that considered place of residence (metropolitan, regional, or rural), age, culture, gender, length of time since injury or diagnosis, how they acquired their injury – traumatic or non-traumatic, level of spinal injury, and where they received their acute care and rehabilitation.

The clinical advisory group comprised a variety of medical, surgical, nursing and allied health disciplines providing spinal cord injury care, working in inpatient and community settings across Queensland.

To begin with, the consumer and clinical advisory groups met separately. This promoted trust, respect, peer support, honesty, comradery and sharing of ideas and opportunities for improving high-quality care. Once they had established and tested their views with their peers, all groups came together to share their experiences and ideas to co-design the service model in a series of workshops.

1.2 Safe and supportive engagement processes

Building safety and trust was essential for collaboration. The following aspects were embedded throughout the process:

- all key stakeholders were given an opportunity to be involved in a way that worked for them
- time was spent building trust to ensure activities were authentic, genuine and safe
- careful preparation, support and discussion of actual and potential risks
- communicating regularly, clearly and inclusively with all stakeholders providing written summaries of discussions for review and further feedback, to close the loop
- a commitment to using shared language; being open with information and addressing power imbalances by ensuring balanced representation from stakeholder groups and encouraging active contributions from all stakeholders
- allowing issues, challenges and opportunities to be shared with differences of opinion respected and acknowledged.

1.3 Trauma-informed approach

Consumer and family engagement were central to the design of the service model. A peak consumer advocacy organisation was engaged at the start of the process to guide and support consumer and family involvement. Their role included supporting the recruitment and establishment of the consumer advisory group and supporting consumers after difficult conversations.

A session on clinician self-care was incorporated in the clinician workshop delivered by an external expert in this field.

Participants were advised and reminded of the support that was available throughout the process.

1.4 Project facilitation

To minimise bias or the perception of bias, the project team was transparent about its role and responsibilities which included:

- defining and communicating the goals and scope of the project and ensuring that all participants understood how their input contributed to the service model
- facilitating inclusivity, collaboration, building trust and ensuring everyone had the opportunity to voice their perspectives
- aligning with Queensland Health's vision and future direction for the health system
- sharing best practice from other jurisdictions
- coordinating and maintaining clear, ongoing communication with all stakeholders, addressing queries, misunderstandings or concerns
- facilitating and navigating decision making, balancing diverse perspectives, priorities, and conflicts to move the project forward
- documenting and analysing feedback and refining elements of the service model
- evaluating the process with participants in an open manner to identify lessons learned and areas for improvement in future co-design projects.

2. UNDERSTANDING DIVERSE PERSPECTIVES

The engagement process was multidimensional and iterative. Many methods were used to enable participation including focus groups, meetings, workshops, individual interviews and a site visit. To enhance equal participation, there was greater emphasis on verbal and visual engagement methods, rather than written methods such as surveys. The consumer and clinical advisory groups were integral to this phase of the co-design.

2.1 Gathering and understanding experiences

The initial phase of engagement, prior to co-design workshops, sought to gather and understand experiences, feelings and perspectives on the system challenges and opportunities, across the care continuum, from a diverse range of stakeholders. This was achieved through empathy, trust, and mutual respect. *Table 1* outlines the stakeholder groups who were engaged during this phase of the co-design.

Table 1: Stakeholders engaged and consulted to understand different perspectives on the system challenges and opportunities across the care continuum

Governance groups	Number of members	Understanding different perspectives on system challenges and opportunities across care continuum	Number of participants
Clinical advisory group (monthly meetings)	16	A full day workshop with clinicians across Queensland caring for people with a spinal cord injury	22*
Consumer advisory group (fortnightly meetings)	8	Focus groups and interviews with consumers and family members, facilitated by members of the consumer advisory group	23^
		Focus groups and interviews with community service providers and personal support workers	11

*included members of the clinical advisory group

^included members of the consumer advisory group

2.1.1 Consumers, families and loved ones

The following questions and issues were explored with consumers and family members, in preparation for the co-design workshops:

- How would you describe the stages of your healthcare journey?
- Describe two to three pivotal points in your journey where healthcare let you down?
- How did this affect you?
- Describe the points in your journey where healthcare was pivotal to your recovery?
- What are your ideas for ensuring an ideal healthcare journey for people affected by spinal cord injury?
- What are your ideas for measuring high quality care for spinal cord injury?

Consumer advisory group members co-facilitated sessions to gather additional insights from other consumers and family members. Debriefing provided by a consumer advocacy organisation was offered to consumers after each session, reflecting a trauma-informed approach.

Feedback and discussion among consumers, carers and family members provided rich and extensive information. A summary of feedback was themed and presented to the Consumer Advisory Group for discussion. Drawing upon the themes about what is important to consumers and carers, 11 principles for high-quality, person and family-centred care were identified.

2.1.2 Clinicians delivering spinal cord injury services

A full day clinician workshop was held in March bringing together a range of disciplines with expertise in delivering spinal cord injury care across Queensland Health. The following issues were discussed at this workshop:

- What principles will guide “good” person and family-centred care by 2034?
- What happens currently in providing care across the healthcare journey?

- Imagine the future state of spinal cord injury across Queensland, what would good rehabilitation look like for a person and their family (different types of injuries such as traumatic and non-traumatic were considered)?
- Thinking about the principles, what key enablers do we need to make future care possible?

Feedback from clinicians was documented and shared. Draft principles for delivering high-quality, person and family-centred care were developed.

2.1.3 Community-based service providers

Community-based service providers were consulted over a series of individual meetings and focus groups. Service providers included personal support workers, referred by consumers, and private providers with specialist skills and expertise in neurological rehabilitation physiotherapy, occupational therapy and exercise physiology. Several key advocacy and support organisations for consumers also participated. The following questions were discussed:

- What is working well in coordinating care and support to people with a spinal cord injury?
- What are the opportunities to work better together to collectively improve the experiences and outcomes for people with spinal cord injuries and their families?
- What system enablers are required to deliver coordinated, high-quality spinal cord injury care across hospital and community settings? Are there partnerships that are working well and what opportunities are there to strengthen these?
- What are your aspirations for a coordinated system that works well together to provide high quality, personalised spinal cord injury care?

Following these sessions, a summary of the discussion was prepared and shared with participants for review and further input or feedback.

3. CO-DESIGNING OUTPUTS

3.1 Co-design workshops

This phase of engagement sought to bring all stakeholder groups together to share their ideas for future service delivery. Five online co-design workshops, based on the healthcare journey, were held between April and August 2024.

Figure 3 outlines details about each workshop. Table 2 below shows the number of representatives from each stakeholder grouping participating in each workshop.

Figure 3: Co-design workshops’ topics

	Workshop One – 18 April 2024 Setting the scene, creating a safe environment and developing shared principles for spinal cord injury care.
	Workshop Two – 7 May 2024 Care continuum – what does good care look like at the acute stage and primary rehab?
	Workshop Three – 21 May 2024 Care continuum - how do we support people with a spinal cord injury to transition back home and into the community?
	Workshop Four – 4 June 2024 Care continuum – what does good care look like in the community and lifelong management?
	Workshop Five – 6 August 2024 Evidence and bringing it all together – draft model for discussion

Table 2: Number of participants in each co-design workshop by stakeholder grouping

Stakeholder groups represented in co-design workshops	Workshop One	Workshop Two	Workshop Three	Workshop Four	Workshop Five
Queensland Health clinicians and staff*	15	13	16	14	19
People with a spinal cord injury and family members	7	9	7	9	10
External organisations		6	11	8	7

*excludes the project team who were facilitators

Several strategies were adopted during the co-design workshops to manage power dynamics and ensure there were equal opportunities for all stakeholder groups to provide input and influence the service model. For example, at least two consumers were involved in each small group discussion (in breakout rooms). Following each co-design workshop, a de-identified summary of the discussion from each small group and a thematic analysis of collective inputs from each workshop were shared with participants for review and further input.

3.2 Feedback on the draft service model

The final iteration of co-design entailed the distribution of a draft document, explaining the future service model. This was shared with more than 300 individuals and organisations, including co-design participants, seeking their feedback. Two options were offered for providing feedback – participation in an online feedback session (three were offered) or submission of written feedback via email. Thirty-eight individuals participated in online feedback sessions. Fifty-four written feedback submissions were received including 25 on behalf of a group. All key stakeholder groups were represented during online feedback sessions. Written feedback was submitted by clinicians, consumer advocacy organisations, researchers, other government departments and community services. During this iteration of co-design, a few stakeholder groups either self identified that they would like to be more actively engaged in the co-design or were suggested by others as being important to engage further. Stakeholder groups that could have been more actively engaged included general practitioners, sleep specialists and social housing representatives. This demonstrates the iterative nature of co-design and the importance of flexible approaches to engagement.

4. DEBRIEF, REFLECTION AND CELEBRATING ACHIEVEMENTS

All participants contributions have been acknowledged through the development of this report and within the service model. This includes featuring stories and videos from some co-design participants about the service model.

A debrief and check-in session was offered to both the consumer advisory group and the clinician advisory group. An external facilitator undertook these sessions giving each group to the opportunity to reflect on the co-design process and share feedback about what worked well and what could be improved.

Once finalised, the service model and this co-design process and outcomes report will be shared with participants and their contributions and achievements acknowledged.

STRENGTHS AND WEAKNESSES

Co-design uses multiple engagement tools and techniques to enable user-centred design. The methods of engagement were fluid and altered based on participant engagement and feedback. For example, consumers were asked about their preferences for participating in ‘online’ or ‘in-person’ workshops. Consumers initially opted to travel for an in-person co-design workshop. However, it was difficult to find a suitable date when most consumers could participate. Therefore, consumers agreed to shift to an online format.

There were pros and cons to using an online modality for co-design workshops. This required a shift in the workshop format from a full day workshop to a series of 90-minute sessions held over six weeks.

The shorter sessions resulted in reduced interactive discussion time. Participants provided feedback after the first co-design workshop indicating that they wanted more discussion time. Therefore, future online co-design workshops were extended to two hours duration. Breakout rooms were used in the online format to facilitate “small group” discussion. This worked well to maximise participation. The benefits of the online format included greater consumer involvement and time for reflection and feedback on each component of the healthcare journey after each co-design workshop.

Some stakeholders requested additional meetings after the co-design workshops to explore gaps and potential solutions in the healthcare journey in more detail. Multiple meetings were held after co-design workshop four, to enable these detailed discussions. A fifth co-design workshop was included to ensure that additional insights and inclusions could be discussed with co-design participants and incorporated into the service model. A summary of the proposed service model was presented and discussed at the final co-design workshop. However, a document detailing the service model was not ready for distribution. It would have been beneficial for this to have been distributed to co-design participants prior to the final workshop.

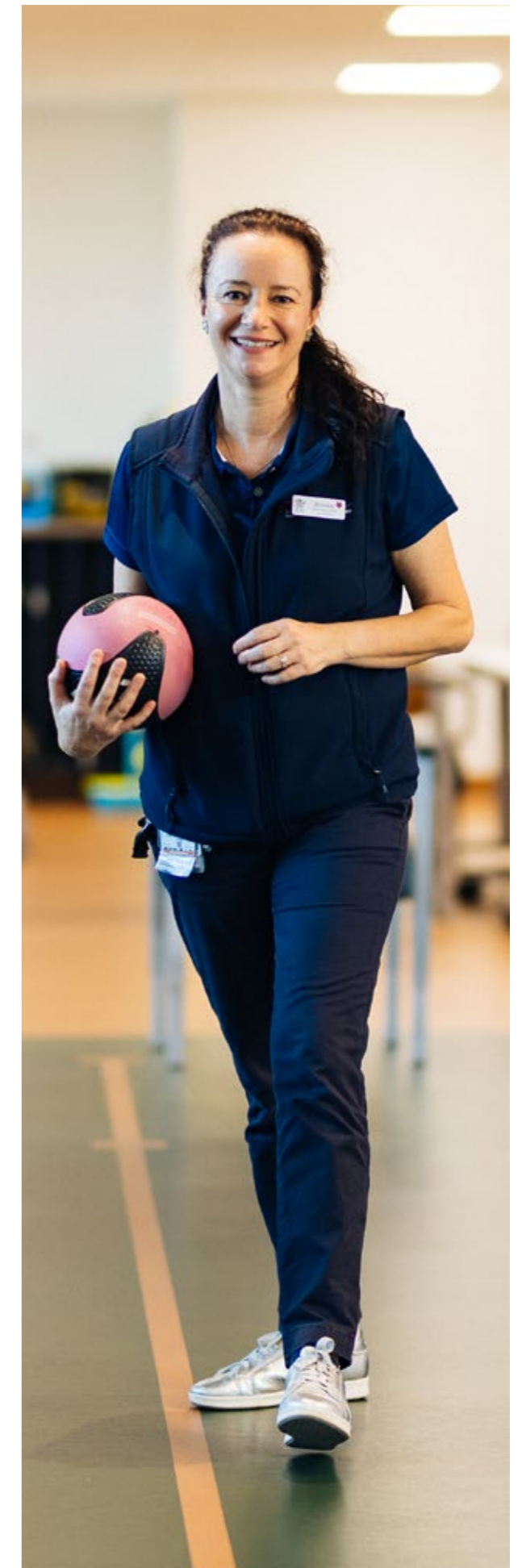
People with a spinal cord injury have diverse needs and it is essential to understand and consider these needs across the healthcare journey. However, time constraints impacted the project team’s ability to engage some underrepresented consumer cohorts that had been identified for inclusion. For example, it was intended to hold focus groups to identify any specific needs or issues experienced by: young women, young men, parents caring for young people, those who became parents after their spinal cord injury and Aboriginal and Torres Strait Islander peoples. Of these groups, the only one that proceeded was the young men focus group. The project team was unable to recruit enough participants for the other focus groups. However, individuals representing these demographics were engaged in other ways, either through the consumer advisory group or in other consultations.

As indicated, there were several concurrent improvement projects occurring alongside the co-design process. These projects also involved consumers and families. Some consumers were engaged across multiple projects which was beneficial for information sharing. Extensive consumer and family consultation was undertaken in June and July 2023 by two consumer advocacy organisations. The views of more than 70 current and past patients were documented. These perspectives also informed the identification of system barriers and enablers.

Although families were consulted, there was only one family member represented on the consumer advisory group and in the co-design workshops. Consultation identified that family members experience unique challenges that are important considerations. There would have been benefit in having more family members involved in co-design workshops.

There were delays in accessing data about health service utilisation for spinal cord injury. This was partly due to complexities in how this data is collected. Also, there were some limitations in sharing data due to privacy considerations. Therefore, health service utilisation was unable to be used during co-design workshops and limited to being shared with the steering committee.

During the co-design process some concerns that were raised were outside the project scope. These were redirected to the appropriate authority within Queensland Health for action. This emphasised the need to be flexible and responsive when co-designing future services.



FEEDBACK AND LESSONS LEARNED

The co-design process posed several unique challenges.

- Balancing the diverse needs and expectations of each stakeholder group was difficult, as each group at times, had different priorities and perspectives on what they considered as high-quality care.
- Navigating the power dynamics between these groups, ensuring inclusive participation and maintaining engagement throughout the co-design were key elements to the success of the project.
- Integrating the feedback from various sources to inform the components of high-quality spinal cord injury care and how services can best be provided across Queensland required careful negotiation and communication with stakeholders.

The number of people who were engaged during process increased over time and participants contributed to identifying other stakeholders who could provide a meaningful contribution. Just one of many examples was that consumers requested a focus group be held with paid personal support workers because they are essential members of their care team in the community. Managing the increased time required to undertake additional engagements proved challenging.

Establishing shared principles during the first co-design workshop, helped set the tone for working together. It also provided a “quick win” output early in the co-design process. Achieving small milestones throughout the process was useful for maintaining momentum and engagement.

During the final iteration of engagement on the draft written document, new insights were identified that had not been raised or discussed during co-design workshops. These new insights contained some divergent points of view. In making decisions about how to incorporate these new insights, the project team the shared principles were extremely helpful as were data on health service utilisation. The project team offered additional information sessions after the service model was endorsed to facilitate transparency in decision making, particularly where there were divergent points of view.

The target audience was broad. It was challenging to write a technical document catering to the needs of all stakeholders. Where possible, the project team, tried to use plain English and inclusive language. This style of writing generated some feedback that the audience for the document was unclear.

Feedback and reflections from the Consumer Advisory Group

Consumers participating in online feedback sessions discussing the draft service model, shared the following reflections:

“I read this document a number of times. It brought me to tears in places. I thought I was re-telling my story.”

“Thank you for your involvement in what I see is one of the best co-design processes that I have ever had the pleasure of being involved in. To the clinicians, thank you for being so open and willing to accept the consumer side of the story and involvement in the process. I think it's led to the production of a well-informed and balanced service model.”

During the final stages of the service model's development, participants' from both the Clinical and Consumer Advisory Groups were invited to provide feedback on the strengths and limitations of the co-design process. Two feedback sessions were offered – one for consumers and the other for clinicians. Independent facilitators conducted these sessions to allow participants to share their feedback openly. The facilitators documented feedback that each group was comfortable sharing with the project team.

The Consumer Advisory Group shared the following feedback about the co-design process:

STRENGTHS OF THE CO-DESIGN PROCESS

- early and regular engagement created a safe space where consumers were comfortable sharing intimate details of care they had received and their daily life since returning home to the community
- feeling heard and understood and that their ideas and suggestions were considered
- story telling with each other empowered them with courage and at the same time learning from one another and they felt they were not alone
- the journey has made them stronger and more confident to navigate the health system and stand up for themselves and others.

LIMITATIONS OF THE CO-DESIGN PROCESS

- a face-to-face meeting with the Clinical Advisory Group would have been valuable acknowledging that there were logistical difficulties in planning this
- online breakout rooms during the co-design workshops felt rushed and discussions were abruptly cut short at times
- greater transparency and explanation on the drivers for the review of the statewide service model would have provided further context and background.

FEEDBACK AND REFLECTIONS FROM CLINICAL ADVISORY GROUP

This session had not been held at the time of publication. Therefore, it cannot be shared.

NEXT STEPS

Queensland Health sincerely thanks everyone who participated for their invaluable contributions. The co-design process and its outcomes have informed the development of Queensland's spinal cord injury service model, with the aim of enhancing the quality of care provided while improving access to services across the state.

These outcomes should be considered in the development of any future spinal cord injury care, including the implementation plan for the service model and other improvements underway across Queensland Health.

It is recommended that spinal cord injury care standards are developed for Queensland, drawing on outcomes from this project, as well as any international guidelines available.

The relationships established during the co-design process must be leveraged for future service planning and implementation of the service model. Building and nurturing these relationships over time is essential.

Lastly, this report on the co-design process and lessons learned, needs to be shared. Co-design is a novel tool in health service planning. This work can provide an important contribution to the development and evaluation of this new and exciting methodology in this field.

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Dawada, P. & A. Knight. (2017). Experience Based Co-Design. Retrieved from Australian Healthcare & Hospitals Association and Consumer Health Forum of Australia: <https://ahha.asn.au/resource/experience-based-co-design-toolkit/>

APPENDIX 1

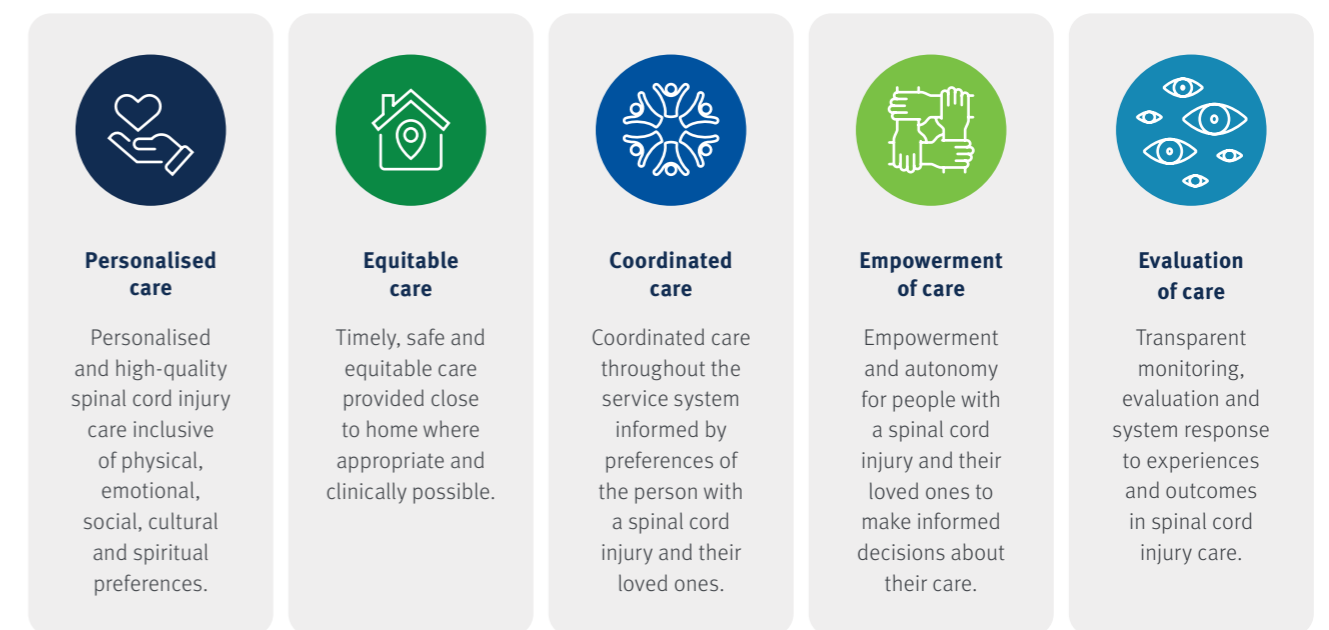
What came out of the co-design workshops?

SHARED PRINCIPLES

An outcome from the co-design process was the development of five shared principles for holistic person and family-centred spinal cord injury care. The shared principles underpin successful delivery of the model and support improved access to safe, high-quality, and timely spinal cord injury care as close to home as possible throughout a person's journey. Figure 4 details the shared principles for high-quality spinal cord injury care. They also support building workforce capability and capacity across the state.

The five shared principles were developed via an iterative process. Following the identification of gaps in care that currently exist, consumers discussed what matters to them and why this is important. Initially, principles were drafted separately by consumers and clinicians. These draft principles were presented at the first co-design workshop. Strong alignment emerged between the two stakeholder groups' principles, emphasising the importance of shared language and a common goal and vision – 'To design a statewide service delivery model that enables high quality, person and family-centred spinal cord injury care across the continuum'. Following feedback, the groups' draft principles were combined and refined, and presented at the second workshop for review and endorsement. The shared principles were revisited in subsequent co-design workshops, to validate suggestions and address differing opinions.

Figure 1: Shared principles for high-quality spinal cord injury care



CO-DESIGN PROCESS AND OUTCOMES REPORT

Table 3 below details what each principle means in practice informed by the discussions of co-design workshop participants.

Table 3: Principles for high-quality spinal cord injury services in practice

Shared principle	What does this principle mean and look like in practice?
Personalised and high-quality spinal cord injury care inclusive of physical, emotional, cultural and spiritual preferences.	<ul style="list-style-type: none"> Trauma-informed, holistic and psychosocial care. Personalised approach to pressure injury prevention, bowel and bladder management. High quality and nutritious food with some choice for personal preferences. Leveraging a person's abilities, interests, goals and aspirations. A sentiment of hope and positivity is promoted throughout the care journey.
Timely, safe and equitable care provided close to home where appropriate and clinically possible.	<ul style="list-style-type: none"> A skilled and culturally competent interdisciplinary workforce that is responsive to and aligned to individual needs, preferences and goals. Best practice care in line with current evidence-based guidelines and recommendations. Risks of neglect, violence and harm are identified and managed. Access to safe and healing environments which includes an accessible, fit-for-purpose gym and a mix of indoor/outdoor quiet and communal spaces. Specialised assistive technology aids rehabilitation and outcomes to achieve an individual's goals.
Coordinated care throughout the service system informed by preferences of the person with a spinal cord injury and their loved ones.	<ul style="list-style-type: none"> A care team, which includes the person, loved ones and carers (including personal support workers) that work together and communicate regularly. Coordinated and integrated care with clear and transparent referral pathways. Systems in place to reduce or prevent fragmentation of care. Family members, loved ones and carers are supported and not overburdened practically, physically and emotionally.
Empowerment and autonomy for people with spinal cord injury and their families to make decisions about their care.	<ul style="list-style-type: none"> Promote choice, informed decisions and autonomy. Enable active participation in rehabilitation activities as each person wants. Consumer, family and carer involvement in planning, design and continuous improvement of services. Value lived experience and enable opportunities to connect with peers. Respectful and compassionate care that upholds a person's dignity and privacy.
Transparent monitoring, evaluation and system response to experiences and outcomes in spinal cord injury care.	<ul style="list-style-type: none"> Centralised data systems to help inform the best interventions and treatment for current and future care pathways. Collection and use of patient reported outcome measures. Transparency in sharing data on trends and outcomes with the community. Some independence in data collection and benchmarking outcomes with spinal cord injury services across Australia.

How care should be delivered

SERVICE DELIVERY MODEL

The co-design process explored core components of the spinal cord injury healthcare journey. This included a shared language to describe these core components which supported equal participation and collaboration. Figure 5 outlines these components.

Figure 5: Care continuum for people with a spinal cord injury



**A person with a spinal cord injury may be readmitted to manage complications or other issues but not require hospital rehabilitation or community reintegration services.*

The concept of networked services across HHSs was discussed during co-design workshops and generally well-received by most participants.

People with a spinal cord injury and their families saw networked services as an opportunity for greater equity of access to services and care closer to home. However, they stressed the need for consistent, safe, high-quality, and personalised care regardless of where it was delivered.

For clinicians, the majority felt empowered and saw it as an opportunity to grow their capability and service capacity. However, some clinicians felt it would be difficult to replicate the expertise of the statewide service without significant investment and change management.

A key enabler for the model is the development of clinical standards for spinal cord injury care in Queensland. By establishing clear guidelines, clinicians can understand what high-quality care for people with a spinal cord injury looks like across a healthcare journey.

In addition, a networked approach provides an opportunity to formally recognise health services that are already providing care to people with a spinal care injury. It offers structure and consistency to service delivery and promotes sustainability.

CO-DESIGN PROCESS AND OUTCOMES REPORT

High-quality care across the healthcare journey

WHAT WE HEARD IS NEEDED IN THE FUTURE DURING THE CO-DESIGN PROCESS

Table 4: Themes from co-design regarding care at the time of initial injury or diagnosis

Key themes from co-design workshops about what is needed	Personalised care	Equitable care	Coordinated care	Empowerment of care	Evaluation of care
Clear referral guidelines for the management of traumatic and non-traumatic spinal cord injuries at the onset of an injury.			✓		✓
Early and accurate diagnosis for non-traumatic injuries and referral protocols to the right specialist care.			✓		
Timely and safe access to surgical interventions for spinal cord injuries outside south east Queensland and minimising unnecessary transitions between acute care and hospital rehabilitation.		✓			
Access to specialist rehabilitation including dignified bowel and bladder management, respiratory management such as ventilation support, skin breakdown management as early as possible.	✓	✓			
Collaborative informed decision-making about treatment and care, including regular, clear, transparent communication and enable empowerment regarding care preferences.				✓	

Table 5: Themes from co-design regarding hospital rehabilitation and community reintegration

Key themes from co-design workshops about what is needed	Personalised care	Equitable care	Coordinated care	Empowerment of care	Evaluation of care
Access to specialist hospital rehabilitation delivered closer to home.	✓	✓			
Greater clinical capability in spinal cord injury management across the state.		✓	✓		
High-quality, person and family-centred rehabilitation includes: <ul style="list-style-type: none"> a holistic approach and ongoing care coordination a caring, healing and dignified environment recognising that this is a time of significant grief, loss and adjustment maintaining connection to family and community including participation in community, social, recreational and sporting events collaborative goal setting, peer support and education access to vocational rehabilitation and support in returning to employment, education or training a strengths-based approach celebrating incremental gains accessing the right assistive technology and equipment greater availability of mental health support including for families greater focus on sexual and reproductive health regular opportunities for patient and family feedback about what is working well and what could be improved home trials prior to discharge preparing a team of personal support workers who are onboarded and trained by the multidisciplinary team choice and options regarding the intensity and timing for rehabilitation sessions. 	✓			✓	
Early commencement of transition and discharge planning, including advocacy and empowerment to support the navigation of funding options around assistive technology, equipment, home modifications and community support. Particularly relevant for people with non-traumatic injuries aged over 65 years.	✓			✓	
Equity of access to community reintegration services. Services provided in or close to a person's community improves coordination of local care providers, increases family involvement and social networks, assists problem solving and skill transfer to the community setting.		✓			

CO-DESIGN PROCESS AND OUTCOMES REPORT

Table 6: Themes from co-design regarding optimising health and wellbeing across the lifespan

Key themes from co-design workshops about what is needed	Personalised care	Equitable care	Coordinated care	Empowerment of care	Evaluation of care
<p>Address barriers to continuity of care after hospital rehabilitation including:</p> <ul style="list-style-type: none"> • access to community rehabilitation and outpatient services in regional and rural areas • long wait times to access community rehabilitation disrupting continuity in hospital rehabilitation • some community rehabilitation providers are generalists without specialist knowledge in spinal cord injury • difficulty attracting and maintaining specialist workforce in regional areas 		✓	✓		
Access to specialist support across Queensland for management of complications and issues such as pain management, urinary tract infections, skin breakdown and bowel and bladder management.	✓	✓			
Consistent policies and standards of care across Queensland Health when people with a spinal cord injury are readmitted to hospital.				✓	✓
Emergency Department staff training and guidelines for managing people with spinal cord injuries including evidenced based practice such as ISNCSCI assessment.	✓				✓
Appropriate equipment in non-specialist spinal cord injury facilities to support the care requirements of people with a spinal cord injury during readmissions to hospital, such as suitable seating, hoists, shower and toileting aids.		✓		✓	



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