

Final Report

Improving Transitions to Community Living for People with Spinal Cord Injury in NSW



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Executive Summary

Over a life course there are nett benefits for people with SCI, their families and for health and disability service systems if better integration and person-centred care lead to:

- people being equipped to lead the management of their own care and recovery
- people accessing the right supports at the right time to enable an effective transition to community settings – leading to long-term establishment within those settings. This avoids adverse impacts on their mental health, self-efficacy, relationships of support, and physical well being
- people staying in hospital beyond only for as long as is useful for their rehabilitation and preparation for community living – avoiding the negative effects of over-staying
- people avoiding being readmitted to hospital for preventable issues.

These benefits are best realised when people with SCI receive person-centred and holistic rehabilitation that prioritises the development of the skills and knowledge required to live their lives with maximum independence. This includes the skills and information they need – presented in accessible formats - to manage their disability in the community and to access essential funding and support systems.

Person-centred care is foundational for improving outcomes for people with SCI who are transitioning to community living. Insight Consulting Australia is preparing a separate report related to improving person-centred care for people with SCI in NSW.

The complex range of funding, insurance and support services that need to be in place for a person's discharge from rehabilitation must be appropriately integrated and coordinated in order to achieve positive outcomes in community living. Bringing community supports into hospital to prepare for discharge can contribute to this integration.

Building on a strong existing culture of holistic SCI rehabilitation in NSW specialist units, this report identifies psychosocial support and the strengthened involvement of families, natural support networks and formal peer support programs as key to building self-management skills. Further investment in holistic aspects of rehabilitation is also recommended, such as recreational and leisure therapy programs trialled in NSW and investing to ensure ongoing access to vocational consultancy for people with SCI in specialist spinal rehabilitation programs in NSW.

This report summarises the key findings of Insight's research and stakeholder engagement on improving transitions to community living for people with SCI in NSW. It reflects the views of a diverse range of key informants and stakeholders whose experiences and expertise relate to SCI transitions to community living, obtained in a series of interviews and focus groups and in an expert dialogue. This work was commissioned by the State Spinal Cord Injury Service (SSCIS) in the Agency for Clinical Innovation (ACI) as part of its broader project to identify options for improving care and support to people with Spinal Cord Injury (SCI) in NSW.

By jointly building personal capacity for self-management and addressing the systemic issues that currently affect people's transitions to community living after a spinal cord injury, this report seeks to improve people's short- and long-term community living experiences and improve outcomes for people with SCI in NSW.

Summary of Recommendations

1. The overarching recommendation of this report is that spinal cord injury care and support services and systems in NSW collaborate with each other and with people with lived experience to:
 - a. continuously improve their combined approaches to putting people at the centre of service design and delivery; and
 - b. provide integrated care and support in partnership with those receiving services, recognising the short- and long-term benefits to individuals and populations (including cost benefits).

This recommendation is provided in the context of a further report being prepared which addresses in greater detail how to strengthen person-centred care for people with SCI.

2. Implement the Action Plan from the Expert Dialogue stakeholder forum (at **Appendix D**).
3. Adopt the recommendations of the *Guide for Health Professionals on the Psychosocial Care of Adults with Spinal Cord Injuries*ⁱ or, at a minimum, the General Principles for the Psychosocial Care of People with SCI (Recommendation 6.1) for people with SCI and for their families.
4. Explore development of a person-centred, longitudinal evaluation framework for improving care and support to people with spinal cord injury in NSW, focussed on people's achievement of lifetime goals and quality of life.
5. Maintain and improve holistic approaches to rehabilitation by committing long-term funds to innovative rehabilitation programs that have been successfully piloted in NSW or other Australian jurisdictions, such as leisure and recreational therapy, and vocational consulting.
6. Implement SCI-specific meal plans in specialist SCI units and promote advice on SCI dietary needs to non-specialist hospitals and units.
7. Increase transitional housing options that enable flexible steps-down for sub-acute rehabilitation for people with spinal cord injury in NSW.
8. Research effective strategies for providing information and resources to people with SCI and their families/networks during and after transition to community living to help them to manage their care.
9. Expand peer support programs to reach people with SCI in specialist and non-specialist healthcare settings during and after their transition to community living (whether newly injured or with new care and support needs related to their readmission).

1. Background

The SSCIS is undertaking work to identify options for improving care and support to people with SCI in NSW. A *Diagnostic Report* was published in 2016 that detailed the spinal cord injury service system in NSW (from time of injury through to community living) and identified areas for change. A final report on this work is currently in the final stages of development.

The diagnostic report concluded that the health system needs to focus on better meeting the lifetime needs of people with spinal cord injury by:

- actively engaging with other sectors (e.g. disability, community services) in collectively improving the quality of life and wellbeing of people with spinal cord injury
- refocusing health services to facilitate people's longer-term participation in community life, away from the current emphasis on the acute care phase
- adopting a truly person-centred practice that addresses the full range of people's needs, including their emotional and psychological wellbeing, as well as their immediate medical needs.

The SSCIS commissioned Insight Consulting to engage with stakeholders on improving transitions from healthcare settings to community living for people with SCI in NSW. In particular, to identify ways to:

- support timely sustainable discharge for people with a spinal injury
- improve collaboration across the health and disability sectors via robust systems and processes
- strengthen person-centred delivery throughout the patient journey into community living.

Insight Consulting has also been commissioned to report on strategies to improve person-centred care for people with SCI in NSW, including consumer and service provider tools for measuring person-centred care. This work is closely related to improving transitions to community living, as person-centred care is a key area of reform in transition planning and support. Stakeholder engagement processes (outlined in section 1.1 below) have informed both areas of work.

Insight Consulting's separate final report on findings and recommendations related to person-centred care should be read and considered as a companion report.

1.1. Method

The findings of this report are based on evidence and insights from:

- a rapid review of research literature, policy publications and other grey literature on barriers and enablers to effective, supported transitions from healthcare settings into community living (see **Appendix A**)
- key informant interviews and focus groups conducted in early 2019 with SCI patients and experts in SCI policy, funding and health and disability care and support (see list of key informants at **Appendix B** and summary analysis of patient interviews at **Appendix C**)
- a stakeholder forum hosted by ACI and facilitated by Insight Consulting on Wednesday 15 May 2019 as an Expert Dialogue with representatives from diverse groups delivering care,

support, services and funding to people with SCI in NSW (see Action Plan from Expert Dialogue at **Appendix D**).

An Advisory Committee of people with expertise and experience in spinal cord injury care and support, has overseen this project and advised on key directions of this final report.

1.2. Project context

The following data provides a context for the key directions outlined in this briefing paper. This data is sourced from the final draft of the ACI report on *Spinal cord injury care and support: current situation and options for improvement*.

Spinal Cord Injury (SCI) in NSW and Australia is usually caused by traumatic events – primarily for men, in younger age brackets. Non-traumatic SCI can be caused by illness or degenerative conditions and is becoming more common as the average age of our population increases.

Specialist Spinal Injury Units in NSW are at Prince of Wales Hospital (POWH) and Royal North Shore (RNSH) Hospital, both in Sydney. Royal Rehab in Sydney has a specialist Spinal Rehabilitation Unit. Over the last seven years, POWH and RNSH have together seen about 130 new cases of SCI per annum. Research estimates by New et al suggest that this may be less than half of the new SCI cases that occur in NSW every year, which they estimate as between 291 and 361 new cases.

It is estimated that approximately 5,445 people in NSW are living with SCI. In 2016-17, there were 8,031 hospitalisations of people with SCI in NSW.

It is estimated that 70% of people with index SCI hospitalisations in NSW per year, or about 320 individuals, are not admitted to a specialist spinal cord injury unit. For example, in 2016, 314 of the 487 index cases were admitted to hospitals other than a specialist unit.

In 2017-18, the median delay for patients in specialist acute units waiting to transition to rehabilitation was 20 days, and the range was between one and 195 days.

In 2016-17, across NSW there were 1,504 people with SCI (as noted anywhere in their hospital record) who were admitted to hospital at least once during the year and 658 of these people were hospitalised at least once for acute overnight care.

People with SCI whose index admission was to a specialist hospital in 2016 experienced lower rates of re-admission in the follow-up period, with 2.4 subsequent acute hospitalisations per patient to June 2018 compared with 2.9 for those whose index admission was to a public hospital and 4.2 for those first admitted to a private hospital.

2. Person-centred care

Health and disability services in Australia and overseas are shifting towards service models that more effectively realise the personhood of service users and the positive health and wellbeing outcomes that may be achieved by partnering with people when planning their care and support needs.

The NSW Agency for Clinical Innovation defines person-centred care as “health care that is respectful and responsive to the needs, preferences and personal circumstances of the patient, carer and family members”ⁱⁱⁱ.

In this paper the term person-centred care refers to whole-of-organisation efforts to partner with people with SCI in their care and support. Genuine partnership requires investment in people’s skills and confidence in self-management, including but not limited to: health literacy of people with SCI and their families; strategies for delivering accessible information; and collaborative planning approaches that sensitively balance people’s periods of vulnerability and learning against their over-all expertise in their own injury and their own individual care and support needs.

During key informant interviews, discussions of person-centred care raised descriptions of approaches (observed, experienced or delivered) that ranged across:

- **consultative care**, in which professionals are respectful, empathetic and acknowledge the importance of the person’s lived experience during the planning process, but retain responsibility for decision making and key directions
- **collaborative care**, in which joint decision-making is exercised in care planning and the person with SCI sets their own planning goals
- **person-led care**, in which the person with SCI self-manages most or all elements of the care and support they require.

This disparity of usage reflects both a lack of consensus among diverse partners around a rigorous definition, as well the changing nature of a person’s involvement over the total journey from injury to community living.

While there was clear support for improving the self-management and person-centred care of people with SCI in their use of health and disability services, frustration was expressed towards significant structural barriers towards delivering flexible, individualised care and support:

- **Not all funding is individualised.** Funding for people injured at 65 years of age or older, provided under the Department of Health’s My Aged Care program, is not based on assessment of need.
- **Individualised funding differs from individualised care and support.** Individualised funding packages under the NDIS currently have generally inflexible and delayed approval processes that impede people’s management of their own care and support and increase their reliance on health and disability services.
- **Person-centred care in health settings is impacted by resource constraints.** Systemic pressures such as hospital waiting lists and periods of high demand, and lack of specialist

services in some geographical areas (especially rural and regional areas), reduce practitioners' capacity to deliver best practice in person-centred care.

The overall quality of specialist care, and the respectful approach of those who provide it, are also foundations for person-centred care. When patients were asked during interviews to reflect on their experiences of partnership and leadership in their care planning, they generally prioritised the dignity and sense of personhood afforded by expert, sensitive and supportive staff.

Stakeholders sought to improve the person-centred capacity for person-centred care in the services, systems and funding schemes that people with SCI use on their transition pathway to community living by recommending solutions aimed at improving flexibility, responsiveness and accountability to longer-term outcomes.

Discussion and recommendations in line with these key directions are outlined in Section 3 below.

From a base of high quality, specialist, flexible and timely care, person-centred approaches to transition pathways can be improved by building people's capacity for self-management of their care plans, personal goals and community living. Core elements for self-management described by key informants and stakeholders were:

- holistic approaches to rehabilitation that build people's skills in all aspects of living
- staggering transitions to community living where possible, to allow people to gradually build the lived experience required to manage their disability
- including people's family and natural support networks and skilling them up, where appropriate, as advocates and self-management partners.

Discussion and recommendations in line with these core elements for self-management are outlined in Section 4 below.

Recommendation

1. The overarching recommendation of this report is that spinal cord injury care and support services and systems in NSW collaborate with each other and with people with lived experience to:
 - a. continuously improve their combined approaches to putting people at the centre of service design and delivery; and
 - b. provide integrated care and support in partnership with those receiving services, recognising the short- and long-term benefits to individuals and populations (including cost benefits).

This recommendation is provided in the context of a further report being prepared which addresses in greater detail how to strengthen person-centred care for people with SCI.

3. Transitions to community living

3.1. Pathways

Transition pathways in NSW are diverse and highly variable in their short- and long-term outcomes.

This project has focused on pathways from specialist spinal units to community living. In 2016/17, only a quarter of index SCI cases (first acute hospitalisations with a spinal cord injury code) in NSW were admitted to a specialist spinal unitⁱⁱⁱ. A key reason for this is that many SCI patients, particularly with non-traumatic injuries, will be transferred to a Spinal Injury Unit (SIU) after an initial period in a non-specialist hospital or unit. However, there is evidence to suggest that some SCI patients in NSW do not receive specialist spinal acute or sub-acute care after their injury^{iv}.

Entry pathways to acute care are relevant to SCI transition pathways, as key elements of rehabilitation and transition planning commence in acute care (noting that SIU pathways only were explored for this project, and the practices of non-specialist hospitals are not known):

- people are introduced to their multi-disciplinary rehabilitation team as early as possible
- elements of rehabilitation such as vocational consultancy may start in acute care
- assessments and applications related to NDIS, icare or My Aged Care generally start as soon as possible
- assessments and applications related to housing or home modifications generally start as soon as possible.

When a patient is transferred to sub-acute rehabilitation, they will generally start working with a new multidisciplinary team, whether or not their rehabilitation is at a different location. Transition to community living becomes the priority focus. A Rehabilitation Pathway map for specialist spinal units is at **Appendix E**.

Pathways from rehabilitation to community living rely heavily on the funding or disability insurance scheme that the person is eligible for, and the housing or home modification arrangements they are able to realise.

People discharged from one of the two Spinal Injury Units to reside in metropolitan Sydney are eligible for outreach follow-up support from the Spinal Outreach Service. People discharged to reside in rural and regional areas may be referred to the Rural Spinal Cord Injury Service for follow-up support. Outside of these follow-up support services, people with SCI may access outpatient clinics attached to Royal North Shore Hospital, Royal Rehab or Prince of Wales Hospital.

Rehabilitation teams attempt to link people with SCI to mainstream health services and disability support services that have specialist SCI knowledge or expertise. However, this is not always possible especially in regional and rural areas where practitioners do not experience high volumes of SCI patients or clients. People who transition to community living under the icare insurance scheme are supported to link with specialist care and support services in the community by their Community Living Facilitator.

Service pathways between acute care and community-based care are best understood as circular, as people may be re-hospitalised from secondary health conditions or comorbidities.

A Transition Pathway map is at **Appendix F**.

3.2. Improving pathways

A person's rate of progress on their recovery, transition planning and community living may be impacted by:

- access to expert care, support and advice (see 3.2.1 and 3.2.2 below), and the timing of that access
- complexity of need (Section 3.2.3)
- patient readiness for rehabilitation, and for transition planning (Section 4.3)
- engagement of family and natural support networks (Section 4.4).

A dominant issue that key informants highlighted as exacerbating these impacts and preventing or delaying their resolution, is the current funding environment. The shift to national individualised disability funding in recent years has created substantial gaps and inequities in funding for people with SCI in NSW who are transitioning to, and living in, the community. These funding gaps and inequities are discussed below (see especially section 3.2.2).

Stakeholders at the Expert Dialogue stakeholder forum put forward potential solutions to improve the capacity of services, schemes and systems to meet the care and support needs of individuals with SCI in NSW. These solutions are outlined in the Action Plan from the forum at **Appendix D**.

The Action Plan includes a call to progress the National Injury Insurance Scheme (NIIS) in NSW in order to establish SCI funding through a no-fault insurance scheme for catastrophic motor vehicle, workplace, medical and general accidents. Roll-out of the NIIS alongside the NDIS – in line with the *Bilateral Agreement between the Commonwealth of Australia and the State of New South Wales on the National Disability Insurance Scheme* – may eliminate funding inequities for people with traumatic SCI, whose funding currently varies with age and circumstance of injury.

A further recommendation in the Action Plan at **Appendix D** is to advocate on the issue of age-related discrimination for funding people who are injured at 65 years or older. It is crucial to pursue this action in tandem with calls to progress the NIIS, in order to ensure that funding gaps for people who are diagnosed with a non-traumatic injury at 65 years or older are also addressed.

Recommendation

Insight Consulting recommends that spinal cord injury care and support services in NSW:

2. Implement the Action Plan from the Expert Dialogue stakeholder forum (at **Appendix D**).

3.2.1. Expert care, support and advice

Acute care and rehabilitation teams that specialise in SCI are more likely to have a working knowledge of how to get the best possible outcome for a person with SCI within person-centred processes. Non-specialist hospitals typically have a low volume of SCI patients^v, and less opportunity to develop their working knowledge of SCI transition pathways and community living.

Patients interviewed for this project spoke about the importance of receiving specialist care and advice, whether within the spinal unit, or from a specialist on their care team while they were in another hospital or another unit. This was important for all aspects of care ranging from surgical dressers, to clinical consultants, to surgeons. Expert care helped patients to feel confident about their health pathway and to understand their likely transition pathway, based on their type of injury

and rate of rehabilitation. Some patients also highlighted the negative impact on their health and wellbeing when not able to access specialist care.

Peers were raised by patients and other key informants as experts that help people with SCI to build their knowledge and understanding of potential community living pathways. Access to peer support was highly valued by those patients who had the opportunity to meet people with SCI through a peer support program. Unlike most other care and support providers, peer support providers can potentially be involved with a person with SCI at every stage of their transition journey, including community living.

The value of conversations with other patients was also raised by the patients interviewed. These conversations helped patients to improve their understanding of their injury, rehabilitation and the systems they were working in. One patient described the relief of realising that the barriers they experienced on a daily basis – whether physical barriers to meeting rehabilitation goals, or systemic barriers related to transition – were not unique. This reduced self-blame and increased motivation for change.

The most important source of expertise that a person can have on their transition pathway is their own expert knowledge. Discussion and recommendations related to improving people's capacity for self-management is at Section 4 below.

3.2.2. The need for expert system navigation

Recognition of the value of specialist SCI knowledge and expertise for people with SCI transitioning to community living, is an acknowledgement of the negative impact of inexpert planning, care and support.

This is a crucial understanding when considering:

- newly injured people are still building their understanding and lived experience of their injury, and are not yet expert in key elements of transition planning such as their ongoing housing/ modification, care, support and equipment needs
- people with new care and support needs related to a readmission to acute care, while holding more expertise and lived experience, are still building their understanding and lived experience of those new needs
- the NDIS as a new scheme does not yet deliver consistent assessment and approval processes, and many NDIS staff are not yet expert in SCI care and support needs
- My Aged Care is focused on people's age-related needs and is not resourced to deliver specialist SCI care and support
- as individualised funding models diversify people's community living pathways, people with SCI and those supporting their transition to community living (whether newly injured or readmitted) report increasing difficulty with knowing what's available and how to refer people to quality and specialist knowledge in community settings – in effect 'diluting' existing expertise in SCI transition pathways.

The different service, funding and insurance schemes that people with SCI fall under cause additional complexities in the navigation of these pathways:

- different – at times, vastly different – entitlements depending on which scheme a person might fall under, with My Aged Care eligibility attracting a non-individualised funding amount not sufficient for purchasing the care, support, equipment and home modifications necessary for living in the community with SCI
- service gaps and unreasonable waiting lists in state and federal disability housing
- lack of coordination and collaboration between different schemes and systems, preventing delivery of integrated, holistic care.

During transitions from acute care, whether for the first time or with new care and support needs, the burden of such administrative complexity is ill-timed. People are highly vulnerable as they manage their own care and support needs and attempt to plan for those needs in community living. Those whose needs have changed significantly may need to make major housing, employment and financial decisions.

Key informants and stakeholders sought to lift the burden of navigating system complexities from people with SCI transitioning to community living from acute and sub-acute care by recommending the establishment of an interagency reference group to drive joint approaches to person-centred care. They also recommended establishment of a high-level function that works across agencies to problem-solve, in acknowledgement of the ‘systems’ expertise and influence required in order to achieve positive and fair outcomes. This function would require authorisation to act and share information across agency boundaries in order to support person-centred care. Its reach would extend from acute care to government services accessed by people living with spinal cord injury, and would include people at every stage of their SCI pathway including those readmitted for secondary health conditions. Key informants and stakeholders saw value in mapping this recommended function against existing positions responsible for advocacy and interagency coordination, in order to avoid duplication and ensure that the recommended ‘system wrangler’ function is designed as a high-level complement to existing roles and responsibilities.

Key informants and stakeholders saw additional value in developing a cross-agency early specialist support coordination role for people with SCI, that would improve people’s access to specialist SCI knowledge and support at the earliest possible stage of their transition. This role would differ from existing NDIS Support Coordinators in its SCI expertise and eligibility to all people with SCI, not only those with additional complex needs.

Solutions recommended to improve the interface of the different systems and frameworks that people with SCI move through after their injury, included:

- improved connections between My Aged Care and NSW Health and Local Health Districts, including escalation pathways and data sharing
- development of a housing pathways study to establish a shared understanding of housing stock, supply and demand for people with SCI.

These recommended solutions are detailed in the Action Plan at **Appendix D**.

3.2.3. Social determinants of health

Social determinants of health are factors related to people’s everyday living and working conditions that influence how likely they are to achieve and maintain acceptable standards of health and wellbeing^{vi}. They contribute to inequities in health outcomes in Australia.

For example, people with SCI who live in rural and remote parts of Australia have less specialist outpatient care options and face access barriers related to below-average accessible transport options and above-average travel times and costs. These barriers to specialist health and disability care and support can impact on people's long-term management of secondary health conditions associated with SCI and increase the risk of poor health and wellbeing outcomes.

Rural and remote location is a clear example because it is a well-recognised determinant of health for people with SCI in NSW^{vii}. Other key vulnerable cohorts recognised by key informants, literature and previous research and consultation, include:

- People with comorbidities. Acquired Brain Injury (ABI), depression and anxiety were the most frequently mentioned comorbid health conditions that were observed to impact on people's pathways and outcomes. Comorbidities may have pre-existed people's injuries or may be associated with their injury or disability experience.
- Socio-economically disadvantaged people with SCI. Those with unstable housing, employment or social capital at the time of their injury or as a result of their injury are at higher risk of experiencing significant delays in access to housing and other forms of care and support.

A full list of cohorts within the NSW SCI population who are at risk of poor outcomes, as identified by key informants during interviews and focus groups, is at **Appendix D**. The diversity of groups listed is cause for reflection on the need to deliver flexible person-centred care on a strong network of essential primary and specialist services.

To address inequities in SCI care and support, key informants and stakeholders sought to establish a better understanding of the problems through research and data collection.

They sought progression of the National Injury Insurance Scheme (NIIS) in NSW to reduce current inequities in SCI support (caused by differences in funding levels and care and support entitlements between schemes).

The need to advocate to resolve age-related discrimination inherent in federal government funding support for people with SCI who are injured after 65 years of age, was put forward by a number of stakeholders who were witness to the negative community living outcomes for people only eligible for My Aged Care, whose age at time of injury made them ineligible for NDIS support.

These recommended next steps are outlined in the Action Plan at **Appendix D**.

4. Building self-management across care and support systems

'Self-management' in this report refers to a person's ability and opportunity to take the lead on planning and managing their care and support needs.

The main systems and schemes through which people with SCI in NSW access funding, care and support are adopting principles to empower people to direct the support they receive.

- The NDIS has established a framework of individualised funding with options for self-management. This is based on increasing international evidence that recognising people's expertise in their own needs and circumstances, through person-centred care and self-directed funding, leads to better long-term outcomes^{viii}.

- Similarly, icare delivers individualised funding in line with customer design principles, such as collaboration and simplification, aimed at empowering clients to partner in their care planning and management. Self-management agreements are made with eligible Lifetime Care participants.
- NSW Health, through its Clinical Excellence Commission, is working to improve person-centred care by focusing on the health literacy of patients and their families^x, and implementing a ‘patient- and family-activated escalation’ model that empowers patients and their families to initiate action from their care team if their health is deteriorating^x.
- An example of investment in health literacy is the recent NSW Health publication of a resource for people with SCI to help them navigate the NDIS, titled, *Your guide to spinal cord injury and the NDIS*^{xi}
- My Aged Care, while inadequate for people with SCI, aims to improve opportunities for people in the general population to maintain independent living arrangements as they age.

These directions towards self-managed care and support were supported by key informants and stakeholders, and were seen as central to achievement of person-centred care in health and disability settings. In their experience, self-management strategies (observed, experienced or delivered) included:

- collaborative transition planning
- encouraging people to take responsibility for their own recovery and transition by building their confidence, physical and mental health and well-being, and sense of independence
- ensuring that people have the information they need to make decisions about their care and support
- actively stepping down the level of care and support provided to people as their rehabilitation progresses (being sensitive and flexible in response to individual circumstances)
- staggering transitions to align with individual readiness and allow people to gradually increase their independent living knowledge and skills.

The degree of optimal self-management for any individual with SCI will be different for everyone. Self-management and individualised funding must be seen as core elements of person-centred care, not as stand-alone examples of person-centred care.

The psychosocial impact of SCI as a life-changing disability may be viewed as a traumatic experience that impacts people’s mental health and wellbeing to varying degrees. Poor transitional experiences (such as extensive delays or inadequate funding or support) can also have a negative impact on people’s health and wellbeing. Early and ongoing access to psychosocial support can improve people’s capacity to engage in their transition planning and to manage their care in the long term. Vulnerable cohorts discussed by key informants tended to be those with minimal capacity to manage their own care, and people with depression and anxiety were often specifically raised as a group who were highly vulnerable in the transition process.

Strategies for building capacity for self-management at each stage of the transition pathway are discussed in Sections 4.2 to 4.4 below. Overall, there is a need to:

- improve access to specialist psychosocial resources for people with SCI and for their families
- integrate services and service systems, so that people self-managing their care can focus on their own needs and goals rather than on navigating systems (see Section 3.1.2 above).

Recommendations

Insight Consulting recommends that spinal cord injury care and support services in NSW:

3. Adopt the recommendations of the *Guide for Health Professionals on the Psychosocial Care of Adults with Spinal Cord Injuries*^{xii} or, at a minimum, the General Principles for the Psychosocial Care of People with SCI (Recommendation 6.1) for people with SCI and for their families.

4.1. Building life outcomes through self-management

Successful provision of lifetime care and support to people with SCI in NSW communities is best measured by integrated, longitudinal datasets on the NSW SCI population.

Recommendation

Insight Consulting recommends that spinal cord injury care and support services in NSW:

4. Explore development of a person-centred, longitudinal evaluation framework for improving care and support to people with spinal cord injury in NSW, focussed on people's achievement of lifetime goals and quality of life.

4.2. Self-management during rehabilitation

Building capacity for self-management is a core function of rehabilitation. As the research evidence behind holistic rehabilitation grows, people with SCI in NSW, other Australian jurisdictions and overseas are investing in increasingly diverse specialist SCI recovery and rehabilitation programs. Examples in NSW include:

- leisure therapy, which builds people's options for engagement in response to changed use of time
- recreational therapy, which builds people's physical and mental abilities
- vocational consultancy, which helps people to return to work through vocation-specific rehabilitation.

These therapies, together with other holistic rehabilitation strategies, can contribute to people's confidence, sense of post-injury identity, quality of life and links with peers and community – gains which in turn build people's capacity to self-manage their care and support and community living.

Maintaining and improving holistic approaches to rehabilitation is core to improving people's self-management capacity.

Tailoring healthcare settings as closely as possible to the needs of the people using them can also improve their self-management capacity. Meals in acute and sub-acute health settings were the clearest example of this during key informant interviews with patients. Patients repeatedly raised meals as inflexible to personal preferences and incompatible with their bowel care requirements. People felt disempowered in their bowel management rehabilitation and also in their general

quality of life when they were unable to exercise control over their meals and mealtimes and unable to ensure that the food they ate was tailored to their health and disability requirements.

Recommendation

Insight Consulting recommends that spinal cord injury care and support services in NSW:

5. Maintain and improve holistic approaches to rehabilitation by committing long-term funds to innovative rehabilitation programs that have been successfully piloted in NSW or other Australian jurisdictions, such as leisure and recreational therapy, and vocational consulting.
6. Implement SCI-specific meal plans in specialist SCI units and promote advice on SCI dietary needs to non-specialist hospitals and units.

4.3. Transitions from healthcare settings to community

Transitions from acute and sub-acute care to community living are difficult for people with SCI to manage because the pace of their transition is influenced not only by their own readiness but by systemic factors such as waiting lists, delays in funding and other approvals, and hospital pressure to free up beds.

Patient readiness is a complex, personal experience that appears by patient interviews to be heavily motivated by physical recovery and achievement of mobility goals. Readiness from a planning perspective, namely confidence and progress in the major life changes and decisions triggered by disability such as SCI, was daunting for the newly injured patients interviewed and subject to the systemic factors listed above.

Key informants and stakeholders sought to stagger people's transitions, in acknowledgement of both the vulnerability and rapid change experienced by people in this period, and the often-sensitive timing of the complex range of processes and systems underway to achieve their discharge. Recommended solutions were:

- improving processes for NDIS approval of flexible transitional 'reasonable and necessary' supports, to work with mainstream supports to help ensure people's return to community living will not fail
- flexible accommodation and funding support options, which might include step-up and step-down models, bridging accommodation, co-living, and models that allow proximity to family in final stages of rehabilitation and transition planning, such as accessible motel accommodation in the local community.

Housing applications, whether for Specialist Disability Accommodation or public or social housing, and home modifications for private and especially rental dwellings are the most difficult elements of a person's transition to achieve within an appropriate time frame, and can cause significant discharge delays. Transitional housing can help people to discharge from rehabilitation when ready without waiting for resolution of delayed housing or home modification approvals.

Additionally, transitional accommodation options help people with SCI to gradually build the lived experience they require to make appropriate decisions about their long-term care and support needs. This helps them to engage more confidently in planning for their final transition and setting goals for community living. Some transitional accommodation models, such as funding accessible motel accommodation in people's local community, prioritise proximity to the person's support

network and community. Other models, such as the transitional housing units trialled at Princess Alexandra Hospital in Brisbane, prioritise rehabilitation in a residential setting that allows people to build lived experience in a supported environment.

Key informants and stakeholders highlighted the need to complement improved transition planning processes and flexible housing and funding support options with more transitional housing stock.

Stakeholders additionally saw value in improving people's access to information on available housing by expanding models such as Housing Hub, or the icare 'Home Hunter' model.

Further details are in the Action Plan from the Expert Dialogue stakeholder forum at **Appendix D**.

Key informants, including patients, sought innovative ways to provide information during transition planning, as people with SCI are quickly overwhelmed with the amount of new information they are required to learn about their injury, their transition planning needs, and the systems they will rely on. Practitioners are seeking to deliver information in ways that people with SCI can remember and refer back to as needed.

Recommendation

Insight Consulting recommends that spinal cord injury care and support services in NSW:

7. Increase transitional housing options that enable flexible steps-down for sub-acute rehabilitation for people with spinal cord injury in NSW.

4.4. Self-management in community living

In community settings, the range of services used by people with Spinal Cord Injury diversifies to include the full remit of services and industries on which any person may rely for their health, wellbeing and community participation (for example education, mental health services, sport and recreation facilities or neighbourhood centres). Considerations in this report for improving care and support to people with SCI following their transition from rehabilitation settings include these services to the extent that they:

- may rely on the expertise and knowledge of SCI specialists
- should be integrated with health and disability care and support in order to most effectively deliver their service to people with SCI.

Actions recommended by stakeholders to improve integration of mainstream services with specialist SCI services are in the Action Plan from the Expert Dialogue stakeholder forum at **Appendix D**.

Gaps in the availability of follow-up support for people with SCI in most parts of NSW are highlighted in the *Diagnostic Report* and also raised by key informants. People in regional and rural areas are at particular risk of experiencing barriers to expert follow-up support. Increased access to transitional accommodation and other actions to stagger people's transitions to community living may go some of the way to addressing these gaps in follow-up support.

Family and peer support providers appear to be powerful providers of information because they can be consistently present before and after transition. Peers have expertise and lived experience that help them to contextualise important information for newly injured people with SCI.

Family members and peer support providers can also be excellent advocates for people with SCI when supported and skilled up in that role.

Recommendation

Insight Consulting recommends that spinal cord injury care and support services in NSW:

8. Research effective strategies for providing information and resources to people with SCI and their families/networks during and after transition to community living to help them to manage their care.
9. Expand peer support programs to reach people with SCI in specialist and non-specialist healthcare settings during and after their transition to community living (whether newly injured or with new care and support needs related to their readmission).

5. Conclusion

Transitions from acute and sub-acute hospital settings to community living for people with spinal cord injury in NSW are complex because they occur during a period of vulnerability for the person on the transition pathway, and because they require the coordination of a range of services and funding schemes.

The recommendations in this report seek to improve processes related to transition pathways, build people's capacity to manage their transitions and community living, and stagger transitions using transitional accommodation and flexible planning and approval processes.

A key concern for stakeholders was that well-designed systems and processes around person-centred care and transitions to community living, are at risk of failing to make a genuine difference for people with SCI without state and federal investment in the basic needs of people with serious permanent injury.

ⁱ NSW Agency for Clinical Innovation 2014, *Guide for Health Professionals on the Psychosocial Care of Adults with Spinal Cord Injuries*, Chatswood.

ⁱⁱ NSW Agency for Clinical Innovation 2015, *Patient Experience and Consumer Engagement: A Framework for Action – Understand, Act, Empower*, Chatswood, p.1.

ⁱⁱⁱ Agency for Clinical Innovation 2019, *Spinal cord injury care and support: current situation and options for improvement*, Final Draft, not published, p.8.

^{iv} Productivity Commission 2011, *Disability Care and Support*, Report No.54, Canberra, p.2.

^v Agency for Clinical Innovation 2019, *Spinal cord injury care and support: current situation and options for improvement*, Final Draft, not published, p.8.

^{vi} Australian Institute of Health and Welfare (AIHW) 2018, "Social Determinants" web page, *Reports & Data: Behaviours and risk factors*, AIHW website, viewed 03.06.2019, <https://www.aihw.gov.au/reports-data/behaviours-risk-factors/social-determinants/overview>.

^{vii} See for example, Agency for Clinical Innovation (ACI) 2017, "4.1: Interview themes" in, *Spinal Cord Injury Model of Care: Diagnostic Report – State Spinal Cord Injury Service (SSCIS)*, Chatswood NSW, pp.33-4.

^{viii} Productivity Commission 2011, *Disability Care and Support*, Report No.54, Canberra, p.951, Appendix E.

^{ix} Clinical Excellence Commission (CEC) 2019, *NSW Health Literacy Framework, 2019-2024*, viewed 01.07.2019, http://www.cec.health.nsw.gov.au/_data/assets/pdf_file/0008/487169/NSW-Health-Literacy-Framework-2019-2024.pdf.

^x Clinical Excellence Commission (CEC) 2017, *R.E.A.C.H Toolkit*, viewed 01.07.2019, http://www.cec.health.nsw.gov.au/_data/assets/pdf_file/0007/362608/REACH-Toolkit-Updated-version-May-2017.pdf

^{xi} NSW Health 2019, *Your guide to spinal cord injury and the NDIS*, viewed 06.06.2019, <https://www.health.nsw.gov.au/disability/ndis/Pages/spinal-cord-injury-booklet.aspx>.

^{xii} NSW Agency for Clinical Innovation 2014, *Guide for Health Professionals on the Psychosocial Care of Adults with Spinal Cord Injuries*, Chatswood.

Appendix A: Rapid Literature Review

This is a rapid review of research and policy literature about optimal delivery of services for people with Spinal Cord Injury (SCI) transitioning from hospital to community-based care. It was the first stage of a stakeholder engagement and consultation process undertaken by Insight Consulting Australia on behalf of the Agency for Clinical Innovation (ACI) to inform options for improving SCI transitions and community-based care and support in NSW. It informed the following stages in the stakeholder consultation process, including key informant interviews, a briefing paper and a stakeholder forum.

Successful community transitions for people with Spinal Cord Injury

Community living for people with Spinal Cord Injury (SCI) is the life they live outside of the hospital system. People with SCI achieve varying degrees of functional independence depending on factors such as their type of injury, personal goals, and pre-injury choices and experiences.

Commonly used measures of successful transition to independent living following SCI are:

- Physical health
 - pain management
 - secondary health complications
 - rates of avoidable hospital re-entry
- Psychological wellbeing
 - rates of mental illness, disorders
- Community participation
 - quality of life, or life satisfaction
 - individual goals
 - sense of autonomy.

These measures are complex and inter-related, as are the mediating factors that facilitate or impede positive outcomes.

While there is a significant and growing evidence base on the service needs of people with SCI, it is arguable that local spinal cord injury research to date has rarely delivered clear insights into what it is like to live in Australian communities with SCI, and what people's goals are during and after their transition – or transitions – from hospital. This is due to factors such as:

- difficulty in recruiting people with SCI from some communities (eg rural, Aboriginal and/or outside of peer support networks) for research and evaluation purposes, affecting the applicability of research findings to more isolated populations of people with SCI
- limited research into long-term outcomes for people with SCI beyond medical outcomes.

Transition experiences

This section addresses inpatient rehabilitation, outpatient rehabilitation and follow-up services as they relate to transitions from hospital to community for people with SCI.

Experiences of 'going home' from hospital

Whalley Hammel (1) highlights key dimensions of inpatient rehabilitation services identified by people with SCI, primarily relating to quality of staff and outward-focused person-centred program design:

- the review of eight qualitative research papers on patients' experiences of inpatient rehabilitation programs found that people with SCI most frequently raised the impact of quality staff who demonstrated empathy and delivered individualised care and shared decision-making
- the review also identified dimensions that grounded rehabilitation in patient's individual goals and lifelong needs (increasingly referred to in contemporary literature as a 'life-course' or 'whole-of-life' approach), namely: individualised content; meeting needs of the 'real world'; incorporating a vision of future life possibilities; incorporating the expertise and partnership of peers; reconnecting the patient's past and future; and the need to address patients' discomfort with the institutional context of most inpatient rehabilitation programs.

Transition services

Person-centred, life-course approach

A whole-of-life approach to SCI rehabilitation and community care is consistent with the intent of the National Disability Insurance Scheme, and with the *WHO Global Disability Action Plan 2014-2021* (2).

A systematic literature review on SCI follow-up programs (3) found that, of the 16 key programs they reviewed, less than half included promotion of wellbeing and community integration as explicit goals. The programs were primarily medically driven and nearly half were delivered by nurses.

The families and natural support networks of people with SCI are consistently raised as integral to their adjustment and independent living. For example:

- Two-thirds of people surveyed by UNSW for SCIA (4, p.28) stated that the most important resource they had for achieving their goals was the support of their family and friends. At the same time many survey respondents expressed a desire to protect personal relationships from being consumed by the 'carer' role.
- Evaluation of the CHOICES transitional accommodation program in NSW by Dorsett (5) found that a key element of the service's success was the space that it provided for people with SCI and their families away from medical institutional settings. This was reported by participants to be crucial to their transition back to the community.

Multi-disciplinary and co-ordinated care

Most outpatient programs delivered by Australian states and territories are delivered by multi-disciplinary teams that include nurses, occupational therapists, physiotherapists and sometimes social workers, and that deliver outreach support for at least the period immediately after transition from inpatient rehabilitation. Multidisciplinary outreach support is generally considered effective for people with SCI because it improves communication and knowledge between disciplines (6).

People with SCI frequently request improved coordination of medical services (4), especially between inpatient and outpatient health services (for example between specialist units and General Practitioners) in order to:

- improve local health practitioners' access to information and expertise about spinal cord injuries
- improve treatment of secondary health complications or unrelated health issues impacted by a person's SCI

- improve timeliness of service delivery and break down bureaucratic inter-agency processes that can result in experiences of delays (particularly related to leaving inpatient rehabilitation), service gaps or duplications, and sub-optimal care for people with SCI.

Living with a spinal cord injury

This section addresses community-based services and optimal living with SCI.

Social exclusion

Multi-faceted social exclusion is a key barrier to community services and activities for people with SCI. A person's experience of one risk factor for social exclusion can heighten their exposure to others. This is true of disability in Australia:

- 7.7% of adults with disability involving severe core activity limitations reported experiencing violence in the last 12 months at the 2016 Australian Census (7), compared with 5.4% of the general population (survey excluded those not living in a family home and those whose surveys were completed by proxy)
- 19% of adults with severe core activity limitations are reported by the Australian Council of Social Service and University of New South Wales (8) to receive an income below the 50% of median income poverty line, and 34% are below the 60% of median income poverty line (not taking account of higher medical and living costs), while rates for adults with no disability are 11% and 16.5% respectively
- Geography is recognised by the Australian Institute of Health and Welfare as a social determinant of health in Australia, as people in rural and remote locations have less access to health professionals including specialists and General Practitioners, and report less information sharing and health care coordination than people in metropolitan locations (9).

Quality of life

A Canadian survey by Noreau et al (10) of 1,549 people with SCI in 2011/12 found that life satisfaction was lowest in those domains most disrupted by limitations associated with SCI (such as physical health and sexual function).

Analysis by Cijssouw et al – in ACI (11, p.30-31) – of the confidence of people with SCI in managing their own health and disability related needs (Disability-Management Self-Efficacy or DMSE) found that increased DMSE was associated with improved community participation and life satisfaction after controlling for demographic and lesion differences.

Together these research findings suggest that life satisfaction for people with SCI may be impacted by the extent to which their health and disability management is perceived to be in their locus of control – and therefore that consultative, person-centred practice in healthcare can positively impact their quality of life.

Health

Pain impact and intensity experienced by people with SCI affects levels of community re-integration, according to a study of 66 people with SCI transitioning to the community (12).

Secondary health conditions were identified in a large-scale Canadian survey of people with SCI as a critical barrier to community participation and a priority unmet service provision need for

people with SCI in Canada. These conditions impacted variously in mobility, independence, and physical and mental wellbeing.

Management of physical health requires a functional health system that provides the equipment, aids and health services and knowledge fundamental to managing SCI. Access to these health necessities is raised in various Australian studies as a barrier to achieving optimal health in the community (4, p.37-8, 13).

Rates of preventable hospital admissions for people with SCI, as well as representing avoidable costs, can be seen as a measure of the performance of local health support, as lower rates suggest more effective prevention and early intervention management of secondary health complications. The two main spinal units in NSW report that readmissions over the last seven years represent 42% of bed days in one unit and 58% of bed days in the other (14). A Victorian study (15) found that, of 356 SCI cases, 40% were readmitted to hospital, and 27% were admitted to the emergency department, for secondary conditions within two years of injury. The average cost per readmission was \$15,172 ± \$20,957 per readmission, and \$670 ± \$198 per visit to the emergency department.

Mental health and wellbeing

People with SCI experience higher rates of depression than the general population.

Two large longitudinal studies of people with traumatic SCI in the US, Hoffman et al (16) and Saunders et al (17) found that depression was related to other health behaviours and circumstances, and their experiences of pain. This is consistent with one finding of a smaller Australian study by Craig et al (18) that depression in people with SCI was significant associated with how they experienced pain (specifically, pain catastrophizing) and fatigue. All three of these studies suggest benefit in practitioner sensitivity to a higher risk of depression in people with SCI who are struggling with pain.

Community care including peer support

Some key barriers to care are experienced by people with SCI across the spectrum of health services. Service provision barriers relating to life-course-focused rehabilitation and care coordination (see 'Transition services' above) and social exclusion (see above) are applicable to community care access.

People with SCI also frequently report physical access barriers, including travel and building accessibility, and quality-of-care issues, in their local mainstream health and social services (4, p.47, 10). In mainstream health services, quality of care issues are primarily related to lack of specialist knowledge and lack of access to or coordination with SCI specialists.

Australian states and territories have innovative service models, for example to address the wicked problem of delivering quality services across the vast geographical distances of our regional areas. However, these initiatives remain isolated and many individuals with SCI continue to receive little or no local specialist care. Some examples of innovation in SCI service delivery are:

- rural coordinators in the NSW Rural Spinal Cord Injury Service that coordinate multidisciplinary care and build capacity in local health services through consultancy and health promotion.

- telehealth has recently commenced as part of Western Australia's new Spinal Outreach Service (19), made possible by statewide investment in telehealth technology to service a range of general and specialist health areas.

Overall there is limited research evidence on the service needs and experiences of people with SCI in Australia's local communities. Achievement of person-centred care in NSW is key to addressing this gap in the evidence base as it will help build local health services' understanding of what services people with SCI need and how they want to use them.

The recent NSW report by UNSW for SCIA (4) highlights accessible housing, financial services and support, and support services for family and carers as some key service gaps.

Community participation

Community participation is generally understood to mean a person's engagement in normative activities, responsibilities and vocations within the community or communities they identify with.

Noreau et al (10) in their extensive survey of Canadian people with SCI highlight the necessity that people with SCI assess their own community participation, as not all measures are applicable depending on individual choice, circumstance and disability. For example, a higher than expected rate of respondents in their survey expressed no desire to achieve paid or unpaid employment.

Family responsibility and activities related to home were nominated by a high rate of survey respondents in this study as activities they wanted to participate more in. In-home mobility; accessing local services; maintenance of physical health; and participation in leisure, recreation and travel were also frequently nominated as activities they wanted to increase participation in. Survey respondents were least satisfied with their physical health and sex life, and were most satisfied with their family life and partner relationship.

People with SCI identified in the UNSW study (4) that their family and peer support networks are crucial to their post-hospital achievements such as study, work, travel and sport.

A Queensland study by Carr et al (20) found that people with SCI were more likely to participate in their community if: they were employed in paid or unpaid work; had an incomplete injury; longer time elapsed since injury; higher functional independence; and less secondary impairments. These enabling factors appear to be inter-related – for example, people with incomplete spinal cord injuries typically experience higher levels of functional independence, and are more likely to achieve employment and community participation.

Key to enabling community participation for people with SCI is achieving community awareness of, and investment in, the basic access rights of people with disabilities and secondary health issues associated with those disabilities. Some researchers posit disablement as an environmental impact that increases or decreases depending on the kind of environment a person with disability is interacting with (21).

Conclusion

Contemporary literature on transitional and community care for people with SCI prioritises:

- a person's life course, not just their time as a patient
- partnership with people with SCI and their family in service planning and delivery

- over-all wellbeing as a cornerstone of physical health
- less institutional transitional and rehabilitative care in order to strengthen links with community based care and lifetime experiences of living with SCI.

This rapid literature review informed the development of interview questions and the Expert Stakeholder Forum.

References

1. Whalley Hammell K. Experience of rehabilitation following spinal cord injury: a meta-synthesis of qualitative findings. *Spinal Cord*. 2007; 45(4):260-274.
2. World Health Organisation. *WHO Global Disability Action Plan 2014-2021*. Geneva, Switzerland: WHO; 2015.
3. Bloemen-Vrencken J, de Witte LP, Post M. Follow-up care for persons with spinal cord injury living in the community: a systematic review of interventions and their evaluation. *Spinal Cord*. 2005; 43(8):462-475.
4. Bates S, Kayess R & Fisher KR. *Research into maximising life choices of people with a spinal cord injury* (SPRC Report 01/2013). Sydney: Social Policy Research Centre, University of NSW, for Spinal Cord Injuries Australia; 2013.
5. Dorsett, P. *Evaluation of the CHOICES Program, Spinal Cord Injuries Australia, Final Report*. QLD: Griffith University; 2013.
6. Queensland Spinal Cord Injuries Service. *An Enhanced Service Model For people With Spinal Cord Injury in Western Australia, Including Review of State Quadriplegic Centre*. WA: QSCIS; 2015.
7. Australian Bureau of Statistics. Experiences of violence and personal safety of people with disability 2016. *Personal Safety Survey*. Canberra: ABS; 2018.
http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4431.0.55.003Main%20Feature_s22016?opendocument&tabname=Summary&prodno=4431.0.55.003&issue=2016&num=&view=
8. Davidson P, Saunders P, Bradbury B & Wong M. *Poverty in Australia 2018*. Sydney: ACOSS and UNSW; 2008.
9. Australian Institute of Health and Welfare. *Survey of Health Care: selected findings for rural and remote Australians*. Canberra: AIHW; 2018, accessed 01.02.2019
<https://www.aihw.gov.au/reports/rural-remote-australians/survey-health-care-selected-findings-rural-remote/contents/summary>
10. Noreau L, Noonan VK, Cobb J, et al. Spinal Cord Injury Community Survey: A National, Comprehensive Study to Portray the Lives of Canadians with Spinal Cord Injury. *Topics in Spinal Cord Injury Rehabilitation/Fall*. 2014; 20(4):249-264.
11. Cijssouw et al in ACI.
12. Donnelly C, Eng JJ. Pain following spinal cord injury: the impact on community integration. *Spinal Cord*. 2005;43(5):278-282.
13. Barclay L, McDonald R, Lentin P, et al. Facilitators and barriers to social and community participation following spinal cord injury. *Occupational Therapy Australia*. 2015; 63:19-28.
14. Agency for Clinical Innovation. *Spinal Cord Injury Model of Care Diagnostic Report*. Sydney: State Spinal Cord Injury Service; 2016.
15. Gabbe BJ & Nunn A. Profile and costs of secondary conditions resulting in emergency department presentations and readmission to hospital following traumatic spinal cord injury. *Injury*. 2016;47(8):1847-55.

16. Hoffman JM, Bombardier CH, Graves DE. A Longitudinal Study of Depression From 1 to 5 Years After Spinal Cord Injury. *Arch Phys Med Rehabil.* 2011; 92(3):411-418.
17. Saunders LL, Krause JS & Focht KL. A longitudinal study of depression in survivors of spinal cord injury. *Spinal Cord.* 2012; 50(1):72-77.
18. Craig A, Guest R, Tran Y, et al. Depressive mood in adults with spinal cord injury as they transition from an inpatient to a community setting: secondary analyses from a clinical trial. *Spinal Cord.* 2017; 55(10):926-934.
19. Government of Western Australia 2018, "New service to support WA people with a spinal cord injury", media release for the Minister for Health, accessed 01.07.2019, <https://www.mediastatements.wa.gov.au/Pages/McGowan/2018/09/New-service-to-support-WA-people-with-a-spinal-cord-injury.aspx>
20. Carr JJ, Kendall MB, Amsters DI, et al Community participation for individuals with spinal cord injury living in Queensland, Australia. *Spinal Cord.* 2017;55(2):192-197.
21. Bricknell S. *Disability: the use of aids and the role of the environment.* Disability Series. Canberra: Australian Institute of Health and Welfare; 2003.

Appendix B: List of Key Informant Interviewees

Organisation	Interview Description	Staff Number
icare	Focus group	2
Royal North Shore Hospital Spinal Unit	Interviews	2
	Patient Interviews	2
Northern Sydney Local Health District	Interviews	2
Prince of Wales Hospital Spinal Unit	Interviews	2
	Patient Interviews	1
Royal Rehab	Interviews	2
	Focus Group	5
	Patient Interviews	2
ParaQuad	Interviews	2
Spinal Cord Injuries Australia	Focus Group	3
EnableNSW	Focus Group	3
Summer Foundation	Interview	1
Young People In Nursing Homes National	Interview	1
FACS Housing/ Disability Policy	Focus Group	2
FACS Housing SWS District	Focus Group	6
Consumer	Interview	1
NSW Ministry of Health	Focus Group	2

Appendix C: Summary analysis of patient interviews

Five interviews were conducted by Insight Consulting with patients of specialist Spinal Cord Injury acute care and rehabilitation units in Sydney^{xiii} (“specialist SCI units”). Patients were asked about their experiences relevant to Insight’s work for the ACI on improving transitions to community living and person-centred care for people with SCI:

- pathways through NSW sub-acute SCI rehabilitation
- readiness to transition to community living
- experiences of collaborative care and shared decision-making
- experiences of holistic care and support.

This analysis of patient interviews identifies strengths and weaknesses of the current rehabilitation pathway for people with SCI, in preparing people for transitions to community living and delivering person-centred care. Definitions of these terms are drawn from the ACI *Diagnostic Report* for a spinal cord injury model of care:

- a typical pathway through specialist SCI units in NSW is described as being: (i) hospital; (ii) rehabilitation; and (iii) transition to community living^{xiv}
- a “truly person-centred approach to care” is described as being: (i) collaborative interaction between health providers and clients; (ii) client-driven goal setting; (iii) a focus on people’s strengths, life experiences and preferences; (iv) flexible, individualised therapy and services; and (v) empowerment of clients to manage their care^{xv}.

Findings from these patient interviews are not representative of the experiences of people with Spinal Cord Injury in NSW specialist SCI units, due to the small number of interviews. Alongside interviews with other key informants such as health and disability service providers, professionals, experts and funding bodies, the patient interviews are a crucial contribution to the patient journey ‘snapshot’ of SCI care and support in NSW in this project.

Patient pathway

From the perspective of the five patients interviewed for this project, key milestones on their pathway towards transition to community living were:

- access to specialists and specialist care
- focus on recovery
- transition planning and readiness.

This analysis uses the term ‘milestones’ to refer to experiences that: were ‘next steps’, building their pathway towards transition to community living; were clear in patients’ minds as important to their outcomes; and were common across patients interviewed.

Access to spinal cord injury specialists and specialist care was spoken of by patients as a point during their journey through the health system where they gained increased confidence in their care and recovery.

All patients interviewed were highly motivated to recover as much functionality and mobility as possible. Most patients spoke of a shift in their **focus from injury or illness to recovery**. For one

patient, this was on commencement of sub-acute rehabilitation. For another it appeared to be earlier, on receiving diagnosis of a non-traumatic SCI and having access to specialist SCI care.

Transition Planning, including: administrative planning (research and enquiry, applications, assessments and reports); making key decisions about major life areas such as housing and employment; and psychological readiness; were closely linked with patients' focus on recovery. All newly injured patients prioritised the achievement of as much physical independence as possible prior to discharge, in order to reduce their dependence on family and personal care, and disruption to housing, employment and long-term life goals.

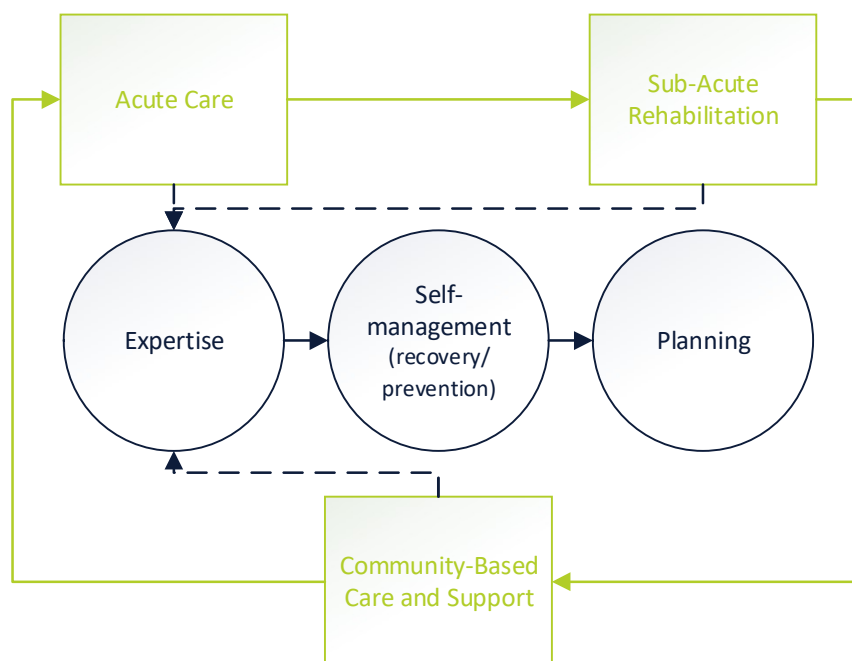
Mapping patient milestones

These milestones, common across the five patient interviews, may be applicable to other parts of a person's SCI care and support pathway if they are considered more broadly, especially recognising the expertise that people with SCI develop in their own injury management and lived experience, alongside the expertise of specialist SCI care and support providers. See Figure 1 below.

Person-centred care

Figure 1: Patient milestones

Milestones may be applicable at each stage of a person's care and support pathway.



Person-centred care

Interview findings on the strengths and weaknesses of person-centred care were complemented by results of the *LBVC Inpatient Patient-Reported Experiences Measure Questions* survey^{xvi} of patient experiences with the healthcare services received. Survey results for the five patients interviewed are in Table 1 below.

Quality of care was a key strength of specialist SCI healthcare services reported by patients, that all reflected on when asked about their experiences of care, planning and decision-making. Specifically, patients appreciated the expert knowledge of specialist SCI staff and teams, and the range of disciplines accessible in specialist rehabilitation teams. Patients were satisfied with the way that rehabilitation teams partnered with them and supported them to plan and make decisions.

A key area of dissatisfaction for patients related to the institutional nature of their care environments, particularly their food and mealtimes, and the loneliness and boredom that can be associated with unstructured time. Patients' lack of confidence in transition planning was apparent in interviews with newly injured patients.

Strengths

Expertise

Specialist care was highly valued by patients as crucial to their recovery and rehabilitation, as this built patients' trust and enabled swift and sound decision making. Expert attendant and personal care provided by people experienced with SCI afforded patients improved dignity and personhood.

The extent to which specialist SCI care was delivered across levels of care, and different areas of the health system, differed between patients. One patient who was required to spend some time in a different medical unit found the lack of access to specialist medical and attendant care during this period to impact significantly on their health and wellbeing. Others (with injury types that allowed higher levels of function and mobility) were satisfied with the integration of specialist care and support with non-specialist units and hospitals.

Multidisciplinary care

Access to a comprehensive range of professionals during rehabilitation supported patients to consider the different facets of their life that would change as a result of their injury. The structure of patients' access to the various disciplines involved in their rehabilitation was also considered positive. Family members' access to multidisciplinary support during rehabilitation was also highlighted as positive and crucial to the recovery process.

Integration of disciplines was generally reported as strong. Patients were supportive of the communication, decision-making and care planning approaches in rehabilitation teams, and positive about the cohesiveness of their teams.

One patient highlighted the need for all levels of staff in specialist units (surgical dressers, nurses, allied health professionals and doctors) to work cohesively in order to prevent communication breakdowns that can pose a risk to patients' health.

Collaborative care

Patients generally expressed that they felt that their rehabilitation team partnered with them on decisions about their rehabilitation goals and offered a collaborative approach to rehabilitation in general, allowing them to set the pace of their progress and offering them the tools and resources to make informed decisions. The inclusion of family in planning and decision making was highly valued. One patient described their partner's increased motivation and skill in providing personal care and initiating some changes required at home after attending planning meetings and rehabilitation sessions. The input of family was seen by some patients to shift the language and approach of all participants in planning meetings – themselves, participating family members and also the rehabilitation team. For example, a patient described the value of hearing a doctor describe the likelihood of their full recovery to family members, as the family asked questions about long-term functioning that the patient had been hesitant to ask.

Weaknesses

Decision making

Two newly injured patients directly expressed a reluctance to make decisions necessary for their transition back into the community. Reasons for reluctance included: desire to delay decision making until the extent of their recovery was clearer; worry about the impact of next steps (particularly concerning housing and employment) on their family; and a sense of overwhelm. A third patient expressed more confidence in engaging with the transition planning but was stressed due to the impact of funding limitations (under My Aged Care) on planning and decision making.

One patient highlighted the value of peer support in building their understanding and confidence in the transition planning process.

Care environment

Key elements of the care environment that patients wished to improve were the food they were served and the isolation that some patients experienced.

Patients repeatedly raised meal programs as inflexible to personal preferences (in terms of both meal serving times and meals served) and incompatible with their bowel care requirements. Meals relate directly to people's health, sense of control, person-centred care and quality of life during extended stays in acute and sub-acute care settings. While patients appreciated the difficulty of individualising meals, food was an important part of their lives and a key area of dissatisfaction.

Patient interviewees from regional areas (two of five) expressed experiences of isolation and boredom in their patient journey. These experiences were related to times when their rehabilitation schedule was not under-way (one was transferred to sub-acute rehabilitation on a Friday night and had to wait until Monday morning to commence rehabilitation, and the other was referring to the Easter and Anzac Day public holiday period). Regional patients did not have regular visits from family and were more reliant on building relationships with other patients and on having personal recreation options that they could engage with at any stage of their rehabilitation pathway.

Conclusion

Access to expert SCI knowledge appears to empower people to focus on their recovery. Planning for transition to community living appears to be closely linked with progress in physical rehabilitation. Patients valued the multidisciplinary structure of their rehabilitation teams and were positive about the way that their rehabilitation team collaborated with themselves and their families. Quality of communication between disciplines and between patient and rehabilitation team was important to most patients as a signifier of quality of care and commitment to patient recovery.

^{xiii} Namely Royal North Shore Hospital, Royal Rehab and Prince of Wales Hospital.

^{xiv} Agency for Clinical Innovation 2017, *State Spinal Cord Injury Service – Spinal Cord Injury Model of Care Diagnostic Report*, NSW, pp.38-40.

^{xv} Agency for Clinical Innovation 2017, *State Spinal Cord Injury Service – Spinal Cord Injury Model of Care Diagnostic Report*, NSW, p.50.

^{xvi} Agency for Clinical Innovation 2018, *Leading Better Value Care (LBVC) Inpatient Patient-Reported Experiences Measure (PREM) survey*, NSW.

Results: LBVC Inpatient PREM survey

Patients were asked to reflect on the unit in which they were currently receiving care to complete this survey.

Table 1: LBVC Inpatient Patient-Reported Experiences Measure (PREM) survey

Survey Question	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5
1. I was kept informed as much as I wanted about my treatment and care. <i>Always, mostly, sometimes, rarely, never.</i>	Always	Mostly	Mostly	Always	Mostly
2. I was involved as much as I wanted in making decisions about my treatment and care. <i>Always, mostly, sometimes, rarely, never.</i>	Mostly	Mostly	Mostly	Always	Mostly
3. My views and concerns were listened to. <i>Always, mostly, sometimes, rarely, never.</i>	Always	Always	Mostly	Always	Always/ Mostly
4. Did the health professionals explain things in a way you could understand? <i>Yes, always; yes, sometimes; no.</i>	Yes, always	Yes, always	Yes, sometimes	Yes, always	Yes, always
5. Do you feel you have been given enough information about how to manage your care at home? <i>Yes, completely; yes, to some extent; no, I was not given enough; I did not need this type of information.</i>	Yes completely	Yes completely	Yes completely	Yes completely	Yes to some extent
6. Did you feel you were treated with respect and dignity while you were in the hospital? <i>Yes, always; yes, sometimes; no.</i>	Yes always	Yes always	Yes always	Yes always	Yes sometimes
7. Overall, how would you rate the care you received while in hospital? <i>Very good; good; neither good nor poor; poor; very poor.</i>	Very good	Very good	Very good	Very good	Very good
8. What would have made your visit better?	Food – would like to bring in own food.	Food	Food. Daily program. Own room.	Nothing in particular.	Would like a transition planning checklist.

Appendix D: Action Plan from Expert Dialogue stakeholder forum

Recommended solutions	How	Next Steps/Who
<p>Collective Reference Group that drives joint approaches by spanning boundaries and unlocking existing capacity. 'Change the script' on person-centred care. Involving:</p> <ul style="list-style-type: none"> • DSS • NSW Health • FACS (especially re: Housing) • Education • Justice • Transport NSW • Disability Reform Council • icare • NDIS • My Aged Care • Attendant Care Industry Association. 	<ul style="list-style-type: none"> • Potentially blended funding. • Joint Key Performance Indicators, ownership and accountability. • Connects into existing strategies, eg: <i>NSW State Health Plan: Towards 2021</i>; National Disability Strategy; Disability Reform Council. • Connects into NDIS initiatives such as: The Thin Markets Project; Complex Support Needs Pathway rollout; and the Exceptionally Complex Support Needs Program. 	<p>Led by ACI.</p> <ul style="list-style-type: none"> • Communicate to MoH detailing origins of project and dialogue outcomes, recommending establishment of collective reference group as an interagency framework for improving data collection, transparency and sharing; streamlining processes and developing joint accountability mechanisms.
<p>'System wrangler' function that acts early on issues:</p> <ul style="list-style-type: none"> • individual and systemic advocacy • escalation of issues • deliver multi-agency solutions • pursue long-term strategic improvement. 	<ul style="list-style-type: none"> • Authorised by multiple agencies (eg via Collective Reference Group) to make things happen across boundaries. • Draw from the NSW Integrated Service Response model for people who have a disability and complex support needs, which is hosted by NSW Health. • Map existing advocacy support and interagency coordination positions, including roles and responsibilities, across different levels of government. This is to avoid duplication and ensure that the recommended 'system wrangler' role is 	

Recommended solutions	How	Next Steps/Who
	designed as a high-level complement to existing positions.	
Progress the National Injury Insurance Scheme (NIIS) in NSW, to achieve care and support for people with catastrophic injury fully integrated with state systems.	<ul style="list-style-type: none"> Progress State/Commonwealth discussions towards implementation of NIIS in NSW, in line with their Bilateral Agreement on the NDIS. 	
Build connections between Local Health Districts, My Aged Care (MAC) and NDIS teams	<ul style="list-style-type: none"> Connections between individuals, and consistent connection points across partner organisations. Earlier NDIS involvement and clearer delineation of responsibilities Escalation pathways. Joint ongoing solutions/ interface improvement. Draw from existing linkages and agreements governing the provision of Aged Care Assessments in NSW. 	Department of Health/ MAC/ NDIS
Build connections between NSW Health and My Aged Care	<ul style="list-style-type: none"> System improvement projects. Escalation pathways. Draw from existing linkages and agreements governing the provision of Aged Care Assessments in NSW. Data sharing/transparency – flagging: pipeline (NSW Health); vacancies (MAC); locations of under-65s in residential aged care facilities (MAC). 	ACI NSW Ministry of Health Department of Health/ MAC
Flexible accommodation and funding support options: <ul style="list-style-type: none"> step-up, step-down 	<ul style="list-style-type: none"> Ongoing communication between ACI and DOH on outcomes of the SA Hospital Pilot. 	ACI Department of Health/ MAC NDIA

Recommended solutions	How	Next Steps/Who
<ul style="list-style-type: none"> • bridging accommodation • SCI shared accommodation • proximity to family. 		
<p>Advocacy on age-related discrimination for funding people who are injured at 65 years and older.</p>	<ul style="list-style-type: none"> • Individualised funding additional to MAC for people injured at 65 years and older (in parity with people with SCI over 65 years who were injured before their 65th birthday). 	<p>ACI NSW Ministry of Health</p>
<p>Early specialist support coordination for people with spinal cord injury.</p>	<ul style="list-style-type: none"> • Cross-agency role. • Version of NDIS Complex Support Needs Pathway for people with SCI, as most will not be eligible. 	<p>NSW Ministry of Health Department of Health/ MAC NDIA</p>
<p>Approval of flexible transitional Reasonable & Necessary supports to work with mainstream supports to ensure return to community will not fail.</p>	<ul style="list-style-type: none"> • NDIA approval of supports which allow people to trial community living options before final transition home. • MAC approval of enhancement supports which allow people with SCI to trial community living options before final transition home. • Draw from (and extend) icare model for approval of interim home modifications, to allows staggered decision-making on major modifications so that decisions can take better account of individual circumstances and people’s lived experiences of their injuries and modification requirements. 	<p>ACI NSW Ministry of Health NDIA Department of Health/ MAC icare</p>
<p>Improve people’s access to housing supply data</p>	<p>eg. via Housing Hub, or other models.</p>	<p>NDIA (SDA) Department of Health/ MAC</p>

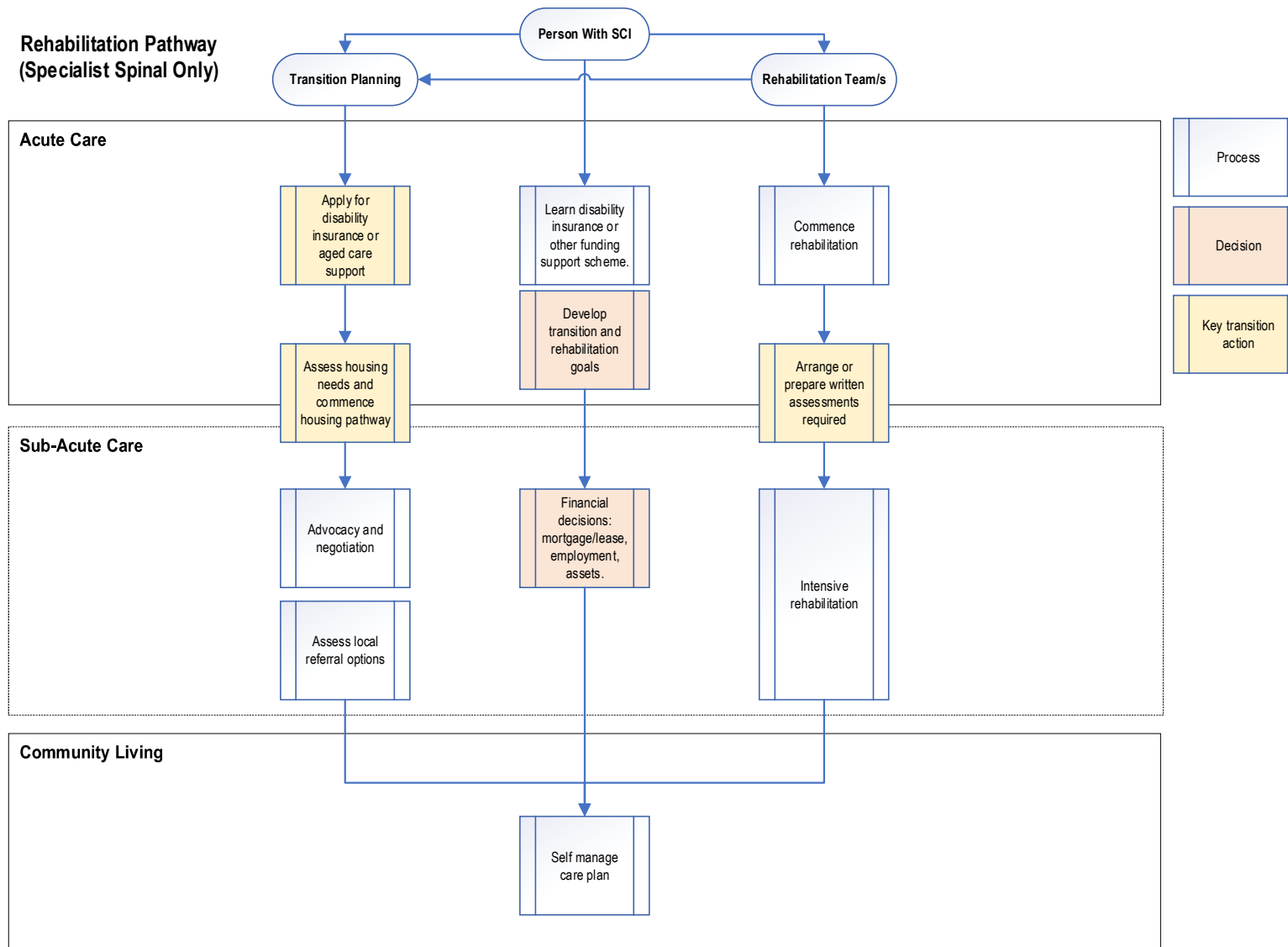
Recommended solutions	How	Next Steps/Who
		FACS icare
Housing pathways study on housing stock, supply and demand and pathways for people with SCI.	Possible Information Linkages and Capacity Building (ILC) grant.	ACI lead. FACS re: ILC grant.

Appendix D: Vulnerable SCI cohorts observed by key informants

Cohort	Reason for vulnerability
Rural and regional	For reasons outlined in Diagnostic Report.
<p>High and complex needs:</p> <ul style="list-style-type: none"> • Comorbidities: <ul style="list-style-type: none"> ○ Mental illness, disorders, eg personality disorders. ○ Drug and alcohol issues ○ Acquired Brain Injury (ABI) ○ Undiagnosed ABI • People who lack family support, social capital (eg prior homelessness, unemployment), resilience, self-efficacy. 	<p>Can be very hard to find solutions for as they are less likely to have community-based supports and transition options.</p> <p>Lack of appropriate resources and options in unit can place staff and patients at risk from some behaviours. Lack of community resources can result in inadequate solutions, eg nursing homes.</p> <p>Rely on more systems, eg Housing – discharge more complex.</p> <p>Those who struggle or feel out of control find it more difficult to adapt to their additional care and support needs. This is crucial, as SCI requires good skin hygiene and good bowel and bladder hygiene and routines to prevent secondary health conditions.</p>
People who previously lived in group homes	Group home model suited some people, eg young people with comorbid SCI and ABI. Model does not exist any more and there are not many housing options that offer the same co-living arrangements designed to meet their needs. People end up in nursing homes but these are unsuitable for their stage of life.
People from non-English speaking backgrounds	Not able or willing to advocate for themselves and not as aware of them options available to them. Barriers may be cultural, language, combination of both. Failure to seek treatment early or appropriately can put them at risk.
People over 65	Partners are ageing as well. Unable to provide and My Aged Care insufficient for the needs. Many end up in a nursing home from a relatively young age.
People with cognitive issues, especially if very minor	Difficult to get access to brain injury resources for minor or borderline patients. Struggle with problem solving or troubleshooting. Not enough community support options.
People experiencing high levels of pain	Find it difficult to engage with rehabilitation and community.
People who have been injured for a long time	Services historically emphasised self-management. People aren't re-engaging with services as their needs change with age. Less common to see adults injured as

	children or who have lived with SCI for a long time.
Women	Not enough information on menstruation, having a family. Less recreation options. Wheelchair skills geared to men.
People gaoled for accident that caused their SCI	Less access to specialist care and support.
People in non-specialist hospitals	Less access to specialist care and support.

Appendix E: Rehabilitation Pathway map (specialist spinal units)



Appendix F: Transition Pathway map

Pathway: SCI Transitions to Community Living

