

State Spinal Cord Injury Service Model of Care for Prevention and Integrated Management of Pressure Injuries in People with Spinal Cord Injury and Spina Bifida

ACKNOWLEDGEMENTS

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The model was widely endorsed through a formal consultation process that involved all Local Health Districts and not for profit / non-government spinal organisations. Detailed written comment with feedback and suggested changes to the model or document were received from individuals and organisations listed in **Appendix 2**.

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FOREWORD

The Agency for Clinical Innovation (ACI) is the primary agency in NSW for promoting innovation, engaging clinicians and designing and implementing new models of care.

The ACI's Clinical Networks, Taskforces and Institutes provide a forum that brings together clinicians, managers and consumers across the NSW health system to design, deliver and support implementation of effective and sustainable models of care. By bringing together clinical and health system leaders from primary, community and acute care settings, we create an environment and capability for innovation, redesign and promotion of an integrated health system.

Pressure injuries affect 80% of individuals with a spinal cord injury (SCI) or spina bifida across their life span. The physiological, mental and economic impact of these injuries can place an enormous burden on individuals, the community and healthcare services.

The ACI State Spinal Cord Injury Service (SSCIS) has developed a model of care to support access to appropriate and effective self-management strategies, risk assessment and early intervention for people with a SCI or spina bifida. The model also supports timely access to necessary care, support, equipment and specialist health care services when necessary.

An integrated approach across the continuum of care is promoted with the aim to improve patient outcomes and limit the psychosocial and economic impact of pressure injuries on the individual, their family and the community.

I am pleased to introduce the Model of Care for the Prevention and Integrated Management of Pressure Injuries in People with Spinal Cord Injuries and Spina Bifida.

On behalf of the ACI, I would like to thank the Project Steering Committee and the members of the SSCIS for lending their expertise, time and commitment to develop this model and guiding principles for implementation across NSW.

Dr Nigel Lyons *Chief Executive, Agency for Clinical Innovation*

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1. EXECUTIVE SUMMARY

The Model of Care for Prevention and Integrated Management of Pressure Injuries in People with Spinal Cord Injury and Spina Bifida was developed by the Agency for Clinical Innovation (ACI) State Spinal Cord Injury Service (SSCIS). The ACI supports the development of models of care that integrate primary services across the state with specialist acute care centres. This includes clear articulation of processes and pathways to ensure appropriate and timely interventions and referrals occur and that there are opportunities to build the skill set of non-specialist clinicians in a supportive manner. It is acknowledged that whilst the incidence and prevalence of children with a spinal cord injury are relatively small, their needs under this Model of Care (MoC) differ substantially from those of young people and adults and will require further elaboration.

Why change current practice?

There are an estimated 6,500 individuals living in New South Wales (NSW) with spinal cord injury (SCI) and spina bifida (SB), who have an overall lifetime incidence of pressure injury (PI) of more than 85%. The social and economic impact of PI on the individual, family and community is immense and can have long term physical and psychological consequences.

In terms of hospital utilisation, the patient cohort is low volume, high cost (on a case basis), complex and relatively stable in terms of numbers. Utilisation of NSW public hospitals over the five-year period from 2006-2011 showed that there was an average of around 580 separations per year and around 16,500 bed-days per year provided by NSW public hospitals for PI management of people with a SCI or SB. This was associated with a relatively long average length of stay of 27 days compared with less than four days for all patients and an average cost per year of just under \$AUD13 million. Referral and treatment patterns are often delayed due to inconsistent, fragmented services and difficult for individuals to navigating the system. Data showing high rates of emergency admissions, late presentations with severe pressure injuries and recurrent admissions suggests there is considerable scope for improvement through prevention and earlier intervention, as well as better service co-ordination and streamlined management practices.

There is a lack of data regarding individuals managed for PI in the community and therefore these data and costs are not included in this report. It could be assumed, however, that with a PI prevalence rate of 30% in an estimated population of 6,500 people with SCI and SB living in NSW, approximately 1,950 of them will have a PI at any one time. Further work involving a whole of government approach will be important for building community costs into the Model of Care analysis.

The nature of paediatric SCI is different to that in adults, with only 29% of injuries being due to traumatic causes with the majority due to non-traumatic causes, such as neurological disease. For these reasons, the specific needs of children are not covered comprehensively in this model and should more detail be necessary regarding paediatric SCI, further work would be required.

Process for developing the Model of Care

Broad stakeholder consultation was conducted with over 130 clinicians, consumers and carers in both hospital and community care settings to explore the issues related to pressure injury prevention and management across the lifespan and stages of pressure injury. Analysis of these interviews identified a number of issues which have been summarised into eight main themes:

- problems with access, particularly to specialist multidisciplinary pressure injury services.
- fragmented care
- need for a stronger focus on prevention
- self-management support
- greater use of health technology
- capacity-building and workforce development
- increased psychosocial support
- resource development.

From these themes three key principles were identified that apply to every aspect of PI prevention and management across all care settings. They are:

- Principle 1 Self-management
- Principle 2 Timely and equitable access

• Principle 3 - Integrated care.

Following completion, the final draft project report with the proposed MoC was circulated widely for comment. It received general endorsement along with constructive feedback that was incorporated into this final report. The range of key stakeholders, included the following:

- Project Steering Committee
- State Spinal Cord Injury Service members, a Network of ACI
- > ACI Executive
- ➤ NSW Ministry of Health (MoH)
- Chief Executives and representatives of Local Health Districts (LHDs)
- Chief Executives and representatives of spinal partner organisations, such as ParaQuad NSW, Spinal Cord Injuries Australia, Northcott Disability Services, and the Lifetime Care & Support Authority
- Other Government organisations including the Department of Family and Community Services (FACS), Ageing, Disability and Home Care (ADHC) Branch
- ➢ General Practitioners New South Wales.

Cost and Utilisation Analysis

An analysis of historical and projected costs and utilisation of adult acute inpatient services showed the following:

- A *relatively low volume*: this cohort had an average of 580 separations and 16,000 bed-days per year. In 2010/11 this activity represented about 0.04% of all separations from NSW public hospitals and 0.3% of bed-days.
- A *relatively high complexity*: the average cost weight (which is a proxy for complexity and cost) for the patient cohort is 5 compared to the average of 1 for all NSW public hospitals patients.
- A relatively high average length of stay (ALOS), but still within the inlier range: suggesting that the services provided are "efficient" or at least "expected". What the data does not show is whether the patient is in an "acute" phase of care for the entire inpatient stay and therefore whether the patient could be treated in a more appropriate setting once the acute phase of care is over.
- A relatively low total cost but a high cost per

individual episode of care. In the five years to 2010/11 the average total inpatient costs associated with treating this cohort was around \$AUD 12.5 million per year or around \$AUD 22,000 per episode.

- Consistent with the complexity of the cohort, the *majority of inpatient services are concentrated* in three hospitals, with the Royal North Shore, Prince of Wales and John Hunter Hospitals providing over half of all PI-related separations for persons with SCI and around a third of separations for persons with SB.
- Over 5 years, around 680 procedures were undertaken (an average of 137 per year). About one-third of all procedures were performed at Royal North Shore Hospital and a further 7% each at Prince of Wales, John Hunter and Wagga Wagga Hospitals. Most of the 82 skin/muscle flap reconstructive surgeries were performed at Royal North Shore Hospital.
- The patient cohort had a *high level of multiple admissions and emergency admissions*. Over the five year period, 45% of the cohort required more than one admission for pressure injury treatment. In addition, around 68% of admissions were emergency (unplanned) admissions.

Service utilisation and cost projections were undertaken over a 10-year period (the "Business as Usual" analysis) to quantify and understand the impact of continuing current practice in terms of service utilisation and cost. In summary, this analysis showed that utilisation and cost would continue to grow in line with the historical trend with an estimated total cost for hospitalisation of \$AUD300 million over the next 10 years. It should be noted that community costs were not included due to lack of data.

The new Model of Care for Prevention and Integrated Management of Pressure Injuries

The Model of Care (MoC) for Prevention and Integrated Management of Pressure Injuries incorporates the following:

- 1. features of the Chronic Care Model¹
- 2. different levels of primary, secondary and tertiary prevention²
- 3. the concept of risk stratification for health promotion with self-management support
- 4. early risk assessment, clinical decision support and care coordination with increasing levels of specialist support for management.

The model illustrated in **Figure 1** shows the person with SCI/SB as central to the model within all care settings supported by an interconnected network of 'providers' as well as the informal support of family, friends and peers. Around this are represented the three levels of 'preventative care' (health promotion, early intervention, rehabilitation and restoration) with each 'provider' assuming a different role and responsibility to ensure that the requisite activities are implemented within a framework endorsing three overarching principles of selfmanagement, access and integrated care.

In essence, the MoC aims to focus on supporting selfmanagement and education strategies for the person with SCI/SB to take ownership over their skin integrity status in the first instance, but also to promote access to essential services and equipment in a timely and equitable manner and to strengthen processes for an integrated approach to care. If this is achieved, it is expected there will be a reduction in the development of serious (\geq Stage 3) PIs and thus demand for specialist surgical intervention.

However, given the complexity and multifaceted nature of PI occurrence and the high likelihood of a person with SCI/SB developing a PI at some time in their lifetime, a focus on supporting the person to reduce the risk of both occurrence and deterioration of a PI is extremely important. As shown in **Figure 2**, with increasing complexity the person will shift to a higher level of risk requiring increased support from health care providers. Enhancing self-efficacy will reduce their level of risk.

Critical components underpinning success of the model in achieving a significant reduction in number and frequency of PIs and their impact on health care and support services as well as good outcomes for the individual are:

Figure 1. Depiction of key aspects of the Model of Care



- improved health promotion
- earlier detection and intervention with improved assessment and decision support
- timely access to equipment, care coordination and community supports and resources
- responsive and knowledgeable health practitioners providing evidence based management and care
- inter-sectoral collaboration with development of key partnerships that will bridge the gap between sectors and government departments.

Recommendations

The six recommendations outlined below have been developed for the implementation of a consistent approach to pressure injury prevention and management in the individual with SCI/SB. They have been informed by the body of evidence and key findings resulting from the project, guidance from the project Steering Committee, and Health Economics Analysis of data provided by the NSW Health Centre for Epidemiology and Evidence (CEE). The recommendations are as follows:

- Provide decision support systems to enable people with SCI/SB, carers and clinicians to access information, expertise and tools to support prevention and appropriate management of PIs.
- 2. Provide timely access to care and equipment to prevent Pls or promote healing of them.
- Develop systems and processes that facilitate integrated care with effective communication between the person with SCI/SB, health care and service providers across sectors.
- 4. Develop systems and processes that facilitate selfmanagement and enhance psychosocial support to the person with SCI/SB and their primary carers.
- Develop multilayered educational strategies for PI prevention and management applicable to the person and all stakeholders across the phases of care.
- 6. Integrate clinical information and data management systems for care coordination, monitoring and outcome evaluation.

Implementation and Evaluation

The priorities for the next steps in implementation include:

• Establishing a multidisciplinary steering committee to assist in planning and supporting

Figure 2. Reducing the level of risk through enhancing self-efficacy



Self Efficacy improved

implementation of the model.

- Developing decision support tools and resources to be available online, to facilitate multidisciplinary risk assessment, evidence-based treatment, referral and triage.
- Defining processes and clinical information systems to improve care coordination and communication across sectors.
- Generating LHD Executive Sponsorship and gaining their assistance to identify local 'spinal champions' from among existing staff, such as wound care nurse consultants and allied health professionals, who can be trained and supported by the specialist SCI services in a hub and spoke model across NSW to build capacity and support implementation.
- Working in collaboration with interested LHDs and local champions to develop and pilot a clinical pathway for PIs in persons with SCI/SB, involving risk assessment, management and regular monitoring of progress, with increasing levels of specialist support for management and triage, referral and escalation based on complexity and response to treatment. This would be supported by suitable tools and resources.

- Completing a comparative gap analysis, with determination of health system barriers (and enablers) for implementation.
- Addressing identified gaps and barriers through the development of defined practice change strategies, supported by a communication and education plan.
- Evaluating the MoC will be essential to ensure that it is implemented as intended, including monitoring of inputs, outputs and outcomes. There will be both formative evaluation, monitoring processes and outputs to assess if short-term outcomes are being achieved, as well as summative evaluation. The latter would include assessment of long term outcomes for the patient cohort, changes in practice and policy, and cost-effectiveness of the MoC.

2. INTRODUCTION

2.1 Context for Spinal Cord Injury in New South Wales

Spinal cord injury (SCI) occurs when there is permanent damage to neural tissue, as a result of trauma or from a non-progressive disease process. Traumatic SCI (TSCI) is caused by a direct or indirect external event (trauma), such as a motor vehicle accident, fall or sporting injury. Non-traumatic SCI (NTSCI) may be due to infection, haemorrhage, ischaemia or inflammation (myelitis) amongst other causes, damaging the spinal cord. The result is a disruption to nerve transmission affecting sensory, motor and autonomic nervous system functions, including control over bladder and bowel elimination.⁴ Other neurological conditions that fall outside these inclusion criteria for the SSCIS due to their progressive nature, such as multiple sclerosis (MS), motor-neurone disease or paralysis secondary to bony metastases may also benefit from this model.

Spinal cord injury can be broadly classified into either:

- paraplegia with impairment of trunk, lower limb and pelvic organ function, or
- tetraplegia (quadriplegia) with impairment of all limbs, trunk and pelvic organs and compromise to respiration.⁵

The extent of impairment may be further classified as:

- complete (American Spinal Injury Association (ASIA) Impairment Scale - AIS grade A), where there is no sensory or motor function below the level of injury, or
- incomplete (AIS grades B-D) with sensory and/or motor sparing below the level of injury to varying degrees (necessarily including the presence of sacral sensation)⁵.

The incidence of spinal cord injury in Australia remains relatively stable at 15 cases per million population or approximately 350-400 cases per annum.⁶ New South Wales (NSW) accounts for a third of these cases treating an average of 115 new spinal cord injury adults in the specialist units.⁷ There is an estimated population of 4,500 people living with a SCI in NSW. The impact of pressure injury (PI) on the person with SCI has previously been acknowledged as a priority in NSW with funding made available in 2003/4 to establish dedicated adult multidisciplinary outpatient services at the Royal North Shore Hospital (RNSH) and Prince of Wales Hospital (POWH). The services are known as The Spinal Plastics Service (SPS RNSH) and Spinal Pressure Care Clinic (SPCC POWH) however, for the purpose of this report they will be referred to as the 'specialist spinal pressure injury services' (SSPIS).

These two services provide a multidisciplinary assessment to adults with TSCI/NTSCI of contributing factors for PI development and devise collaborative plans for treating the problem which includes appropriate post intervention rehabilitation for equipment review/represcription, return to seating, physical reconditioning and functional reassessments. As these outpatient services have developed so has the demand and complexity of the patients presenting for assessment. Whilst the benefits of a multidisciplinary approach to PI management have been reported to reduce length of stay, increase interdisciplinary practice and support a shared or integrated care philosophy,⁸ the services are facing referrals where the person requires extensive and prolonged interventions to address multiple issues before they can begin to commence healing. The result has been reduced ability for people to access the services therefore deteriorating while waiting, further compounding the demand and pressure for access to the services.

The requirements of children with SCI are very different to adults and, given the generally prolonged length of stay, their care must accommodate the need for child companionship and schooling. The tertiary paediatric hospitals, Children's Hospital Westmead (CHW) and the Sydney Children's Hospital (SCH), provide a spinal cord injury and disease service for children as part of their rehabilitation departments. They offer a consultancy and management service for children and adolescents with acquired spinal cord pathology from birth until they leave school or reach 18 years of age. Planning for transition from paediatric to adult services begins for adolescents from the age of 16 years in both hospitals. A small number of NT SCI cases from the Hunter New England Local Health District (HNELHD) are managed locally at the John Hunter Children's Hospital (JHCH).

The children's hospitals have access to the specialised equipment and specialists required to manage children and adolescents with SCI, particularly in the following areas relevant to PI:

- Rehabilitation specialists, clinicians and therapists
- Surgeons plastics, urology, orthopaedics, scoliosis and neurosurgery
- Pain management

Paediatric patients are generally defined as being under the age of sixteen years, with occasional exceptions to preserve continuity of care. Unlike adults, SCI in children is not reported nationally and there are no agreed reporting criteria or national database. The number of paediatric patients admitted to hospital with SCI in NSW is very small in comparison to adults. At the CHW there are 50 children and adolescents receiving treatment from the SCI service, with an additional three to 10 new cases per year. The SCI Service at the SCH is currently treating 25 children and adolescents in total, with between one and three new SCI cases per year. The nature of paediatric SCI is different to that in adults, with only 29% of injuries being due to traumatic causes. The majority are due to non-traumatic causes, such as neurological disease. For these reasons, the specific needs of children are not covered comprehensively in the model and should more detail be necessary, further work would be required.⁹

2.2 Context for Spina Bifida in New South Wales

Neural tube defects are congenital anomalies arising from disruption in the development of brain and spinal cord in early pregnancy. Spina Bifida (SB) occurs where there are defects in the vertebrae covering the spinal cord, with exposure of and damage to the nervous tissue. Babies born with SB may have varying degrees of spinal cord injury resulting in paralysis of the lower limbs and bladder and bowel incontinence, depending on the location and type of defect.⁶

Hydrocephalus is reported to be as high as 90% in individuals with SB,¹⁰ impacting on executive functioning and manifesting through such things as learning difficulties, memory retention and the ability to selfdirect health management.^{10, 11} This means that many adults with SB will never achieve independence or the ability to direct their health management and therefore they require a much more intensive support role from health care providers, including case management.

SB is classified depending on whether the malformation is closed or open:

- Meningomyelocele SB spinal cord and meninges protrude through the opening in the spine.
- Meningocele SB meninges protrude through the opening of the spine.
- SB Occulta malformed vertebrae are covered with skin¹².

(Meningocele SB and SB Occulta do not usually result in neurological sequelae.)

Current prevalence rates for SB are 1.8 / 10,000 live births in Australia. Although approximately 83% survive past the initial neonatal period of 28 days¹², there is a continued increased risk for mortality and morbidity across their life. There is an estimated population of 2,000 living in NSW (J. Dicker, personal communication, August 8, 2012).

SB is a congenital condition that requires lifelong health management. ^{13, 14} Seventy per cent have an unspecified neurological level, with 28% and 2% respectively identified as having paraplegia and tetraplegia. For people with SB, presentation to hospital with preventable issues such as PIs and urinary tract infections is common. In 2005 it was estimated that SB hospital admissions in NSW cost \$AUD 2.5 million, increasing at 5% per annum.¹⁵ In 2007 in NSW there were 549 people registered with adult clinics with a very low attendance rate of 40%.¹⁵ Optimising medical management of these clients is essential to reduce morbidity and mortality.^{13, 16} There is evidence that adverse health complications from SB contribute to disadvantage in all areas of life when compared with able bodied peers.¹⁷ Cognitive issues, present in the majority of this population, create an additional barrier to effectively accessing care and selfmanagement of health.13, 14

In 1999 NSW paediatric clinicians working in the speciality of SB formed a collaborative for the purpose of networking and sharing information on SB between two Sydney based children's hospitals. The following year, the collaborative expanded to include the adult SB services from Westmead and Royal Prince Alfred (RPA) hospitals together with Northcott Disability Services (NDS). The SB service at JHCH joined the group in 2003.

There is strong evidence that young people with SB and their families struggle to find appropriate adult health care services that can understand and support the complex care requirements that arise as part of the condition.¹¹ Clinicians from the collaborative had been striving to improve the access to health care for their adult population and with this purpose in mind were able to gain the support of the Greater Metropolitan Clinical Taskforce (GMCT) Transition Network in 2004 to advocate for the development of a state-wide service. Finally, funding was made available in 2009 for a state-wide team to provide multidisciplinary clinical consultation, case management, education and support to health professionals as well as young people and adults with SB across NSW. The Spina Bifida Adult Resource Team (SBART)¹⁸ is funded by the NSW Ministry of Health, hosted by Northcott Disability Services and supported by the NSW Spina Bifida Collaborative Group.

Despite these positive moves towards integrated care, a person with SB remains at high risk of significant comorbidity, particularly renal failure and development of PI.¹⁴ A person with SB and PI does not currently have access to the SSPIS, which creates further health care inequity and poor health outcomes for an already disadvantaged group.

2.3 Context for Pressure Injury

Pressure injury is a significant concern to people with limited mobility and/or sensation as these factors remain the highest risk for PI development.¹⁹ In addition, there are economic incentives for health care services to address PI risk as they are costly to treat.²⁰

There are multiple terms used to describe PI including pressure ulcers, pressure sores, decubitus ulcers, bed sores, pressure necrosis and ischaemic ulcers, however, there is an international consensus from peak wound associations to use the term 'pressure injury' to allow for the new classification of 'deep tissue injury – un-stageable'. PI is defined as "localised injury to the skin and/or underlying tissue usually over a bony prominence, as a result of pressure, or pressure in combination with shear and/or friction".²¹ The European Pressure Ulcer Advisory Panel (EPUAP) and American National Pressure Ulcer Advisory Panel (NPUAP) have devised a staging system to describe the extent of PI (**Table 1**), which has been adopted by the Australian Wound Management Association (AWMA) in the Pan Pacific Clinical Practice Guideline for the Prevention and Management of Pressure

PI STAGE	STAGE DESCRIPTION
STAGE 1	Pressure injury presenting as intact skin with non-blanchable redness of a localised area usually over a bony prominence. Dark skin tones may be difficult to detect this way. May have variation in skin colour, changes to skin temperature or palpable differences
STAGE II	Partial thickness loss of dermis presenting as a shallow, open wound with a red / pink wound bed, without slough. May also present as an intact or ruptured serous filled blister, shallow crater. Bruising is indicative of deep tissue injury and maceration, dermatitis or excoriation are not included under the definition of Pl
STAGE III	Pressure injury presenting as full thickness tissue loss in which subcutaneous fat may be visible but bone, tendon or muscle are not exposed. Can include undermining and tunnelling. Slough or necrotic tissue may be present as long as it does not obscure the depth of tissue loss. Depth is different depending on anatomical location (nose vs. lower abdomen)
STAGE IV	Pressure injury presenting as full thickness tissue loss with exposed bone, tendon or muscle. Can extend into supporting structures (fascia / tendon or joint capsule) making osteomyelitis possible
UNSTAGEABLE	Pressure injury presenting as full thickness tissue loss in which the base of the PI is covered by slough (yellow, tan, grey, green, brown or necrosis (tan, brown, black) that prevents the determination of the true depth, and therefore the stage. Stable eschar of the heels (dry, no erythema) serves as a natural biological cover and should not be removed
SUSPECTED DEEP TISSUE INJURY – DEPTH UNKNOWN	Purple or maroon localised area or discoloured, intact skin or blood-filled blister due to damage of underlying soft tissue from pressure and/or shear. The area may be preceded by tissue that is painful, firm, mushy, boggy, warmer or cooler as compared to adjacent tissue. Deep tissue injury may be difficult to detect in individuals with dark skin tone.

Table 1. International Staging / Grading Classification of Pressure Injury²²

Injury ²¹ for use in the Australian healthcare context.

International studies reporting PI prevalence in the spinal cord injured population report broad variations depending upon the clinical context, stage in the patient's journey or behaviours that place them at additional risk. This is summarised in Table 2 below.

Table 2. International pressureinjury prevalence rates inacute and community spinalcord injury / spina bifidapopulations

CARE SETTING	AVERAGE (%)
Acute setting (adult) ^{23, 24}	43.5%
Community setting (adult) ²⁵⁻²⁹	34%
Acute setting (paediatric) ³⁰⁻³²	27.7%
Community (paediatric) ³³	29%
Lifetime prevalence 28	82.9%

National demographic data for people with SCI reveal socioeconomic disadvantage, fewer in a relationship and lower levels of education than the general population. In addition, less than half return to the workforce following the event of SCI.⁶ Similarly, the cognitive issues present in the majority of people with SB, creates barriers to effectively accessing care and self-managing their condition. ^{10, 11} This in addition to adverse health complications contribute to disadvantage in all areas of life when compared with able bodied peers.^{8, 34}

3. PROCESS FOR DEVELOPING MODEL OF CARE

The evidence and key findings from this project resulted from a review of the literature and broad stakeholder consultation, using semi-structured interviews, focus groups and workshops with key informants identified through purposive snowball sampling. Consultation occurred across the continuum of care settings from acute care through to rehabilitation and community care and included paediatric and transitional phases in both metropolitan and rural settings. The participating clinicians worked in the speciality of SCI/SB, PI, plastics & reconstructive surgery, and rehabilitation or were general clinicians with an interest in SCI/SB. The disciplines represented were:

- Medical
- Occupational Therapy

- Social Work
- Surgical
- Nursing
- Dietetics
- Physiotherapy
- Clinical Psychology

Clinical, business and data managers, spinal partner organisations, consumers and carers also contributed to the consultation. Key findings and the initial MoC concepts were tested with the project Steering Committee prior to distribution to the broader group.

The methodological process for reviewing key themes is described in Figure 3, which demonstrates stakeholder contribution and validation at each stage of the thematic review.



Quantitative data was also obtained from various sources including NSW admitted patient data, Centre for Epidemiology and Evidence (CEE), NSW Ministry of Health, the NSW Spinal Cord Injury Database (SCID), Spinal Plastics Service (SPS) and Spinal Pressure Care Clinic (SPCC) databases.

Figure 3. Thematic review process.

4. CURRENT PATIENT JOURNEY

John's story

John is a 48 year old man who had a spinal cord injury after a car accident in 1986 leaving him with paralysis in his legs. He was married, with a job and living in a house that he and his wife had bought in a small country town in NSW. Although John was reasonably well, he did have a few medical problems like diabetes, high cholesterol, reflux, spasm and chronic pain. He was a smoker and drank moderate amounts of alcohol on a daily basis.

In 2007, John visited his doctor because he had developed two pressure injuries on the skin under his 'sitting bones'. He thought the injuries had originally started by scraping his skin during wheelchair transfers. The doctor arranged community nurses to do dressings, but after three months his wounds had not healed and John required admission to his local hospital for surgical debridement. He stayed in hospital for four months. Over the next four years he spent 69% of his time (two years and four months) in hospital with 10 separate admissions for management of sepsis or wound breakdown. During this time he developed anaemia, high white cell counts, low blood protein and low vitamin levels, all of which affect healing. Progressively, he lost his employment, his marriage and house, and began drinking excessively to cope with feelings of depression.

In 2010, John was reviewed by the specialist multidisciplinary spinal pressure care service. His wound was large and deep with tunnels and colonised with a difficult to treat bacteria. He was recommended to have skin flap surgery in 3-4 months to give the local hospital time to correct blood protein, anaemia and vitamin deficiencies and optimise his condition. A bone biopsy showed methicillin resistant staphylococcus aureus (MRSA) which meant that John needed very strong antibiotics through a drip followed by a year of taking antibiotic tablets to get rid of the infection, but was at risk of the infection flaring up and causing breakdown of his healed PI. John also had difficulty adjusting to his lengthy hospitalisation, requiring psychological intervention. Because he was weak he had to be transferred to a rehabilitation unit close to his new home to continue with his graduated seating protocol, equipment trials and re-strengthening program prior to discharge.

This is a real story, only the name has been changed.

What is wrong with this story?

- John received reactive, fragmented and protracted care
- Delayed and prolonged ineffective treatment lead to chronic infection, poor mental/physical condition, poor health outcomes, significant impact on marital, financial and accommodation status
- Inefficiency in bed day utilisation
- As the condition continued, the number of admissions increased

Table 3. Representative Patient Journey before introduction of Model of Care

The following table represents a typical current 'patient journey' of a person with SCI or SB. It illustrates how quickly a PI can deteriorate, if not promptly treated according to best practice principles, resulting in prolonged delay in healing and return to active community participation, increased costs of care and poorer patient outcomes.

SEVERITY/ GRADE OF PI	TYPICAL TIMEFRAME	TYPICAL CURRENT 'PATIENT JOURNEY' SEEN IN INDIVIDUALS WHO DEVELOP A PRESSURE INJURY WHICH THEN DETERIORATES
Ċ,		 Fully engaged in community participation Employed Recreational pursuits fulfilled A situation or event may result in early signs of PI development which can deteriorate to Stage II within 12 hours
Ě	2 – 4 weeks	 If early intervention strategies are not commenced the Stage II pressure injury may not heal and / or deteriorate Unable to access resources to manage pressure injury Ignorant of resources to manage early pressure injury
	1 – 2 weeks	 The wound deteriorates to Stage III-IV pressure injury Odour, lots of ooze, red, hot skin surrounding area GP sends to local hospital
	4 weeks	 Local hospital presentation Surgery to clean wound Treated with intravenous antibiotics Bed rest No engagement in community participation No vocational recreational pursuits
Ĩ	5 weeks	 If the wound does not heal or deteriorates the individual is referred to or presents to the emergency department of a spinal specialist hospital Major surgery is required to fill wound cavity More intravenous antibiotics and fluids Bed rest Deconditioning No engagement in community participation No vocational or recreational pursuits possible Isolated from support networks
	2 weeks	 Rehabilitation Graduated return to seating program Assessment of transfers, wheelchair skills Re-education on maintaining skin integrity Strengthening and reconditioning program
e le contraction de la contrac	6 weeks	 Continuing graduated return to seating for 6 weeks Gradual community reintegration Gradual return to vocational and recreational pursuits

TOTAL DELAY OF APPROXIMATELY 4 – 6 MONTHS

5. CASE FOR CHANGE

John's story is not an uncommon one for people with SCI and SB. These people are at risk of a range of medical complications throughout life and the effects of ageing can be profound. Once formed, PIs are often slow to heal and can lead to unplanned presentations and admissions to hospital, having a detrimental effect on a person's health, quality of life, family dynamics and society.

People with PI may experience pain, disfigurement, further disability and loss of independence.³⁵ Other effects include social isolation, alteration of body image, lost of income, odour and drainage.³⁶ The treatment of a PI necessitates prolonged modification and restriction to activity levels that can have a negative psycho-social impact on the person and their family.³⁷ For the child with SCI/ SB, PIs have a significant impact upon education, with disruption and prolonged absences from schooling, in addition to impediments to play, capacity to play and engage in recreational activities.³⁸

Mortality due to sepsis is also a very real risk to people once PI occurs.³⁸ If the wound remains present over a long period of time, life expectancy can be reduced by as much as 50.3% compared to a 14.6% reduction in life expectancy where PIs have been present for less than 3 months.³⁴

5.1 Impact of Pressure Injury on Heath Care Services

PI management is very expensive. In Australia, PI management has been reported to cost as much as \$350 million per annum although this figure is based upon evidence from 1997 and is likely to be a gross underestimation of current costs.³⁹ Australian hospital PI incidence was predicted to be 95,695 cases per annum with a median of 398,432 bed days lost at a median cost of \$AUD285M, ⁴⁰ but this data does not separate out service utilisation for people with SCI or SB and PI.

Data from the United States of America (USA) for people with SCI shows that the estimated cost of care for PIs in this group is very high, reaching \$US1.2–1.3 billion annually, whereas prevention would cost about one-tenth of this figure.⁴¹

5.1.1 Hospital Utilisation for Pressure Injury Management for combined group of People with SCI and SB in NSW between 2006-2011

Analysis of data over the period 2006 to 2011 showed that:

- Forty-five percent of people with SCI or SB had more than one admission for PI management.
- A high number of patients were admitted with advanced PIs 19% of patients with a Stage 4 PI and 17% with a Stage 3 PI.
- The majority of admissions (68%) were unplanned admissions through an emergency department.

Table 4 provides a snapshot from 2010-2011 of key utilisation variables, highlighting the complexity of this cohort of patients. Although it represents a relatively small proportion of bed-days and separations overall, the number of bed days is disproportionate to the number of separations (0.3% of all bed days compared to 0.04% of all separations). This is in part explained by the fact that the average cost weight of these patients is around five times greater than the average cost weight for all patients and the high ALOS.

5.1.2 Hospital Utilisation for PI Management of People with SCI

NSW patient data for people admitted with SCI and a primary diagnosis of PI revealed that over the five year period from 2006 to 2011 there were in total around 2,900 separations and around 82,500 bed-days.

The average length of stay per annum for a person with SCI and PI ranged from 26.7 to 34.1 days over the five year period, which is more than seven times higher than total state bed day average. Sixty per cent of people with SCI and PI had paraplegia, with 35% designated as having tetraplegia and 5% have an unspecified neurological level.

Figures 4-6 show the number of PI, episodes of care and total bed days by LHD, for people with SCI with less severe (stages \leq 2), severe (stages \geq 3) and unspecified PIs, respectively. Of note is that the majority of inpatient services for SCI (59% of the total bed days) were concentrated in three LHDs and hospitals (Royal North Shore Hospital in Northern Sydney LHD (NSLHD), Prince of Wales Hospital in South Eastern Sydney (SESLHD), and John Hunter Hospital in Hunter New England (HNELHD) with established inpatient, outpatient and/or communitybased spinal cord injury services. In addition, a greater proportion of more severe PIs (48% with \geq stage 3 PI) were in these three LHDs (**Figure 5**). It is likely that this reflects, at least in part, inflows from other LHDs for specialised surgical and interdisciplinary team management.

Table 4. Key utilisation variables for patients with a SCI and a PI whencompared to all patients admitted to NSW Acute Public Hospitalsin 2010-2011.

2010–11	NSW ACUTE PUBLIC HOSPITALS	SCI PATIENTS WITH PI
Average Length of Stay (ALOS)	3.8	27
Separations	1,576,866	673 (0.04%)
Bed-days	5,918,473	17,949 (0.3%)
Average Cost Weight (ACW) per separation	1.05	5

Data sourced from the NSW Health Annual Report, and derived from data provided by the CEE and NSW MoH.

Figure 4. Total bed days, episodes of care and number of pressure injuries (Stage \leq 2) in people with spinal cord injury across NSW for the period 2006 – 2011.



Source: NSW Admitted Patient data, Centre for Epidemiology and Evidence, NSW Ministry of Health

Figure 5. Total bed days, episodes of care and number of pressure injuries (Stage \geq 3) in people with spinal cord injury across NSW for the period 2006 – 2011.



Source: NSW Admitted Patient data, Centre for Epidemiology and Evidence, NSW Ministry of Health

Figure 6. Total bed days, episodes of care and number of pressure injuries (Stage unspecified) in people with spinal cord injury across NSW for the period 2006 – 2011.



Source: NSW Admitted Patient data, Centre for Epidemiology and Evidence, NSW Ministry of Health

It is important to note that the data does not capture the number of patients with existing PIs admitted for other reasons who receive PI management during that admission.

An unexpected outcome from analysis of this data was the finding that people with less severe (\leq stage 2) PIs have comparable bed day usage to people admitted with more severe (\geq stage 3) PIs. This could indicate inappropriate inpatient management of less severe PIs. However, it should be noted that a significant number of the PI episodes were coded as "unspecified".

Procedures

In NSW public hospitals between 2006-07 and 2010-11 the number of procedures provided to patients with SCI admitted with PI was 683. Nearly half (44%) of these procedures, together with the large majority of skin/muscle flap reconstructive surgeries, were conducted at RNSH (NSLHD) (**Table 5**) and POWH (SESLHD) where the two SSPISs are located. The majority of surgical activity in the remainder of hospitals related to excisional debridement or application of negative pressure wound therapy (NPWT). The top three most common procedures, which represent over two thirds of all procedures, were:

- Non-excisional debridement of skin and subcutaneous tissue (36%)
- Excisional debridement of soft tissue involving bone or cartilage (25%)
- Excisional debridement of skin and subcutaneous tissue (15%).

Approximately 12% of all procedures were skin flaps and less than 10% were split skin graft procedures. Amputations and excisions of ulcer of skin and subcutaneous tissues were relatively rare.

Debridement is an appropriate management for heavily contaminated or acutely infected wounds.⁴² Application of negative pressure wound therapy (NPWT) is an

increasingly appropriate management for stage III / IV wounds where bony infection (osteomyelitis) is treated concurrently.⁴³ Of concern, although it involves relatively few cases overall, is the number of surgical amputations for PI conducted outside of the hospitals with SCIUs. According to American Clinical Practice Guidelines, amputation should only be considered if the limb is not viable, there is overwhelming infection or malignancy and / or it is no longer functional.⁴⁴ Amputation of lower limbs has a significant impact on wheelchair seating and can lead to further PI development, particularly over the ischial tuberosities (ITs), as illustrated by Emily's story below.

Furthermore, amputations have been reported to reduce life expectancy in people with SCI by 35.4%³⁸. The current NSW data suggest there are a number of people with SCI and SB who have not had an opportunity for a multidisciplinary, early intervention PI management strategy, which may have reduced the need for amputation.

5.1.3 Hospital Utilisation for Pressure Injury Management by People with Spina Bifida

Analysis showed that over the period 2006 – 2011 around 390 separations and nearly 8,600 bed days were provided to people with SB who had PI as a primary diagnosis. **Figure 7** shows how these separations are distributed across NSW hospitals. Twenty three admissions to private facilities over the same period accounted for 728 bed days. The average length of stay for a person with SB and PI per annum ranged between 19.5 and 26.8 days over the five years and whilst this is less than the average for people with SCI it is still 5-6 times higher than the total state bed day average. **Figures 8-9** show the number of PIs, episodes of care and total bed days by LHD, for people with SB who have less severe (stages \leq 2), severe (stages \geq 3) and unspecified PIs, respectively.

Table 5. Proportion (%) of the total number of procedures undertaken in people with SCI / SB and pressure injury (2006 – 2011) in NSLHD and SESLHD compared to the rest of the State.

	DEBRIDEMENT (%)	NPWT (%)	SSG (%)	SKIN FLAP (%)	AMPUTATION (%)
NS/SES LHD	58	47	82	88	17
Other LHDs	42	54	18	12	83

Data sourced from the NSW Health Annual Report, and derived from data provided by the CEE and NSW MoH.

Emily's story

Emily is a 20 year old woman who was born with spina bifida and hydrocephalus. She came with her mum to the Spina Bifida Clinic for a second opinion regarding a pressure injury on her right foot that had become infected. She had been told that amputation was the only option for her, but Emily could not cope with the thought of losing her leg. The staff at the clinic agreed that she should try all other treatment options before accepting this opinion. Emily could do standing transfers and shuffle over very short distances with support and needed to maintain this level of independence. Unfortunately in the following year Emily was admitted to a second metropolitan hospital for cellulitis which required a right below knee amputation, an option Emily had previously rejected but now came to terms with. She subsequently developed a stage IV pressure injury under her right ischial tuberosity (sitting bone).

The Spina Bifida Clinic first became aware of Emily when contacted by the Community Nurse with concerns about Emily's mental health and wellbeing. The Spina Bifida Adult Resource Team (SBART) became involved and helped Emily with a new referral to a plastic surgeon, equipment review and arranging referral to a psychologist to assess and manage issues related to depression and body image. After another year Emily underwent a buttock rotation flap repair. On discharge from hospital Emily was referred to a case manager and allied health services. Four months after surgery and four years following her initial pressure injury on her foot Emily is pressure injury free, linked to an employment agency and playing wheelchair sport.

This is a real story, only the name has been changed.

Figure 7. Total bed days, episodes of care and number of pressure injuries (Stage \leq 2) in people with Spina Bifida across NSW for the period 2006 – 2011.



Source: NSW Admitted Patient data, Centre for Epidemiology and Evidence, NSW Ministry of Health Similar to SCI separations, three LHDs account for one-third of bed day utilisation by people with SB (**Figures 8-9**).

Figure 8. Total bed days, episodes of care and number of pressure injuries (Stage \geq 3) in people with Spina Bifida across NSW for the period 2006 – 2011.



Figure 9. Total bed days, episodes of care and number of pressure injuries (Stage unspecified) in people with Spina Bifida across NSW for the period 2006 – 2011.



Source: NSW Admitted Patient data, Centre for Epidemiology and Evidence, NSW Ministry of Health

With regard to the SB data, 26% of the PI stages were unspecified which indicates a problem with either clinical documentation of PIs or coding of PI stages. This is particularly important as unspecified PIs accounted for nearly one quarter of overall bed days.

5.2 Historical Service Utilisation and Cost

Data was extracted for the period 2006/07 to 2010/11 for all people with a SCI or SB being treated for a PI in a NSW public hospital. Cost data for this period was based on the average cost per cost weighted separation (CWS) (**Table 6**). Table 6 demonstrates the severity of PIs against episodes of care and total bed days. Unlike the SCI data, there were more people admitted with severe PIs with higher bed day usage.

Over the five year period it was found that:

- The number of separations rose from 554 in 2006/07 to 673 in 2010/11, showing an average growth of around 5% per year.
- The number of bed-days grew on average by 2.6% per year from 16,285 in 2006/07 to 17,949 in 2010/11.
- The number of cost weighted separations (CWS) increased from 2,694 to 3,789, representing an increase of around 10% per year. The main driver of this is an increase in volume, not complexity, as the average cost weight has remained stable.
- The annual cost of treating this group of patients in the acute care setting is just over \$AUD12.5 million with growth in cost over the period (from \$AUD10.7M

to \$AUD16.8M per year) attributed to the combined effect of growth in volume and cost indexation.

5.3 Business as Usual (BaU) - Current and Predicted Hospital Utilisation by People with a SCI or SB Requiring Treatment for a Pressure Injury

Projections for a 10-year period taking a BaU approach were undertaken to quantify and understand the impact of continuing current practice in terms of service utilisation and cost (**Table 7**) and to assist with planning implementation and evaluation of the MoC using it as a 'basis' for comparison.

Projections over a 10 year period from 2010/11 show that:

- The number of separations could increase by around 4% per year, which is slightly lower than the current trend.
- The number of bed days could increase by around 4% per year, which is likely to reflect the net effect of a slight reduction in the ALOS and an overall increase in predicted increase in hospitalisations.
- Complexity of patient care may increase marginally, which along with an increase in separations and the application of cost indexation, will increase the cost of care by around 14% per year. However, caution should be used when interpreting this figure as there is uncertainty around the methodology for cost escalation.

	AVERAGE PER YEAR 2006/07 TO 2010/11	TOTAL OVER PERIOD
Number of separations	578	2,888
Number of bed days	16,502	82,511
Sum of cost weights	3,022	15,111
Average Length Of Stay	29	N/A
Average Cost Weight Separations	5	N/A
Total Cost (\$)	12,645,968	63,229,841
Average cost per episode (\$)	21,879	N/A

Table 6. Service utilisation and cost data for people with SCI or SB with PIs inNSW Public Hospitals in the 5-year period 2006/7 to 2010/11

Table 7. Summary of the 'Business as Usual' Projections for people with a SCI or SB requiring treatment for PI

BUSINESS AS USUAL	10 YEAR TOTAL
Number of separations	8,053
Number of bed days	220,281
Sum of cost weights	52,816
Sum of total National Weighted Activity Unit (NWAU)	57,318
Average length of stay	27
Average cost weight separations	7
Total Cost \$AUD	303,248,998

5.4 Community Management

There is a lack of data regarding the management of PIs for people with SCI/SB in the community. It is estimated that there are currently around 1,950 people with SCI and SB with PIs in NSW. This is based on the 30% community prevalence rate for the 6,500 people with SCI and SB living in NSW.

Table 8 outlines the expected timeframes for healing for PIs which are managed in the community.^{19, 21,} ²² It also identifies the resources required, as well as their frequency and timeframes, based on clinicians' experience, expert opinion and non-admitted occasions of service. It demonstrates the increasing use of resources over longer periods of time, which are required to manage increasingly complex clinical and psychosocial sequelae of PI.

Although the PI may heal within the timeframes indicated in **Table 8**, the skin remains fragile and more prone to breakdown for a much longer period, reaching only up to a maximum of 80% of the tensile strength from the original intact skin.⁴⁵ Further breakdown of re-wounded skin reduces the tensile strength even further. It can take up to a further two years for skin structure to mature and complete healing in complex wounds. This has important practice implications for continuing close follow up in those at greatest risk of recurrence due to excessive shear, friction or ischaemia.

The SSPIS clinicians report there are frequently delays of

months and in some cases years, in people being referred to these services without having had an appropriate management plan in place. Anecdotal evidence suggests this may occur for various reasons, including underestimating the significance of the problem, not being aware of available specialist services or not wanting to refer unless the situation escalates.

Clinical experience shows that when wound healing is delayed for more than three months the chance of conservative healing is reduced, the risk for psychological injury is increased and patient treatment becomes more expensive with increased complexity, hospitalisation and surgical intervention more likely. A strong case can be made for enhanced linkages between specialist SCI services and SB services, and between SCI/SB services and local hospital/community health staff who may have less expertise, familiarity or resources to manage Pls in people with a SCI or SB. This will help ensure best practice recommendations from specialist services are implemented and regular follow up and wound monitoring is undertaken. Barriers to the implementation of best practice care in non-specialised settings may include an inability to access necessary equipment such as a suitable pressure relief mattress, community based occupational therapy services, or temporarily increase attendant care hours to maintain 24-hour bed rest.

Community costs were not included in this analysis due to lack of available data. Further work involving a whole of government approach will be important for building community costs into the MoC analysis.

Table 8. Expected timeframes and resources required for improvement andhealing pressure injuries in the community

PRESSURE INJURY STAGE	TIME TO IMPROVE	TIME TO HEALING	COMMUNITY RESOURCES	REQUIRED FREQUENCY OF INTERVENTION
Stage II	7 - 14 days	14 - 21 days	 GP Nurses Occupational therapists Attendant carers Dietitian Alternating air mattress General wound dressings 	Monthly 2 visits / week 1-2 visits Increased hours < 6 wks 1-2 visits < month 1-2 months
Stage III / IV	14 - 28 days	4½ - 5 months	 GP Community nurses Specialist wound care nurse Occupational therapists Attendant carers Dietitian Social work Alternating air mattress Specialist wound dressings 	Fortnightly 3 visits / week 1-2 visits 3 -4 visits Increased hours > 6 wks 3-4 visits Monthly 3 - 5 months 3 - 4 months
Deep, infected wound with exudates, slough and necrosis		5 – 6 months	 GP Nurses Specialist wound care nurse Occupational therapist Attendant carers Dietitian Psychologist Alternating air mattress Specialist wound dressings 	Weekly 2nd daily 6-8 visits 4-6 visits Increased hours > 12 wks 4-6 visits Fortnightly > 6 months 4-6 months

6. MODEL OF CARE

6.1 Key Principles of the Model

Broad key themes emerging from the consultations with over 130 stakeholders across the continuum of health and community care in NSW are described below. An overarching concept for the model was prevention at all levels, involving primary, secondary and tertiary prevention strategies, to manage increasing levels of risk for Pls in the person with SCI/SB.

Analysis of these interviews identified a number of issues which have been summarised into eight main themes:

- Problems with access Both consumers and clinicians reported limited access to essential equipment, assessment, information, advice and expertise from required disciplines and increased attendant care support to maintain bed rest. People living in rural/ remote areas of the state and people with SB also reported issues around equity of access, particularly to specialist multidisciplinary pressure injury services.
- *Fragmented care* There was overall consensus that a lack of communication and collaboration between sectors and services contributed to fragmented service provision and sometimes protracted management, with consumers often finding it difficult to navigate the system.
- Need for prevention There needs to be a stronger focus on preventing pressure injuries before they occur, and on how to collaborate with consumers to develop lifestyle and behaviour change strategies to prevent a pressure injury from recurring.
- Self-management support Both clinicians and consumers expressed the necessity in most cases for the person with SCI/SB to assume responsibility for their injury / condition and play an active role in coordinating and managing their care.
- Greater use of health technology A key avenue identified for addressing gaps in access, collaboration and communication was through increased use of health technology, such as videoconferencing, email/ phone help line.
- Capacity-building and workforce development It is neither possible, nor appropriate that the specialist spinal and SB services assume the entire care

responsibility for this population. Clinical support and regular education sessions should be provided to build the capacity of the workforce in local areas for clinicians, consumers and carers so that suitable management and onward referral occurs for these patients.

- Increased psychosocial support The person with SCI/SB needs adequate psychosocial intervention to assist with the emotional and psychological impact of their injury/disability to minimize the development of inappropriate coping mechanisms, together with personal care support to ensure they can maintain integration into the community.
- *Resource development* There need to be sufficient resources to allow for best practice pressure injury management including equipment, workforce and finances to fund the additional costs incurred by the person with SCI/SB.

From these themes, three key principles were identified.

- Principle 1 Self-management
- Principle 2 Timely and equitable access
- Principle 3 Integrated care.

For the purpose of this MoC, a principle has been defined as a statement of intent for what is to be achieved. The premise is that the principles and their related strategies apply to every aspect of PI prevention and management across all care settings.

PRINCIPLE 1: Self-Management

Individuals to take ownership of their condition and actively contribute to care planning or have appropriate support to do so

A broad range of self-management models have been developed and implemented, both locally and internationally. These include the Flinders University Model (Programme) for Chronic Condition Self-Management ⁴⁶, the Stanford Chronic Disease Self-Management Program ⁴⁷ and the United Kingdom National Health Service Expert Patients Programme ⁴⁸.

Jayne's story An example of self-directed self-management

Jayne has had paraplegia for 10 years. One night she notices a scrape on her buttock during her routine skin inspection. She remembers that she bumped against her wheelchair tyre during one of her transfers that day. After cleaning and covering the area, she puts herself to bed and positions herself off the grazed area. She makes a list of people she needs to call in the morning to inform them of her situation. This includes her attendant care coordinator, local doctor and the occupational therapist working at her local community health centre.

Jayne currently receives 1½ hours per day for personal hygiene in the morning and a check at bed time. She tells the coordinator that she has additional care requirements and will need extra time for bowel care in bed, set up with medications and fluids, telephone etc, an extra service in the middle of the day for meal preparation and repositioning and to make sure she is OK, in addition to her night check which will require more meal preparation, replenish fluids etc. The occupational therapist was able to give advice on several pressure reducing mattress companies who could provide equipment on the same day. Her local doctor was able to make a home visit the next evening and recommends referral to the community nurse for wound monitoring and dressing as well the insertion of a temporary catheter. The community nurse comes the next day.

This is a real story, only the name has been changed.

When considering the principle of self-management in the context of children with SCI / SB, there needs to be a greater emphasis on the family unit and how they can empower the child to make decisions taking into account the child's level of development and cognitive capacity.

NSW Health has defined three levels of self-management which need to be modified to include the family unit when working with the child, as described below.

Self-Directed Self-Management is where individuals can make informed decisions to effectively self-manage with minimal health professional input after developing the requisite knowledge, skills and confidence to care for themselves and source appropriate assistance when required.⁴⁹

Collaborative Self-Management is when decisions are made in partnership with responsive multidisciplinary health care providers. The individual can identify their needs and priorities. The health care provider delivers information and teaches skills based on needs and priorities. The healthcare provider gives support aimed at enhancing self-efficacy.⁴⁹

Steven's story An example of collaborative self-management

Steven is 8 years old when he was in a car accident and suffered a complete C7 spinal cord injury. Staff observed a 'boggy' area on the back of his skull on removal of his Philadelphia collar. This pressure injury broke down during Steven's rehab admission. Wound management, including education for the family regarding the importance of skin care, was commenced. The wound was almost healed when Steven was discharged, however it broke down shortly afterwards. His family identified the skin breakdown was caused by the temporary wheelchair set up as Steven regularly forgot to protect the area.

The spinal CNC provided advice and support to Steven's family as they commenced their wound management. The CNC engaged with local nurses to work with the family and together they worked out a plan that took the family's goals into consideration. She liaised with the OT and Lifetime Care Support Authority (LTCSA) case managers to facilitate funding and advocate for a new wheelchair. She also provided remote support to the family, the local community nurses and the spinal team on a weekly basis using wound photography via email to monitor progress. Steven's new wheelchair arrived two weeks after Steven's plan was developed and his wound healed within one month.

Peter's story An example of collaborative self-management

An OT phoned the spinal specialist seating service to advise that a client Peter (a 20 year old man with tetraplegia residing in a remote rural location) had red marks on his buttock cheeks. His carer had noticed the marks two weeks ago but was unable to determine the cause. He called the community nurse who commenced treatment for thrush and suggested limiting sitting time however with little improvement. The nurse also made a referral to the OT at the initial assessment. The situation had now become extremely urgent because Peter was about to depart on a cruise leaving Sydney in five days' time. Discussion between staff of the seating service and the OT revealed that his wheelchair cushions were still within but close to the end of the manufacturers recommended usage time.

Due to time constraints it was not going to be feasible to obtain new cushions in time and, neither Peter nor the clinicians were sure whether the same cushion type should be used in the future. The seating service was able to send (via overnight freight) a gel pad in good condition for loan, and a custom made piece of foam to supplement the suspected collapsed foam in Peter's current cushions. Because the OT was not able to visit Peter prior to the cruise, the seating service clinicians briefed the family on the plan, explaining the method for fitting the custom foam pad and how to do a hand check under the ischial tuberocities (sitting bones) before and after making the changes to check for improved clearance. Peter trialled this revised cushion in the few days prior to the cruise without any re-appearance of red marks. Peter was able to complete his cruise.

Supported Self-Management involves coordinated and intensive support from health, disability and other community service providers for individuals assessed as having low capacity to self-manage. These individuals will be high risk for PIs and have complex comorbidities. Case management is a suitable approach to care for these individuals in order to anticipate, co-ordinate and connect health and social care, whilst fostering self-efficacy.⁴⁹

Thomas' story An example of supported self-management

Thomas is 29 years old and has a lumbar myelomeningocele spina bifida with associated hydrocephalus. He recently experienced the death of his mother, who was his primary carer. On attendance at a Spina Bifida Clinic, staff noticed that he was poorly groomed and incontinent. During the consultation, Thomas admits that his elderly mother had helped him with personal care, making his meals and ordering his continence equipment. He had run out of catheters and didn't think about ordering any more. When staff asked where he usually got his catheters from, he became upset stating "That was Mum's job! I don't know how to do it or where she got them from!".

Staff suggested that they could help Thomas with placing an order and get someone to come and help him with showering. Thomas was resistant because his mother always used the phone to make the order and staff wanted to use the internet. He allowed staff to make a referral to attendant care services for personal care and domestic assistance, but he was clear that he didn't need any help from anyone. However, he did agree to SBART coming to his home for a visit. This follow up visit occurred within the next week and over a period of three visits they were able to support Thomas to accept attendant care and case management. Thomas also identified some vocational and recreational goals that SBART were able to facilitate for him.

PRINCIPLE 2: Timely and Equitable Access

Develop a service delivery model that is flexible in meeting the needs of people with SCI / SB and PIs and provide timely and equitable access to services, equipment and resources across the continuum of care

Timely and equitable access to appropriate community services, primary and specialised health care, equipment and education are essential to facilitate this preventative model. These are often more difficult for people with SCI living in rural communities to access than for those residing in metropolitan areas. Thirty seven per cent of people with SB and approximately 30% of people who sustain SCI return to live in rural and remote regions of NSW, where in addition to a general workforce shortage and undersupply of health practitioners, few rural health professionals are specifically skilled or adequately resourced to address the unique, often complex needs of the SCI population.

Figure 10 demonstrates the interconnectedness and range of the services, care, equipment and resources that are required in a timely fashion to support the person and their family to prevent occurrence, deterioration or recurrence of Pl.

• Personal care Alternating air • Domestic assistance mattress Nutritional support • Electric high-low bed • Informal support Family/ systems • Slide sheets Carer • Dressing products • Transfer aids Psychological Cushion and wheelchair maintenance / replacement Equipment Care Person Resources Services • Primary health Telehealth services • Electronic media Spinal consumer Screening and organisations assessment tools • Specialist health Education & services information Psychosocial material support services Diversional therapy Partnerships concepts between sectors

Figure 10. Core access elements required to support the person

PRINCIPLE 3: Integrated Care

Care is connected and aligned with collaboration occurring within and between the health and community care sectors for patients with complex, long term problems cutting across multiple services, providers and settings³⁷

Integrated care can be defined as the provision of person centred care in which health and community services work with each other and the client to ensure coordination, consistency and continuity of care occurs through the different stages of PI prevention and management. Relationships are nurtured and maintained through involvement in planning where expected activities are clear to all involved and supported to reach a common goal. The model is not only contingent on engagement of the individual with SCI or SB, their care providers, the health service, primary care and other community providers, but also on intersectoral collaboration to bridge between sectors and government departments.

6.2 Model of Care Development

The Model of Care for Prevention and Integrated Management, developed through a collaborative process of stakeholder consultation with clinicians, consumers and carers, focuses on health promotion, prevention and early intervention. It aims to maintain the health status of a person with SCI or SB and reduce the extent and number of PIs through improved self-management support, better risk identification, employment of risk reduction strategies, and mobilisation of early treatment strategies. Critical to all of this is a system for monitoring and detecting deterioration to ensure timely and appropriate referral to more specialised services.

This requires a collaborative, proactive approach involving the person with SCI or SB, family members and carers, community resources and organised health systems, as illustrated by the Wagner's Chronic Care Model¹ in **Figure 11**. The approach is recommended by the World Health Organization for management of all chronic conditions across care settings. What is not





Functional and Clinical Outcomes

Source: EH Wagner. Chronic Disease Management: What Will It Take To Improve Care for Chronic Illness? Effective Clinical Practice, Aug/Sept 1998, Vol 1.

overtly stated in Wagner's model is the fundamental need for partnerships between and across the community and the health care system, with an informed motivated patient at the centre. The "person-centred medical home"⁵⁰ model provides an example of a way to wrap a primary care provider and their integrated care team around the person and their family, acting as a gateway to more specialised services as required.

In 1975, Leavell and Clark further developed their initial agent, host, environment model ² and advocated for a model delineating three levels of prevention (namely primary, secondary and tertiary). This has been widely applied in both public health practice and ambulatory care delivery worldwide to promote health and to arrest disease processes at different points along the continuum. Further, the conceptual model linking risk stratification with the level and type of intervention required is outlined in Section 6.4.

6.3 Risk Assessment and Management

In the context of SCI, numerous individual risk factors have been identified that include various demographic, physical, psychosocial, behavioural and environmental elements⁵¹ although to what extent and how they might interact to increase risk is less clear. Incorporating a systematic process of risk evaluation into the model would support better decision-making, treatment planning, communication, monitoring and reviewing risk with consistent application of policies, procedures and practices. Commonly used tools for assessing PI risk in general hospital populations, such as the Waterlow and Norton scales, have not been tested for their appropriateness and validity in the SCI population and therefore likely to be less useful.³⁶ A scale developed specifically for SCI has been insufficiently tested and devotes little attention to psychosocial risk factors.⁵² The Glamorgan risk assessment tool is used in the paediatric context as it has been formulated specifically to the requirements of children.^{53, 54} Additionally, tools used are in addition to and not a replacement for clinical judgement. Of greater importance is the action taken to address risk once it is identified.

The complexity and multi-faceted nature of PI occurrence was underscored in a detailed qualitative study which examined daily routines and activities, personal choices, motivating influences, lifestyle challenges, and prevention techniques and strategies within life contexts for people with SCI.⁵⁵ The authors conceptualised a person's risk profile in terms of interacting physical, mechanical, health-

Table 9. Example of psychosocial 'liabilities' and 'buffers' (latter shown in bold)

PSYCHOSOCIAL 'LIABILITIES' AND 'BUFFERS'

- Poor awareness of cause and skin care versus good knowledge of preventative techniques
- Depression/hopelessness, perceived lack of control versus **positive**, **resilient**, **high self-efficacy and self esteem**
- Disengagement versus motivation
- Poor planning, problem-solving and inflexibility versus good planning, problem-solving and flexibility
- Risk-taking versus cautiousness
- Isolation versus social support
- Lack of attendant care and finances versus adequate care/finances

Adapted from Clark et al, 2006⁵⁵

related behaviour, psychological, social and environmental "liabilities" and "buffers" (as shown in **Table 9**), which, when taken together, influence the nature, frequency and severity of "change events" that unfold in the context of daily life and in PI risk episodes.

Given the high likelihood of a person with SCI/ SB developing a PI at some point in their lifetime, a focus on supporting the person to reduce the risk of both occurrence and deterioration of a PI is extremely important. An effective way this can be achieved in the majority of people is to support and empower the person to self-manage. This strategy is supported by findings from an American study of over 600 people with SCI five years or more since injury, in whom 70% reported having experienced no PIs or a PI soon after injury, but few later on.⁵⁶ Seventeen percent, however, were classified as recurrent (developing a PI every couple of years) and 9% as recalcitrant (reporting a PI arising at least once a year). A further 4% had PIs on an almost constant basis, often requiring hospitalisation. It is clear that in these latter 'high-risk' groups, with their low capacity for self-management and various significant behavioural, psychological, social and environmental predisposing factors (as shown in Table 10), contact and intervention may need to be structured differently for harm minimisation using assertive follow-up, classic conditioning techniques and more support through a third party.

Table 10. Example of personal and environmental characteristics for riskstratification for adults to determine service types, intensity andextent of specialist intervention needed

LEVEL OF RISK	PERSONAL/ENVIRONMENTAL CHARACTERISTICS
Low	 Employed, high school or better education Self-management skills with high capacity to direct care, problem solve and troubleshoot Good health literacy, general protective health behaviours and high engagement with primary health care providers Adjusted to disability with good coping skills Good social support
Moderate	 Increased time since injury/ageing Socioeconomic and educational disadvantage One co-morbid condition* Obesity, smoking, poor continence management Recent illness or hospitalisation Recent weight loss / gain Inappropriate or old (>5 years) equipment History of blanching marks to skin High number of car and commode transfers Postural asymmetry of trunk, pelvis or lower limbs with fixed contractures Limited interaction with primary health care providers Reduced capacity to direct care, problem solve and troubleshoot Hydrocephalus
High	 Significant mental health, drug & alcohol use, severe traumatic brain injury or severe hydrocephalus diagnosis Two or more chronic co-morbidities* Malnourishment Damaged or no equipment Musculoskeletal upper limb impairment affecting transfers Previous history of pressure injuries and plastic surgery (sacrum>IT>trochanter) Poor coping, low self-efficacy and motivation, poor adjustment and acceptance of disability, behavioural disengagement Poor social support/isolation Obesity, smoking, poor continence management

*includes metabolic, respiratory, cardiac, renal and hepatic impairments / disease

6.4 The Model of Care for Prevention and **Integrated Management** of Pressure Injury

The Model of Care for Prevention and Integrated Management of Pressure Injury builds on the key principles and themes defined through the consultative process and outlined in section 6.1, as well as the specific models discussed in section 6.2, to develop a responsive, personcentred, integrated systems approach. The model focuses on:

- evidence-based practice
- organisation and/or coordination of care, practice systems and provider roles
- improved person self-management support
- increased access to expertise and resources, and
- greater use of clinical information.

Figure 12 represents the three-tiered MoC incorporating risk stratification with levels of prevention or intervention from largely self-management at the base, comanagement in the centre and specialist management at the peak. The diagram also demonstrates how individuals can shift from higher to lower levels of risk and push back the health care interface through increased ownership or support to manage their condition. When

applying this model to a paediatric context, there needs to be consideration of the developmental level of the child and recognition of the importance of a family centred approach to improving self-efficacy.

There is a key role for specialist spinal PI services and other specialist services to build capacity at a local level through development of networks, promoting opportunities for management with shared care, provision of education programs, and supporting the clinician to develop the skill required to confidently manage these groups of people. Opportunities exist within existing Spinal Outreach and Rural SCI Services to develop and support specialist spinal nurse 'champion' roles to provide expert support/liaison/ linkage, communication, self-management support, education, case management and coordination in a hub and spoke model.

It is possible that demand for the specialist spinal PI services will increase in the short to medium term as the model is implemented and thus may also lead to increased surgical activity, as awareness of the model is promoted. The MoC strongly recommends that care of complex patients and those requiring surgical advancement or rotation flap repairs be performed under the care of the specialist plastic surgeons in the spinal cord injury units in Sydney, where the person can receive expert interdisciplinary medical, nursing and allied health management.

Figure 12. Reducing the level of risk through enhancing self-efficacy



With implementation of this new model, providing improved health promotion, earlier detection and intervention with improved assessment, decision support, timely access to equipment and care coordination, a

Adapted from the Kaiser Triangle, Expert Patient Program ³

significant reduction in frequency and/or severity of PIs is expected. This will result in shorter hospital length of stay, reduced duration of bed rest at home and less work days lost.

7. PHASES OF CARE

The MoC identifies three main 'phases' along the PI patient journey (see **Figure 13**), where interventions occur to either prevent occurrence, deterioration or recurrence of PI in this patient population. The remainder of this chapter will outline what is required and how this can be achieved for each phase.

Figure 13. Phases of Care along the PI Patient Journey



7.1 Phase 1: Health Promotion

The person, carer or parent will take active measures to prevent PI.

Health promotion is the core function of the first level of prevention described by Leavell and Clark.² Interventions at this stage are designed to prevent a disease or condition from occurring.

When applied to this MoC, this phase of the patient journey is concerned with preventing pressure injury from taking place. Some of the key activities used in this phase include screening, education and/or population health measures.

Table 11. Patient Journey – No Pressure Injury (PI)

PERSON WITH NO PI	RECOMMENDED TIMEFRAME	RECOMMENDED MANAGEMENT SSTRATEGIES TO MONITOR AND MAINTAIN SKIN INTEGRITY
Ŀ	Ongoing	 Fully engaged in community participation able to report gaps in ability to fully participate to appropriate service Has the appropriate equipment to support and assist with mobility, activities of daily living, community access and prevention of pressure injuries Vocational and recreational pursuits fulfilled Directs attendant carers in activities of daily living Participates in improving health literacy Accesses resources available to support independence Maintains personal health record Has a good understanding of early intervention strategies required when early signs of pressure injury are evident Has discussed with health care and support services escalation plan and needs if health or skin integrity are at risk of deterioration
Ċ	3 – 6 monthly	 Visits GP Medication Screening Health checklist Review of change in risk factors which may require escalation plan to prevent deterioration
Ċ	Annually	• Visit to spinal specialist /multidisciplinary team is recommended, in particular for individuals at risk of pressure injury and or deterioration of SCI related issues
Ċ	As required – monthly	 Accesses Community Health Services Catheter changes Equipment assessment checklist Equipment and aids prescription Assisted to achieve goals of health management plan

Table 12. Model of Care Principles applied to the Health PromotionPhase of Care 1

NO PRESSURE	PHASE 1 - HEALTH PROMOTION
Ĵ.	AIM - To support the individual to self-manage or to direct their care and interventions to
Pressure injury care, support and prevention strategies for an individual with a SCI/SB	
Self-management	To achieve self-management the individual will have: • Well-developed self-management skills or is competent with guiding care • Good health literacy • Access to educational resources / information & advice • Well-developed adjustment skills
Assessment of risk of pressure injury	The individual / their carers will require knowledge and understanding on how to undertake regular assessment of skin status and level of risk for pressure injury.
Management of skin integrity &/or pressure injury	 To prevent skin breakdown the individual / their carers will require: Knowledge and understanding on how to maintain clean and healthy skin and how to implement injury prevention, early intervention and pressure relieving strategies. Information on where to seek advice and support when a pressure injury does not improve with early intervention strategies.
Care / support	The individual will require sufficient care and support to maintain skin integrity and prevent skin breakdown.
Equipment	 The individual / their carers will require: Access and ability to use appropriate equipment that helps prevent pressure injury. Information about where and how to access supply, review, replacement (purchase/hire), or repair of their equipment which will help them prevent and/or manage pressure injury.
Management of general health	 To maintain their general health the individual will require: Regular contact with their general medical practitioner (GP) Periodic review of general/physical / mental / emotional health status (including nutritional screening), functional capacity & equipment. Access to information and advice for pressure injury prevention, early intervention and management. Processes for recording health history (ie personally controlled electronic health record). Support and guidance in completing a Health Management Plan which clearly outlines their health care & support needs and is available to their care/support providers. Annual referral to spinal specialist multidisciplinary team for review
Access to community based clinicians (eg RN, OT, dietitian, physio, psychology)	 The individual will require: Access to appropriate health information, eg. nutrition, podiatry services for lower limb health, etc. Access to information and advice for pressure injury management. Timely referral to community based clinicians with the aim of optimising health maintenance, physical and psychological health, nutritional status, and community access and independence. Nutritional screening, education and planning.

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NO PRESSURE INJURY	PHASE 1 - HEALTH PROMOTION Maintenance of skin integrity and prevention of pressure injury
Peer support	The individual is encouraged to access local peer support programs for people with a SCI.
Spinal and pressure injury management specialist services	 The individual will require: Information about how to seek referral to spinal specialist services. Annual referral for multidisciplinary spinal specialist review and assessment Support and guidance on how to action spinal specialist advice and recommendations provided in their transfer of care plans at discharge from specialist services regarding assessment, prevention and early intervention strategies for pressure injury, and a successful transition and return to community living. Timely referral to spinal specialist pressure injury and seating services if risk of pressure injury increases or skin breakdown occurs.

7.1.1 Outcome Measures for Phase 1 may include the following:

- The individual does not develop a PI.
- The individual's level of risk is reduced or maintained.
- The individual, carer and / or family is aware of and supported to do what needs to be done to protect the skin from PI.
- Equipment is well maintained and assessed as required.
- The individual, carer and / or family is able and / or supported to recognise when PI is occurring and take necessary steps to prevent progression.
- Screening and assessment tools flag opportunities for health care providers to work on potential physical and psychological health related problems.
- The individual, carer and / or family has high engagement but low interaction with primary health providers.
- Care of the individual is coordinated / managed
- Increased knowledge and awareness of nutrition in prevention of PI.
- Nutritional status is optimise and healthy weight maintained.

Example of a resource to support health promotion in young people and adults with SCI.

The Spinal Outreach Service (SOS) developed a questionnaire (SOS-HQ) to assist in the identification of new problems, raise an alert for areas of risk (eg red and yellow flags) and prompt preventive care activities. It can be used to develop a General Practice Management Plan and plan team care arrangements. Covering the SOS-HQ in sections can facilitate a 12-month cycle of preventive health care, allowing systematic monitoring and increasing intensity/coordination of professional input for those identified with greatest need. This document is available from: http://www.aci.health.nsw.gov.au/networks/spinalcord-injury/resources (cited November 2013)

7.2 Phase 2a - Intervention (Pressure Injury ≤ Stage II)

The person, carer or parent will take active measures to prevent PI from deteriorating.

Health maintenance is the core function of the second level of prevention described by Leavell and Clark.² Actions at this stage are designed to identify specific illnesses at an early stage with prompt interventions to prevent a disease or condition from deteriorating.

When applied to this MoC, this phase of the patient journey is concerned with early identification and interventions geared toward preventing PI from worsening. Some of the key activities used in this phase include diagnosis, prompt treatment and disability limitation.

Table 13. Patient Journey – \leq Stage II Pressure Injury (PI)

PERSON WITH NO PI	RECOMMENDED TIMEFRAME	RECOMMENDED EARLY INTERVENTION AND MANAGEMENT STRATEGIES TO PROMOTE HEALING AND PREVENT DETERIORATION
S.	Ongoing	• A situation or event results in early signs of PI development which can deteriorate to Stage II within 12 hours
ê.	Within 12 – 48 hours of evidence of Stage II PI	 Stage II Pressure Injury Cause identified Community nurse contacted Individual with SB contacts SBART Air mattress hire company is contacted Specialist spinal seating service is contacted Attendant care coordinator is contacted regarding need for increased care requirements Early pressure injury therapy commences with patient's full understanding of what is required (eg. complete 24hour bed rest)
e E	Within the first 2 – 4 weeks of Stage II Pl	 Community Nurse: Completes comprehensive assessment with wound CNC / specialist Seeks advice from SSPIS Seeks advice from specialist spinal seating Service Monitors wound therapy Refers to community OT for equipment review if applicable Seeks increase in care hours from ADHC to support 24 hour bed rest Assesses psychological state
e contraction de la contractio	Approximately 6 – 8 weeks following development of Stage II PI	 Return to seating program supervised by Community nurse and OT Follows recommended intervention strategies outlined in the Restoration and Rehabilitation section – Table 17-, to support return to full community participation

Table 14. Model of Care Principles applied to Intervention (≤ Stage II) Phase of Care 2a

BREAKDOWN OF SKIN INTEGRITY (Pressure Injury ≤ Stage II)	PHASE 2A - INTERVENTION (PRESSURE INJURY ≤ STAGE II) Early intervention and management of pressure injury and reduction/removal/ minimisation of risk(s) causing the pressure injury
Ĩ	 AIM: To support the individual to: Reduce risk behaviours / factors Seek increase in support to facilitate and implement early intervention strategies Seek primary health care review and early intervention pressure injury management strategies Seek referral to specialist services when improvement is not evident &/or deterioration occurs Receive timely specialist advice and intervention
Pressure in	jury care, support and management strategies for an individual with a SCI / SB
Self-management	 To support ongoing self-management following breakdown of skin integrity the individual will require: Assessment of readiness to change pressure injury risk behaviours. Assessment of ability to direct carers in the care and support required to implement early intervention strategies. More directive processes to assist with decision making. High/increased level of assistance to identify, initiate and coordinate management strategies.
Assessment of risk of pressure injury	 To determine change in level of risk for pressure injury resulting in skin breakdown, the individual will require: Assessment of: change in level of risk and causative factors risk of further deterioration of skin breakdown/wound readiness to make changes to reduce pressure injury risk behaviours.
Management of skin integrity &/or pressure injury	 To manage the loss of skin integrity / pressure injury ≤ Stage II the individual will require: Access to information and advice for pressure injury prevention and management. Assessment of readiness to implement and sustain (and or ability to direct their carers to implement) early intervention pressure injury management strategies. Shared care arrangements – individual/carer, GP, community based health care staff, specialist advice. GP who can provide overall management. Increased level of assistance and support from health care provider to ensure all early intervention strategies to manage pressure injury are initiated, maintained and regularly reviewed for effectiveness. Contact with specialist spinal cord injury service to flag potential deterioration and / or compliance with treatment.
Care / support	 The individual with a pressure injury ≤ Stage II will require: Support from clinicians with motivational interviewing techniques to establish pressure injury management planning. An increase in care/support hours or access to respite care arrangements where pressure injury management strategies can be supported and risk for deterioration minimised, including extended periods of bed rest.

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BREAKDOWN OF SKIN INTEGRITY (Pressure Injury ≤ Stage II)	PHASE 2A - INTERVENTION (PRESSURE INJURY < STAGE II) Early intervention and management of pressure injury and reduction/removal/ minimisation of risk(s) causing the pressure injury
Equipment	 The individual with a pressure injury ≤ Stage II will require: Timely access to emergency supply of pressure reducing equipment and personal / domestic assistance.
Management of general health	 To maintain their general health the individual with a pressure injury ≤ Stage II will require: Staff familiar with motivational interviewing techniques to support the individual to make health improvements. Increased frequency of review of physical / mental / emotional health status (including nutritional screening), functional capacity and equipment. Care coordination from primary health care provider/ GP with support from local spinal champion or escalation to spinal pressure injury specialist CNC. Baseline pathology testing. Assessment of pain and pain management plan.
Access to community based clinicians (eg RN, OT, physio, dietitian, psychology)	 The individual with a pressure injury ≤ Stage II may require: Clear communication pathways between clinicians and health sectors to ensure a consistent and considered management approach. Referral to a dietitian for those identified at nutritional risk. Appropriate nutritional supplementation for wound healing. Professional psychological support to make behaviour changes and to maintain pressure injury management strategies. Social work support to manage impact of pressure injury on employment, income and community access. OT assessment of and management strategies for risk factors for pressure injury related to equipment and activities of daily living. Referral to drug & alcohol services as required.
Peer support	The individual with a pressure injury ≤ Stage II should be referred to or encouraged to contact local peer support services who provide support and encouragement in reducing risk behaviours and in implementing and maintaining early intervention pressure injury management strategies.
Spinal and pressure injury management specialist services	 The individual with a pressure injury ≤ Stage II showing signs of deterioration and or increase in level of risk will require: Information and advice from a spinal specialist pressure injury service. Referral to spinal seating specialist service. Referral and timely access to spinal specialist pressure injury service: If wound does not heal within specific timeframe or there is deterioration in wound / health status, for debridement and/ or negative pressure wound therapy (NPWT), Care coordination provided by specialist spinal pressure injury CNC Follow up surgical review to assess appropriateness of flap surgery.

7.2.1 Outcome Measures for Phase 2a may include the following:

- the individual's PI does not deteriorate
- the PI heals without hospital intervention
- the PI heals within two weeks for the low, four weeks for the moderate and six weeks for the high risk individual
- the individual, carer and/or family accesses / is supported to access the PI management resources
- the individual, carer and/or family is aware of / supported to do what needs to be done to prevent deterioration
- assessment and management tools support health care providers to develop PI management plans in collaboration with the individual
- local health care providers are supported to provide PI management to these individuals
- care of the individual is coordinated / managed
- psychosocial effects of PI management are reduced.

Example of a resource to support community based PI intervention for young people and adults with SCI/SB.

Lighthouse Health Group provides an e - health wound service via phone, computer, photography or videography to provide access to expert wound care advice. They advertise a 24 hour response time on receipt of required forms and report a 70% reduction time for wound healing when using this method (conducted with rural clients) <u>http://www.lighthousehealthgroup.com/</u> <u>content/view/67</u> (cited January 2014)

7.3 Phase 2b - Intervention (PI \geq Stage III)

The person, carer or parent will take active measures to prevent PI from deteriorating.

Health maintenance is the core function of the second level of prevention described by Leavell and Clark.² Actions at this stage are designed to identify specific illnesses at an early stage with prompt interventions to prevent a disease or condition from deteriorating.

Stage III and other more severe PIs are described

depending on the extent of muscle and bone destruction. It is well documented that once injury involves deep musculature or disruption to the fascia, it is necessary to seek a surgical opinion^{21, 22} and the likelihood for surgical intervention to heal the defect is thus increased.

Despite the severity of these PIs this phase of the patient journey is still concerned with early identification and interventions geared toward preventing PIs from deterioration. However, the clinical context in which this occurs will be different. The key activities used in this phase include diagnosis, prompt treatment and disability limitation.

Table 15. Patient Journey – Intervention (PI \geq Stage III)

PERSON WITH A ≥ STAGE III PI	RECOMMENDED TIMEFRAME	RECOMMENDED EARLY INTERVENTION AND MANAGEMENT STRATEGIES TO PROMOTE HEALING, PREVENT DETERIORATION OR ESCALATE FOR SPECIALIST SERVICES
e Cr		• A situation or event results in early signs of PI development which which rapidly deteriorates to \geq Stage III pressure injury
	Within 12 – 48 hours of evidence of deterioration to ≥ Stage III PI	 Stage III / IV Pressure Injury Cause identified Community nurse contacted Appointment with GP is arranged Individual with SB contacts SBART Pressure injury / wound therapy is commenced Air mattress hire company is contacted Attendant care coordinator is contacted regarding need for increased care requirements
<i>k</i> r	Within 2 – 4 weeks of evidence of ≥ Stage III PI	 Community Nurse: Completes comprehensive assessment Initiates and monitors wound therapy Refers to community OT for equipment review Contacts SSPIS for specialist advice on wound therapy Refers to Specialist Spinal Seating Service Completes application for increased care hours to support 24hr bed rest Care hours increased by ADHC to support 24 hour bed rest Assesses psychological state
X	As soon as lack of wound healing or deterioration is evident	 Urgent referral to Specialist Spinal Pressure Injury Service for: Comprehensive assessment of: Readiness to change Need for surgical intervention (eg Debridement+ NPWT, flap surgery) Liaison with local services Admission to hospital for surgery / post op management

Table 16. Model of Care Principles applied to Intervention (\geq Stage III) Phase of Care 2b

BREAKDOWN OF SKIN INTEGRITY (Pressure Injury ≥ Stage III)	PHASE 2B - INTERVENTION (PRESSURE INJURY ≥ STAGE III) Management of severe pressure injury and reduction/removal/minimisation of risk(s) causing deterioration of the pressure injury wound
)	 AIM: To support the individual with a pressure injury ≥ Stage III to: Mitigate and reduce risk behaviours / factors causing deterioration of pressures injury wound. Obtain increase in care and support to facilitate implementation of wound management strategies. Receive timely specialist advice and intervention Seek urgent referral to specialist services when improvement of wound is not evident &/or deterioration occurs.
Pressure i	injury care, support and management strategies for an individual with a SCI / SB
Self-management	 To support ongoing self-management in an individual with a pressure injury ≥ Stage III they will require: Support and guidance to change pressure injury risk behaviours. More directive processes to assist with decision making. High/increased level of assistance to coordinate / direct care, support and management strategies.
Assessment of risk of pressure injury	 To determine change in level of risk for the deterioration of the pressure injury ≥ Stage III, the individual will require: Comprehensive assessment of: o change in level of risk and causative factors, o risk of further deterioration of the pressure injury wound, o readiness to address causative factors and comply with pressure injury management strategies.
Management of skin integrity &/or pressure injury	 To manage the pressure injury ≥ Stage III, the individual will require: Increased/high level of assistance from health care provider to manage and regularly review effectiveness of pressure injury wound. Assessment of readiness to comply with (and or ability to direct their carers to comply with) pressure injury wound management strategies. GP to seek advice and guidance from spinal pressure injury management specialist service. Care coordination from primary health care provider/ GP with support from local spinal champion or escalation to spinal pressure injury specialist CNC. Shared care arrangements – individual/carer, GP, community based health care staff, specialist advice and guidance. GP to seek urgent referral to spinal pressure injury management specialist service if wound does not improve or shows signs of deterioration and / or compliance with treatment.
Care / support	 The individual with a pressure injury ≥ Stage III will require: Urgent application for increased attendant care hours to support 24hr bed rest. If 24hr in home attendant care not available, access to respite care arrangements where pressure injury management strategies can be supported and risk for deterioration minimised. Increased/high level of assistance from health care provider to manage and regularly review effectiveness of pressure injury wound. Support from clinicians with motivational interviewing techniques to establish and sustain pressure injury management plan.

Table continues on page 44

Table continued from page 43 **BREAKDOWN OF** PHASE 2B - INTERVENTION (PRESSURE INJURY ≥ STAGE III) **SKIN INTEGRITY** Management of severe pressure injury and reduction/removal/minimisation of (Pressure Injury risk(s) causing deterioration of the pressure injury wound ≥ Stage III) • The individual with a pressure injury \geq Stage III will require: Equipment • Urgent access to emergency supply of pressure reducing equipment (eq air mattress) and personal / domestic assistance. Management To maintain their general health the individual with a pressure injury \geq Stage III will require: of general health • Staff familiar with motivational interviewing techniques to support the individual to make health improvements. Increased frequency of review of general health and physical / mental / emotional health status (including nutritional screening), functional capacity and equipment. • Support from health care provider to ensure all strategies to manage pressure injury are initiated, maintained and regularly reviewed for effectiveness. • Assessment of pain and pain management plan. The individual with a pressure injury \geq Stage III will require: Access to community based clinicians • Clear communication pathways between clinicians and health sectors to ensure a consistent and considered management approach. (eg RN, OT, physio, dietitian, psychology) Referral to a dietitian if identified at nutritional risk. • Appropriate nutritional supplementation for wound healing. Professional psychological support to make behaviour changes and to maintain pressure injury management strategies. Social work support to manage impact of pressure injury on employment, income and community access. • OT assessment of and management strategies for risk factors for pressure injury related to equipment and activities of daily living. • Referral to drug & alcohol services as required. The individual with a pressure injury \geq Stage III should be referred to or encouraged to Peer support contact local peer support services who provide support and encouragement in reducing risk behaviours and in implementing and maintaining early intervention pressure injury management strategies. The individual with a pressure injury \geq Stage III showing signs of deterioration and or increase Spinal and pressure in level of risk will require: injury management specialist services • Urgent referral and timely access to spinal specialist pressure injury service: o If wound does not heal within specific timeframe or there is deterioration in wound / health status, o for debridement and/ or negative pressure wound therapy (NPWT), o for referral for surgical review to assess appropriateness of flap surgery. • Timely referral and access to specialist spinal seating services. • Care coordination provided by specialist spinal pressure injury CNC. Urgent referral and timely access to the Spina Bifida Adult Resource Team for the person with Spina Bifida.

7.3.1 Outcome Measures for Phase 2b may include the following:

- The individual's pressure injury does not deteriorate.
- Pressure injury heals with timely minor surgical intervention.
- Pressure injury heals with timely major surgical intervention.
- The individual, carer and/or family member accesses / is supported to access the PI management resources.
- The individual, carer and/or family member is aware of / supported to do what needs to be done to prevent deterioration.
- Assessment and management tools support health care providers to develop PI management plans in collaboration with the individual.
- Local health care providers are supported to provide PI management to these individuals.
- Coordinated care is shared between specialist and local services.
- Psychosocial effects of pressure injury are reduced.

Example of a resource to support hospital based PI intervention for young people and adults with SCI/SB.

The Hunter Spinal Cord Injury Service has developed a wallet sized health management plan designed for individuals with spinal cord injury to complete, which they can give to hospital staff to assist in completing admission care plans to ensure that care is centred on the individual's need.

7.4 Phase 3a Restoration and Rehabilitation

The person identifies personal goals and collaborates with the rehabilitation plan to prevent recurrence of Pl.

Arresting the injury process is the core function of the third level of prevention described by Leavell and Clark.² Actions at this stage are designed to rehabilitate individuals to restore an optimal level of functioning.

When applied to this MoC, this phase of the patient journey is concerned with strengthening, reconditioning and community reintegration following PI healing. Some of the key activities used in this phase include retraining, re-education and forming linkages with the appropriate health service provider.

Table 17. Patient Journey – Restoration and Rehabilitation

PERSON RECOVERING FROM A PI	RECOMMENDED TIMEFRAME	RECOMMENDED INTERVENTION AND MANAGEMENT STRATEGIES TO PROMOTE STRENGTHENING, RECONDITIONING, AND COMMUNITY REINTEGRATION AND PREVENT RECURRENCE FOLLOWING PI
e Leve	Within the 2 – 4 weeks following acute hospital management of Pl	 Community admission / hospital transfer to rehabilitation centre Graduated seating protocol Seating assessments Equipment trials +/- prescription Reconditioning/retraining/strengthening Functional assessment Re/education Community reintegration goals
e la	Within the 6 – 18 months following acute hospital management of PI	 Transition from hospital to community living and independence Referral to Spinal Outreach Service (SOS), Paediatric Spinal Outreach Service (PSOS)(Metro/Rural/Hunter) or SBART post discharge from hospital / service Other community referrals as identified Gradual return to vocational, educational or recreational pursuits Transitional services cease and long term support continues
e la	On completion of restoration and rehabilitation phase	 Fully engaged in community participation Vocational, educational and recreational pursuits fulfilled

Table 18. Model of Care Principles applied to Restoration and RehabilitationPhase of Care 3a

RECOVERING FROM A PRESSURE INJURY	PHASE 3A - RESTORATION & REHABILITATION Restoration of skin integrity and rehabilitation / return to community living
L.	 AIM: To provide the appropriate: Rehabilitation Structured return to seating program Education in self-management, risk minimisation and pressure injury prevention Psychosocial interventions to support readiness to maintain strategies to prevent recurrence of pressure injury Comprehensive multidisciplinary discharge and transfer of care plan Supported /phased transition to return to active community living.
Pressure i	njury care, support and management strategies for an individual with a SCI / SB
Self-management	To return to self-management following a period of hospitalisation/activity reduction due to pressure injury the individual will require support to access education / information to prevent recurrence.
Assessment of risk of pressure injury	To prevent recurrence of pressure injury the individual will require:Assessment of ability to monitor and minimise pressure injury risks on a regular basis.Assessment of readiness for change.Support to implement change.
Management of skin integrity &/or pressure injury	 During recovery from pressure injury the individual will require: Clear documented plan / protocol for a gradual stepped return to seating, with regular review of progress and skin integrity. Information and education about the changed characteristics and fragility of the newly healed pressure injury wound / surgical wound. Information and education about prevention and early intervention strategies to ensure skin integrity of newly healed wound to prevent recurrence.
Care / support	 The individual recovering from a pressure injury will require: Support to implement, monitor and report on response to return to seating protocol. Support during short / medium term transitional period before returning to full activity. Support to implement change that will reduce recurrence of pressure injury. Referral to appropriate community support services. Referral to respite care or supported transitional accommodation if adequate attendant care support is not available on discharge home, minimising risk of recurrence of pressure injury. Consider ongoing support needs of carers / family in their role to support PI prevention and early intervention.
Equipment	 The individual recovering from a pressure injury will require: Equipment assessment by OT. Access to mobility equipment which will progress the healing towards long term return to full mobility aids. Submission of request for replacement / new equipment if it is a contributing factor for pressure injury.

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RECOVERING	PHASE 3A - RESTORATION & REHABILITATION		
FROM A PRESSURE INJURY	Restoration of skin integrity and rehabilitation / return to community living		
Management of general health	To maintain their general health during recovery from a pressure injury, the individual will require:Staff familiar with motivational interviewing techniques to support the individual to make health improvements.		
	 Increased frequency of review of physical / mental / emotional health status (including nutritional screening), functional capacity and equipment to ensure recovery continues and recurrence of pressure injury is prevented. 		
	• Care coordination from primary health care provider/ GP following discharge from hospital / rehabilitation.		
	 Spinal specialist advice and recommendations provided in transfer of care plans at discharge from specialist services are enacted by local health services to ensure continued improvement, prevention of recurrence of pressure injury, and a successful transition and return to community living. Assessment of pain and pain management plan. 		
Access to	The individual recovering from a pressure injury in the community or following discharge from		
community based clinicians	 Outpatient rehabilitation program eg. physiotherapy (PT) 		
(eg RN, OT, physio, dietitian,	• Clear communication pathways between clinicians and community health sectors to ensure a consistent and considered management approach.		
psychology)	 Referral to a dietitian if identified at nutritional risk. Professional psychological support to make behaviour changes that will prevent recurrence. 		
	of pressure injury.		
	• Social work support and plan return to employment and active community living.		
Peer support	The individual recovering from a pressure injury should be referred to or encouraged to contact local peer support services who provide support and encouragement in reducing risk behaviours and in implementing prevention and early intervention pressure injury management strategies to prevent recurrence following discharge from hospital.		
Spinal and pressure injury management	The individual recovering from a pressure injury will require:Inpatient rehabilitation program, particularly following surgical repair and/or long term bed rest.		
specialist services	 Slow stream progression of seating protocol. High support for monitoring and reporting on response to seating protocol. 		
	 Assessment of strength / function / nutritional state / level of understanding / equipment trials by multidisciplinary rehabilitation team 		
	• Discharge planning meeting/s involving inpatient and community health care providers.		
	• Health questionnaire completed prior to discharge to identify goals for transition period.		
	 Comprehensive multidisciplinary discharge summary indicating specific areas of ongoing risk with recommended strategies outlined. 		
	On discharge from hospital:		
	o Progressive community reintegration plan is available.		
	 Keterral to community spinal service for transitional support. Consideration of referral and transfer to transitional facility for supported community. 		
	reintegration.		
	• Referral for community case management to support long term transitional period for individuals at high risk of pressure injury recurrence.		
	• Clear communication pathways between clinicians and consistent processes across health and government sectors to ensure a coordinated approach to the support and care provision for an individual with a SCI/SB to prevent recurrence of pressure injury.		

7.4.1 Outcomes Measures for Phase 3a may include the following:

- The individual successfully completes community reintegration plan.
- The individual does not develop a recurrence of pressure injury.
- The individual accesses / is supported to access the PI prevention resources.
- The individual is aware of / supported to do what needs to be done to prevent recurrence.
- Psychosocial effects of pressure injury are reduced.
- There are minimal psychological ill effects resulting from the extended time required and the impact/restrictions on life and active community participation of pressure injury management strategies.

Example of a shared care partnership approach that supports PI restoration and rehabilitation in young people and adults with SCI

The Spinal Pressure Care Clinic situated at Prince of Wales Hospital formed a partnership with ParaQuad NSW using a shared care model for PI management over a five year period (2003 – 2007). The results demonstrated that hospital length of stay was 55 days under a shared care arrangement, compared to 144 days for a hospital only admission.

7.5 Phase 3b Quality of Life **Maintenance**

The person, carer or parent identifies personal goals and collaborates with the rehabilitation plan to prevent sequelae of chronic PI.

There are some situations where healing of a PI is not the primary focus due to various factors. These include the individual's:

- readiness to follow the prescribed treatment and rehabilitation requirements
- physical condition or capacity to commit to the level of interventions, and
- capacity to truly appreciate the situation they find themselves in.

Occasionally there are no definitive surgical options available. However, there is an ethical responsibility to ensure that the individual is supported to work towards changing health behaviours and to minimise harm from their PI.

This phase of the patient journey is concerned with identification of the barriers to implementing PI strategies, providing interventions satisfactory to the individual geared towards preventing deterioration of the PI or of other sequelae as a result of the PI. The key activities used in this phase include identification and referral, treatment and/or focussing on developing quality of life goals with care planning for life with a chronic Pl.

Table 17. Patient Journey – Quality of Life Maintenance		
PERSON WITH A SCI/ SB LIVING WITH A CHRONIC PI	RECOMMENDED INTERVENTION AND MANAGEMENT STRATEGIES THAT FOCUS ON DEVELOPING QUALITY OF LIFE GOALS FOR LIFE WITH A CHRONIC PI	
No.	 Living with a chronic PI which is managed without clinical intervention Fully engaged in community participation Vocational and recreational pursuits fulfilled 	
Ŷ	 In situations where there is an acute deterioration of the chronic PI Intervention from GP / community nurse Referral to SSPIS The individual should be reviewed by the multidisciplinary team. However, the individual may be unwilling or unable to receive the prescribed treatment & rehabilitation Plan developed by individual in consultation with team (which includes, where relevant, advanced care plan) Clear plan including escalation pathway documented for community key stakeholders Required external support services offered to individual and carers 	
	 Community key stakeholders Oversee plan Continue to provide harm minimisation strategies Continue to offer external support services as appropriate Acute episodes of PI deterioration are managed locally Person referred to specialist outpatient clinics for ongoing assessment 	

Table 20: Model of Care Principles applied to Quality of Life MaintenancePhase of Care 3B

LIVING WITH A CHRONIC PRESSURE	PHASE 3B - QUALITY OF LIFE MAINTENANCE
INJURY WHEN SKIN INTEGRITY CANNOT BE RESTORED	Chronic pressure injury
	AIM: To support the individual with a chronic pressure injury to live an active and fulfilling life, prevent deterioration of the pressure injury and its sequelae by promoting health and wellness strategies.
Pressure i	njury care, support and management strategies for an individual with a SCI / SB
Self-management	To support self-management by an individual living with a chronic pressure injury, they will require assessment of their ability to self-manage and or direct/communicate their care and support needs.
Assessment of risk of pressure injury	To live with a chronic pressure injury the individual will require assessment of their level of risk in relation to living with and possible deterioration of the wound, its causative factors and their readiness to implement wound management strategies.
Management of skin integrity &/or pressure injury	 To support the individual to manage a chronic pressure injury, they will require: Access to information and advice for pressure injury wound management and possible sequelae, and on how to prevent deterioration. A directive and proactive approach to the determination of treatment goals which are clearly documented, and regularly followed up, monitored and reviewed. Interventions that support these goals whilst minimising harm of further deterioration.
Care / support	 The individual with a chronic pressure injury will require: Support from clinicians with motivational interviewing techniques to establish and sustain pressure injury management plan. Skilled and informed attendant care to prevent deterioration of the chronic pressure injury wound. Assistance from health care provider to guide and regularly review chronic pressure injury wound to prevent deterioration.
Equipment	The individual with a chronic pressure injury will require review and recommendations of appropriate pressure reducing equipment and personal / domestic assistance.
Management of general health	 To maintain their general health the individual with a chronic pressure injury will require: Staff familiar with motivational interviewing techniques to support the individual to make health improvements and enhance and maintain quality of life. Assessment of underlying mental health condition. Referral to drug and alcohol services, if at risk. Increased frequency of review of general health and physical / mental / emotional health status (including nutritional screening), functional capacity and equipment. Support from health care provider to ensure all strategies to manage pressure injury are initiated, maintained and regularly reviewed for effectiveness. Clear communication between all health care providers. Assessment of pain and pain management plan. Developing quality of life goals with care planning for life with a chronic P
	Table continues on page 52

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LIVING WITH A CHRONIC PRESSURE INJURY WHEN SKIN INTEGRITY CANNOT BE RESTORED	PHASE 3B - QUALITY OF LIFE MAINTENANCE Chronic pressure injury
Access to community based clinicians (eg RN, OT, physio, dietitian, psychology)	 The individual with a chronic pressure injury will require timely access to a range of community based clinicians who use a multidisciplinary approach to preventing deterioration of the chronic pressure injury wound and maintaining general health including: Clear communication pathways between clinicians and health sectors to ensure a consistent and considered management approach. Referral to a dietitian if identified at nutritional risk. Appropriate nutritional supplementation to prevent deterioration of general health and chronic wound. Professional psychological support to make behaviour changes and to maintain chronic pressure injury wound management strategies. Social work support to manage impact of chronic pressure injury on employment, income and community access. OT assessment of and management strategies for risk factors related to equipment and activities of daily living that may result in a deterioration of the chronic pressure injury wound. Referral to drug & alcohol services as required.
Peer support	The individual with a chronic pressure injury will require referral to local peer support services for appropriate support and encouragement in reducing risk behaviours which may result in deterioration of their general health and chronic pressure injury wound.
Spinal and pressure injury management specialist services	 The individual with a chronic pressure injury wound showing increase in level of risk and or deterioration or wound / health status will require: Urgent referral and timely access to spinal specialist pressure injury service or the Spina Bifida Adult Resource Team (for the person with Spina Bifida) Care coordination provided by specialist spinal pressure injury CNC. Timely referral and access to specialist spinal seating services.

7.5.1 Outcome Measures for Phase 3b may include the following:

- The individual's PI does not deteriorate.
- The individual does not experience a sequelae of PI.
- The individual accesses / is supported to access the PI management resources.
- The individual is supported to develop life goals to maintain quality of life while living with a chronic PI.
- The individual is aware of / supported to do what needs to be done to prevent deterioration.
- Assessment and management tools support health care providers to develop PI management plans in collaboration with the individual focused on quality of life goals.
- Local health care providers are supported to provide PI management to these individuals.
- Coordinated care is shared between specialist and local services.
- Psychosocial effects of pressure injury are reduced.

Example of a resource designed to help document and communicate the needs of a person with chronic and complex conditions which may be useful in relation to people with a SCI/SB with a PI which cannot be healed to maintain quality of life

The Victorian Department of Human Services has developed a shared support plan for consumers with complex and / or multiple issues. There is a similar example for the child with a chronic condition. These plans allow for clear documentation and communication between all relevant health care providers involved in the care of the person with complex needs.

http://docs.health.vic.gov.au/docs/doc/Sharedsupport-plan (Cited January 2014)

8. RECOMMENDATIONS

The aim of the six recommendations arising from the project to develop the PI MoC is to ensure the implementation of a consistent approach to PI prevention and management in the person with SCI/SB. They have been informed by the body of evidence, key findings, clinical consensus, guidance from the project Steering Committee and data analysis.

- Provide decision support systems to enable people with SCI/SB, carers and clinicians to access information, expertise and tools to support prevention and appropriate management of PIs.
- 2. Provide timely access to care and equipment to prevent PIs or promote healing of PIs.
- 3. Develop systems and processes that facilitate integrated care with effective communication between the person, health care and service providers across sectors.
- 4. Develop systems and processes that facilitate selfmanagement and enhance psychosocial support to the person and primary carers.
- 5. Develop multilayered educational strategies for Pl prevention and management applicable to the person and all stakeholders across the phases of care.
- 6. Integrate clinical information and data management systems for care coordination, monitoring and outcome evaluation.

The recommendations focus on the MoC in terms of promoting access to the required resources and building the capacity of the people and clinicians to manage the risks associated with PI prevention and management. The recommendations provide guidance to inform the implementation of the MoC at a statewide level. 8.1 Provide decision support systems to enable people with SCI/SB, carers and clinicians to access information, expertise and tools to support prevention and appropriate management of PIs

Development of clinical decision support systems (DSS), using available information technologies, provides the opportunity to enhance clinical decision-making, ensure management is consistent with best practice and to improve health service delivery for people with SCI/ SB. It may be particularly useful for clinicians who don't have expertise in the special needs of people with a SCI/ SB in relation to the prevention and management of PI. It is expected the DSS will provide access to a suite of tools and resources to assist in comprehensive clinical assessment, decision-making and treatment planning, including pathways for escalating care, with additional support from a clinical expert when required to assist development of an appropriate clinical management plan.

ACI will:

- Develop a spinal cord injury website that will include the following information for clinicians working with adults and young people:
 - checklists
 - pathways
 - flowcharts
 - assessment tools
 - links to existing resources, such as clinical practice guidelines
 - information about specialist spinal PI services, referral criteria and processes.
- Scope options for the development of an 1800 phone number to provide timely advice, information and guidance on PI prevention and management to the individual and to health care workers.

Work with LHDs to link rural, remote and regional LHDs that cannot identify local PI champions with other LHDs with champions able to support rural, regional or remote LHD work.

Local Health Districts and/or Medicare Locals can:

- Establish and document agreed clinical pathways that will support timely access to treatment and services.
- Establish links on local websites or portals to resources on SCI website for clinicians working with people with a SCI/SB who have a PI.
- Establish an email account (or similar) that will provide a secure process for the individual and / or health care workers to send wound photography and history for clinical assessment.
- Identify, recruit and support a local clinical champion with expertise in wound and PI prevention and management to advise regarding specialist resources on the specific needs and risks for people with a SCI / SB and how to access expert advice when needed.

8.2 Provide timely access to care and equipment to prevent PIs or promote healing of PIs

Broad stakeholder consultation during the project revealed a strong consensus view that there are marked delays in provision, as well as an inadequate supply, of attendant care services and pressure-relieving equipment, both of which are critical to the prevention of PI development and deterioration. Where the person with a SCI/SB requires pressure relieving equipment to prevent PI at times of increased risk eg during illness, ambulance transportation or arrival at a health facility, prompt availability of this equipment is imperative.

ACI will:

- Undertake cross agency consultations to develop multi sectoral solutions in relation to access to care and equipment issues.
- > Host a workshop to support solution development.
- > Develop a consumer guide.
- Develop a supported transition accommodation model.

Local Health Districts and/or Medicare Locals can convene a local committee to:

- Review capacity of local Hospital in the Home services (and eligibility criteria) to determine if packages can be made available.
- Identify community-based services and develop agreement around priority of access to service and identify which clients receive multi-agency care plans and access to a key worker.
- Explore opportunities for service flexibility, service substitution and diversion to increase attendant care hours or access to short-term emergency care.
- Coordinate access to community health services and clinicians (ie. occupational therapists, social workers, dietitians, psychologists) that provide home visits.
- Enable early access to psychological assessment and support to address and minimise PI risk behaviours and maximise acceptance of prevention and early intervention strategies.
- Develop processes for access to equipment at point of care through loan pools and other mechanisms.

8.3 Develop systems and processes that facilitate integrated care with effective communication between the person, health care and service providers across sectors

The person with SCI or SB should be supported and encouraged to direct and manage their own care. However, many individuals who develop PI have complex issues and co-morbidities requiring a multidisciplinary and cross sector approach. Using an integrated care model will facilitate a streamlined and coordinated approach to the provision of health, support and care services the individual with a SCI/SB and PI requires across the care continuum.

ACI will:

Scope options for the development of a framework that supports the delivery of integrated services between NSW Health and the Department of Family and Community Services.

Local Health Districts and/or Medicare Locals can:

- Work together to establish service pathways and systems that support:
 - Common practices, processes, protocols and systems with defined clinical pathways and linkages with service providers.
 - Health management or care coordination plans.
 - Local agreements and systems to identify and support persons with SCI / SB who require coordinated care planning and coordination by primary nurses, discharge planners or chronic and complex care coordinators.
 - Case conference and discharge planning meetings involving all stakeholders.
 - Partnerships with community service providers in the non-government (NGO) sector to streamline service delivery.
- Identify and implement infrastructure that will support service pathways and care coordination such as:
 - Secure communication infrastructure / e-health technology.
 - Personally controlled electronic health records (PCEHR), electronic medical records (eMR), clinical information management systems.
 - Electronic medical record 'PI risk alert flag'.
- Use technology to drive integrated and coordinated care.

8.4 Develop systems and processes that facilitate self-management and enhances psychosocial support to the person and primary carers

A major element underpinning the model is supporting the person with SCI or SB to manage their own condition. There are varying levels of self-management which can be implemented to support the individual to actively collaborate in their care as informed partners. Such services need to be readily available, accessible and flexible in service delivery for this patient population. There is a strong role for peer involvement in any support strategies developed and support for informal carers needs to be considered. ACI will:

- Identify and document existing case management and coordinated care and self- management support tools for inclusion in a Spinal Cord Injury Pressure Injury Prevention and Management tool kit.
- Support training for designated staff/peer mentors to develop skills in motivational interviewing and coaching.
- Scope a self-management support module that can be incorporated into existing coaching systems.

Local Health Districts and/or Medicare Locals can:

- Provide psychological screening and comprehensive psychosocial assessment as a standard part of the process of care planning and service delivery.
- Provide access to age appropriate individual / family counselling, cognitive-behavioural therapy and other psychological interventions.
- Provide ongoing case management for individuals with high support needs.
- Provide links to Psychosocial Strategy for People with a SCI information and decision support tools.

8.5 Develop multilayered educational strategies for PI prevention and management applicable to the person and all stakeholders across the phases of care

Education underpinning the model must be flexible, evidence-based, and tailored to meet the needs of different audiences. A range of resources and approaches will be required to target child / adolescent and adult consumers, personal care attendants, informal carers, generalist and specialist health care providers.

ACI will:

Review current resources, educational strategies and other teaching programs/models for inclusion in a Spinal Cord Injury Pressure Injury Prevention and Management tool kit. Local Health Districts and/or Medicare Locals can implement self-management support strategies from the tool kit.

The CEC can promote awareness of the MoC during when promoting the of Pressure Injury Prevention and Management Policy requirements.

8.6 Integrate clinical information and data management systems for care coordination, monitoring and outcome evaluation

This project highlighted that currently available health data about PI in persons with SCI or SB was not easily identifiable and did not reliably represent activity across NSW, therefore was not helpful in guiding the development of a MoC nor will it help inform health service planning. The development of statewide data collection systems modelled on current specialist PI services data collections which capture inpatient, outpatient, ambulatory and community based care and support related to the management of people with SCI/ SB and PI are required to better quantify activity, inform health service planning, and evaluate patient outcomes.

Consideration could be given to conducting a statewide community PI point prevalence survey using a similar design to the Victorian Quality Council survey first undertaken in 2003.⁵⁷ It is acknowledged, however, that the NSW CEC, in its soon to be released Pressure Injury Prevention and Management Policy, recommends annual point prevalence surveys for pressure injury be conducted within health care inpatient and community based ambulatory health services.

Under the current Australian Coding Standards, SB is not coded as an additional diagnosis unless it is specifically related to the principal diagnosis. Whilst there may be opportunities to advocate for changes to coding practices for this high care group in the future, discussions with coders and clinicians may identify ways to leverage off existing data sources to more clearly document the link between principle diagnosis and SB.

ACI will work with the CEC to determine the best means of assessing the prevalence of PIs and the value of establishing a prevalence survey and/or the establishment of a database to monitor prevalence of PI in people with a SCI/SB.

9. CURRENT AND FUTURE CONTEXT

ACI supports the development of models of care that integrate primary services across the state with specialist acute care centres. Such models align with the strategic direction of NSW Health, as outlined in the NSW 2021 Plan to Make NSW Number One.⁵⁸ They align particularly with Goals 11 and 12, as follows:

Goal 11 - Keep people healthy and out of hospital

- Reshaping to focus on wellness and illness prevention in the community
- Coordinated preventative health strategies reduce the burden of pressure injury management
- Reducing behaviours and lifestyle risk factors that lead to pressure injury development
- Create partnerships between acute and community service providers to ensure coordinated management of care
- Improving pressure injury management by primary health care providers.

Goal 12 - Provide world class clinical services with timely access and effective infrastructure

- Deliver programs to improve patient/family journeys and access to care
- Reduce current rates of unplanned and unexpected hospital readmissions
- Planned surgical patients are admitted within a clinically appropriate time
- Promote opportunities for patients to provide feedback on their experience.

It is clearly important to develop policy frameworks that support delivery of care "in the right place at the right time", in order to improve health outcomes for patients/family with PI. Underpinning this is the need for clear articulation of processes and pathways to ensure appropriate and timely interventions and referrals occur and that there are opportunities to build the skill set of non-specialist clinicians in a supportive manner.

Implementation of this model will also assist health care services to meet the requirements of the 8th standard

(Preventing and Managing Pressure Injuries) of the National Safety and Quality Health Service Standards released by The Australian Commission on Safety and Quality in Health Care (ACSQHC).⁵⁹

To ensure sustainability, the MoC must interface effectively with the NSW Health systems, programs and economic environment, factoring in developments such as activity based funding (ABF), eHealth and telehealth. This may require a reorganisation or redesign of current resources, where practical, or ensuring that the needs of the population group are considered during broader planning to support the change in practice. Important contextual issues to consider are outlined below:

9.1 Selected Speciality and Statewide Service Plan for Spinal Cord Injury

The Statewide and Rural Health Services and Capital Planning Branch of the Ministry of Health developed a service plan for spinal cord injury, which was released in December 2010, providing a framework to coordinate and plan service delivery. There are four recommendations in this Plan that the MoC addresses and therefore the Model needs to be considered during the implementation process of the Plan. The four recommendations are:

- **Recommendation 1**. To better define referral pathways, criteria for admission and readmission to adult statewide spinal cord injury services in NSW, including rural patients.
- Recommendation 3. To develop an integrated service model for statewide non – inpatient, outreach and hospital support, in consultation with local and rural centres and services. This model needs to incorporate a process and mechanism for capacity building in the non – specialised services.
- Recommendation 4. To progress a transition model of care for adults with spinal cord injury, in partnership with other agencies, that includes

the development of a transitional accommodation strategy and other support services.

• **Recommendation 10**. To modify the NSW Spinal Cord Injury Database (SCID).⁶⁰

9.2 Lifetime Care and Support Scheme (LTCSS)

The Lifetime Care and Support Authority (LTCSA) of NSW is responsible for the administration of the Lifetime Care Support Scheme (LTCSS) which provides reasonable and necessary treatment, rehabilitation and attendant care services to people severely injured in motor vehicle accidents in NSW, regardless of who was at fault in the accident. The Scheme commenced in 2006 and covers people who have sustained a spinal cord injury as well as other catastrophic conditions.

Each participant is provided with a LTCSS Coordinator who assists participants to:

- understand what services are available and how they work
- maximise the benefits of the services received
- regain previous level of community engagement
- organise required care and other services.

Clinicians working with people who are LTCSS participants need to have an understanding of the Scheme, its processes and people to ensure the person with a SCI receives timely and appropriate care.

The Scheme requires formal requests for care and services, which are considered based on the following criteria:

- Will the person benefit from the request?
- Is the request appropriate?
- Is the provider appropriate?
- Does the request relate to the injury sustained in the accident?
- Is the request cost effective?

Over time as the number of participants in the Scheme grows and individuals age, the likelyhood of them developing a PI will increase. The MoC provides guidance to the LTCSS and coordinators around the benefits of approving service requests for prevention, early intervention and treatments for PI. The Model can also provide support for improving approval processes and may facilitate prioritisation of clinical issues.

9.3 National Disability Insurance Scheme

Approximately 70% of disability care and support services are funded by state and territory governments. The need to support the most vulnerable people in the Australian community, the people with a disability, is acknowledged. Many people with a disability will require financial, accommodation and service support throughout their lifetime.

The National Disability Insurance Scheme (NDIS) is supported by commonwealth, state and territory governments and is in the process of being implemented. The states and territories will offer a mix of government provided services, funded services from the not – for – profit sector or self – managed funding. ⁶¹

The overarching principles of the Scheme are as follows:

- 1. People with a disability have equal rights.
- 2. Supports are needed to allow people with a disability to exercise their rights.
- 3. Individuals with a disability should have choice in prescribing their access needs.
- 4. Cultural, systemic and environmental obstacles to access and participation for people with a disability should be removed.⁶²

With the roll out of NDIS individuals will have greater control in managing their care packages. This is a significant change which will help in relation to the MoC as it advocates for timely access to increased care and support to allow the individual with a SCI/SB to implement early intervention strategies such as bed rest with the aim of promoting healing and preventing deterioration of PIs in their early stages. Conversely, people with SCI/SB will need to carefully manage their funding allocation and plan for unexpected increases in care requirements such as these.

9.4 Activity Based Funding

The NSW Ministry of Health is currently implementing a funding reform which moves away from traditional Commonwealth block funding to a more responsive and accountable activity based model. Activity Based Funding (ABF) allows LHDs to be more flexible and responsive to the clinical needs of the local population and generate incentives for service improvements and efficiencies. ABF will also provide greater transparency and assist in overall public health planning. Adequate funding in the future will be reliant on good data collection and clinical documentation processes to ensure all issues which add to the complexity and burden of caring for individuals with a SCI/SB and PI are accounted for including the level of disability, rurality, indigenous status, and public/ private classification.⁶³

In the future ABF will also apply to non-admitted and ambulatory health care services capturing data which better quantifies activity and cost and in turn helping inform service planning to address demand. The MoC recommends timely access to ambulatory multidisciplinary services for people with a SCI/SB to provide prevention, early intervention and management in the community reducing the need for hospitalization.

9.5 Information Technology

The use of technology is part of daily life for most people. Use of email to correspond with family and friends, the internet to manage household bills or electronic transfers to purchase items rather than using cash are some examples of how technology has been able to revolutionalise society, saving time and money. This is also the case in the NSW healthcare system, where people are interacting with technology every time they visit their doctor, get a blood test, go to their chemist to fill a prescription, or spend time in hospital.

The Personally Controlled Electronic Health Record (PCEHR) system ⁶⁴ is a key element of the Australian Government's National Health Reform Agenda, designed to provide better health services and outcomes for all Australians. Together with telehealth and the National Broadband Network, the PCEHR system will improve accessibility to health services and patient information, significantly enhancing health outcomes. The person with a chronic condition will benefit from storing important health information in the one place and choosing with which of their care providers they can share this information. This system will help to support the principle of integrated care outlined in this Model and therefore forms one strategy across the care continuum.

Telehealth is another initiative that commenced in NSW Health in 1996. It has now grown to cover over 280 facilities supporting 35 clinical services. Telehealth connects patients, carers and health care providers via voice and/or video between two or more sites. It has been found to improve access to quality care, particularly for people living in rural and remote areas of the state. This has particular relevance for people with SCI and SB, as many live in rural areas of NSW. Being able to utilise this technology reduces the need to travel and therefore the potential for PI deterioration. It is also relevant to this Model for the purpose of providing clinical support/ supervision and education between stakeholders from various care settings and facilities.

9.6 Medicare Locals

Medicare Locals will be the General Practice (GP) and primary health care partners of LHDs, responsible for enabling better integrated local GP and primary health care services to meet the needs and priorities of consumers and communities. As this MoC has a strong focus on prevention and early intervention, it aligns with services provided by the GPs and Medicare Locals. These include:

- Improving the patient journey through the provision of integrated care and coordinated services linking primary health to hospitals (eg the 'person-centred medical home' model.⁶⁵
- Working closely with LHDs to ensure that health needs of their community are met.
- Identifying gaps in services for local communities.
- Supporting primary medical, nursing and allied health care providers to adopt and meet quality standards (ie. preventing PI's in the National Safety & Quality Healthcare Standards).

10. NEXT STEPS

The 'Business as Usual' case has demonstrated that whilst the patient cohort is low in volume, it is relatively complex with a high cost per separation. The projected costs are over \$AUD300 million over the next 10 years.

Data showing high rates of emergency admissions, late presentations with severe PIs and recurrent admissions suggest that there is considerable scope for improvement through prevention and earlier intervention, as well as better service co-ordination and streamlined management practices.

There also appear to be opportunities for greater use of non-acute health care facilities and support services once the acute phase of care is completed. Given the concentration of services and the relatively low volume of patients, efforts by LHDs and relevant service providers will need to focus on areas where the greatest impact can be achieved in reducing the incidence, severity and need for hospitalisation for PIs in people with a SCI/SB. This includes improving clinical practice through education, access to clinical decision support tools and resources to assist early multi-disciplinary risk assessment, appropriate referral and triage, and intersectoral care coordination, with increasing levels of specialist support for management and overall capacity building.

The following section highlights steps in developing an implementation plan for the MoC.

10.1 Implementation Planning

The Model of Care contains six recommendations, with each containing a range of strategies. Following completion of a comparative gap analysis of existing services against the recommendations MoC, LHDs may wish to prioritise which solutions are implemented and sequence the order of implementation based on their importance and the impact on the stakeholders involved.

ACI SSCIS priorities in the implementation of the MoC will include:

 Establishing a multidisciplinary steering committee to assist in planning and supporting implementation of the model. Representation will include health professionals who care for SCI/SB patients, wound care and community management experts, managers and policy-makers from health and other relevant government departments, consumer organisations, carers and patients.

- Developing decision support tools and resources to be available online, to facilitate multidisciplinary risk assessment, evidence-based treatment, referral and triage.
- Generating LHD executive sponsorship to build capacity and support implementation (refer to Section 10.2).
- Aligning implementation strategies with those recommended in the CEC Pressure Injury Prevention and Management Policy and the National Safety and Quality Health Service Standards (NSQHSS) Standard 8 – Preventing and Managing Pressure Injuries.
- Evaluation of the MoC by monitoring inputs, outputs and outcomes to determine its success and value in achieving its intended improvements to people with a SCI/SB with a PI and the services that support them. There will be both formative evaluation, monitoring processes and outputs to assess if short-term outcomes are being achieved, as well as summative evaluation. The latter would include assessment of long-term outcomes for the patient cohort, changes in practice and policy, and cost-effectiveness analysis (Refer to Section 12).

10.2 Generate Local Health District Executive Sponsorship

Successful implementation will only be achieved if the LHD executives are prepared to sponsor the project. They will need to have a clear understanding of how their LHD will benefit from implementing the Model. Once executive sponsorship is established, the primary outcomes will be:

- Identification of an implementation lead or local 'champion', who can be trained and supported by the specialist SCI services in a hub and spoke model to build capacity and a 'community of practice', supported by suitable tools and resources described in Section 10.1.
- Working in collaboration with pilot LHD sites and their local champions to develop an integrated clinical pathway for the management of PIs in persons with SCI or SB, spanning the continuum from early risk assessment and intervention through to referral and escalation based on complexity and response to treatment. This would also involve developing processes and tools supported by clinical information systems and models such as 'person-centred medical home' for care coordination across sectors 'customised' to their environment, before wider implementation (Recommendations 8.3 and 8.6).
- Development, piloting and evaluation of an alternative cost-effective / efficient model of supported transitional care for the management of people with SCI following completion of acute care PI interventions in one of the tertiary Spinal Cord Injury Units at the Royal North Shore or the Prince of Wales Hospitals. This would facilitate patient flow and access, allowing a period of further bed rest, wound healing and consolidation and/or for rehabilitation (commencing at four weeks post-operatively) involving a graduated return to sitting, equipment review/trials and education as part of discharge planning and community reintegration to occur in a more appropriate setting.

10.3 Develop a Comprehensive Communication Plan

As with the introduction of any change, communication is vital to ensure the goal of the MoC is achieved. The communication needs to be adapted depending on the audience, but the messages should be similar. The ACI communication plan will assist in the implementation of the Model to ensure that consideration of the objectives, target audiences, key messages and action plan occur to maximise the effectiveness of the implementation.

10.4 Complete a Comparative Gap Analysis

With the decision support tools, integrated clinical pathways and knowledge gained through pilot work outlined in Section 10.2, the identified 'champion', in conjunction with their local implementation group, can undertake a comparative gap analysis to determine health system barriers and enablers for implementation. The intention of a gap analysis is to inform LHDs of the requirements of each 'phase of care' at a facility level.

Appendix 1 outlines what health services can do to support the individual with a SCI/SB to prevent and or manage pressure injury in line with the phases of care described in Section 7. This may be of use to guide the gap analysis.

10.5 Address Identified Gaps

A working party will need to prioritise gaps, develop defined practice change strategies, implement and manage change within available resources or develop business cases where additional resources are required to support essential change.

11. ENABLERS FOR IMPLEMENTATION OF THE MODEL OF CARE

Enablers describe the components of the Model that are required to support implementation. These are:

- Workforce
- Interagency collaboration
- Technology.

11.1 Workforce

PI prevention and management requires a multidisciplinary team, preferably using an interdisciplinary approach, to ensure the person with SCI/ SB has timely access to relevant information, expertise, equipment and resources to promote and maintain health, functioning and independence. The consultation process of this project uncovered significant gaps in workforce across metropolitan and rural settings. On some occasions clinicians reported waitlists exceeding 12 months, particularly for community OT and assistive technology and seating therapists.

The interdisciplinary (sometimes referred to as transdisciplinary) approach involves a team of professionals who work together to share knowledge and skills across disciplines. It improves teamwork, communication and cooperation, and provides integrated care to provides integrated care to patients / clients resulting in a reduction in duplication and allowing for better patient centred care.^{66, 67}

LHDs must consider how to use the skills and talents of the current workforce to their best advantage. This is particularly so in areas where there are known shortages of certain disciplines. Services need to look at innovative workforce or practice models which can ease the demand and go some way to filling the service gaps. Specific examples include:

- Development of local clinical champions with expertise in wound and PI management through access to additional education, training and support with access to specialist resources on the specific needs and risks for people with a SCI/SB.
- Diversional therapist to facilitate leisure and recreational programs. Such activities are

designed to support, challenge and enhance the psychological, spiritual, social, emotional and physical wellbeing of people.⁶⁸ Diversional therapy might cancel out the need for social work or psychology interventions for the person with SCI/SB and PI who is restricted to complete bed rest at home.

- Allied health assistants who work under the supervision of allied health professionals could also support the person to complete leisure activities and facilitate completion of rehabilitation goals following complete PI healing.
- Consultant allied health therapists to provide advice and clinical supervision to nursing staff, therapy assistants or early career allied health practitioners at several sites with the aim of independently implementing a therapy plan. This model works well in areas where there are workforce shortages.
- Trans-disciplinary procedures, protocols, assessments, prescriptions which allow 'other disciplines' to perform tasks essential to the care of the patient. EnableNSW has developed guidelines that allow RNs, OTs and physiotherapists to prescribe pressure care mattresses and cushions.⁶⁹
 Similarly, people with wounds on their feet can be treated by a GP, RN or podiatrist, and most recently, there has been discussion about increasing the scope of primary care/preventative health functions by pharmacists.

11.2 Interagency Collaboration

This MoC is unique in that it is attempting to integrate and standardise care across different levels of prevention, traversing several care settings in a group of people that already have significantly higher care requirements than the general population. Various government agencies are involved in service provision and support for the person with SCI/SB, including the NSW Ministry of Health, Lifetime Care and Support Authority, Department of Education and Communities and the Department of Family and Community Services responsible for Ageing, Disability and Home Care, Housing NSW and Community Services. However, there are also 'partner' organisations that are stakeholders in the speciality of SCI/SB. These organisations include:

- Northcott Disability Services: Providing the Paediatric Spinal Outreach Service for children under the age of 18 who have sustained a SCI as a result of trauma or disease. Team members frequently work with schools and provide training to teachers' aides. Northcott Disability Services also hosts the NSW Ministry of Health funded Spina Bifida Adult Resource Team (SBART). The SBART assists with transition of people with SB from paediatric to adult health services, supports SB clinics in NSW and provides support and education to the people with SB, their families and health professionals.

- **ParaQuad NSW**: Providing a range of community services which include a multidisciplinary community team known as The Spinal Wellbeing Service; transitional, respite and permanent accommodation across three sites in Sydney and Newcastle; community development, advocacy and attendant care services. In addition to this BrightSky Australia, a subsidiary of ParaQuad NSW, provides specialist continence, wound care and nutrition products.

- **Spinal Cord Injuries Australia (SCIA)**: Providing services in the areas of advocacy, information, accommodation, community, personal and peer support, regional services, injury prevention, employment & intensive exercise recovery.

Collaboration between all of these stakeholders is critical if implementation of the Model is to be successful.

Implementation of aspects of the MoC will also be enhanced through collaboration with the 'pillar' organisations of health – CEC and the Health Education and Training Institute (HETI).

11.3 Technology

Technology has an important role to play in facilitating improved access, communication and care coordination between hospital and community based health professionals and care agencies, as well as providing education. The potential for greater use of telehealth to provide clinical specialist support to rural and remote clinicians has already been mentioned. Information and communication systems that support information sharing across care settings and geographical boundaries between different service providers is essential for care planning, coordination and monitoring. It is acknowledged that the current roll out of the electronic medical record (eMR) across NSW Health has issues in terms of statewide accessibility, which will have implications for supporting information sharing, care planning, coordination and monitoring.

12. EVALUATION / MONITORING

Evaluation of the MoC is essential and achieved by monitoring inputs, outputs and outcomes to determine its success and value in achieving its intended improvements to people with a SCI/SB with a PI and the services that support them. By building evaluation into the early stages of model implementation, data on effectiveness can be collected and provide evidence to support ongoing service development work. This will ensure that efforts are focussed where they can have the most impact. Measuring the impact of the strategies implemented is essential to ensure sustainability and to identify areas needing further support to improve service delivery.

Two types of evaluation will be included in the framework. The first is formative evaluation which takes place throughout the project and consists of monitoring processes and outputs to assess if short-term outcomes are being achieved in the most cost effective way and through a robust quality framework.

The second is summative evaluation which occurs at the end of the implementation phase to determine whether the project objectives have been met and produced the desired results. Summative evaluation focuses on long term outcomes for the patient cohort, such as reduced extent and number of PIs, with related improvements in health, increased participation and quality of life, efficiency and effectiveness of the MoC.

Once the model has been implemented, it is intended that formative evaluation will occur at six and 12 month intervals and summative evaluation at three years.

13. ACRONYMS

ABF Activity based funding	
ACI Agency for Clinical Innovation	
ACSQHC. Australian Commission for Safety and Quality Health Care	
ADHC Ageing, Disability and Home Care Branch	
AIS American Spinal Injury Association Impairment Scale	
ALOS Average length of stay	
AUD Australian dollars	
AWMA Australian Wound Management Association	
BaU Business as usual	
CEC Clinical Excellence Commission	
CEE Centre for Epidemiology and Evidence	
CHW Children's Hospital Westmead	
CNC Clinical nurse consultant	
CWS Cost weighted separations	
DOA Day only admission	
DOSA Day of surgery admission	
DSS Decision support systems	
eMR Electronic medical record	
EPUAP European Pressure Ulcer Advisory Panel	
FACS Department of Family and Community Services	
GMCT Greater Metropolitan Clinical Taskforce	
GP General Practitioner	
HETI Health Education and Training Institute	
HNELHD . Hunter New England Local Health District	
IT Ischial tuberosity	
JHCH John Hunter Children's Hospital	
LHD Local Health District	
LTCSA Lifetime Care and Support Authority of NSW	
LTCSS Lifetime Care and Support Scheme	
MDT Multi-disciplinary team	
MoC Model of Care	
MoH Ministry of Health, NSW	
MRSA Multi-resistant staphylococcus aureus	
NDS Northcott Disability Services	

MS..... Multiple sclerosis NDIS National Disability Insurance Scheme NGO Non-government organisation NPUAP.... National Pressure Ulcer Advisory Panel NPWT..... Negative pressure wound therapy NSLHD.... Northern Sydney Local Health District NSW New South Wales NTSCI Non-traumatic spinal cord injury NWAU National weighted activity unit OT Occupational therapy / therapist PCEHR Personally controlled electronic health record Pl..... Pressure injury POWH Prince of Wales Hospital PSOS Paediatric Spinal Outreach Service PT..... Physiotherapist RN Registered nurse RNSH Royal North Shore Hospital RPAH Royal Prince Alfred Hospital SB..... Spina bifida SBART..... Spina Bifida Adult Resource Team SCI..... Spinal cord injury SCIA Spinal Cord Injury Association SCID Spinal Cord Injury Database SCH Sydney Children's Hospital SCIU Spinal Cord Injury Unit SESLHD... South Eastern Sydney Local Health District SOS Spinal Outreach Service SOS-HQ.. Spinal Outreach Service Health Questionnaire SPCC Spinal Pressure Care Clinic SPS Spinal Plastics Service SSCIS State Spinal Cord Injury Service SSPIS...... Specialist spinal pressure injury services USA...... United States of America TSCI...... Traumatic spinal cord injury \$AUD Australian dollar

14. APPENDIX 1

Spinal Pressure Injury Prevention and Management Model of Care Steering Committee

Joanne Brady	Team Leader, Spina Bifida Adult Resource Team, Northcott Disability Services
Robert Duncan	Consumer Representative, ParaQuad NSW
Auria Garcia	A/Senior Program Officer, Attendant Care & Physical Disability Unit, Ageing, Disability & Home Care
Tonina Harvey	General Manager, Community Services, ParaQuad NSW
Jade Johnston	A/Team Leader, Spina Bifida Adult Resource Team, Northcott Disability Service
Antony Jones	Consumer Representative, Spinal Cord Injuries Australia
Kylie Jones	Service Manager, Hunter Spinal Cord Injury Service
Greg Killeen	Senior Policy & Advocacy Advisor, Spinal Cord Injuries Australia
Lucija Lavrencic	Clinical Nurse Consultant, Spinal Plastics Service, Royal North Shore Hospital
Alison Loudon	Service Manager, Lourdes Hospital & Community Services, Dubbo
Julie – Anne Macey	Clinical Nurse Consultant, Rehabilitation, the Children's Hospital, Westmead
Neil MacKinnon	Manager Service Coordination, Lifetime Care & Support Authority
Margaret Macpherson	Service Manager, New England Brain Injury Rehab & Northern Spinal Cord Injury Services
Sarah McBurney	Occupational Therapist, Wheelchair Seating Specialist, Bathurst Base Hospital
Mary McCarthy	Nurse Unit Manager / Stomal Therapist, Surgical Ward, Dubbo Base Hospital
James Middleton	Director, State Spinal Cord Injury Service
Frances Monypenny	Network Manager, State Spinal Cord Injury Service, Agency for Clinical Innovation
Alyssa Rogan	A/Service Manager, New England Brain Injury Rehab & Northern Spinal Cord Injury Services
Chris Shipway	Director, Primary & Chronic Care Service, Agency for Clinical Innovation (Chair)
Joanne Trebus	Clinical Leader, Ferguson Lodge, Lidcombe
Bill Tyrell	Clinical Nurse Consultant, Wound / Continence, Lismore Base Hospital
John Vandervord	Director, Division of Surgery & Anaesthesia, Royal North Shore Hospital

15. APPENDIX 2

Feedback and comments on the draft model of care received

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Dr Ross Hawthorne	Senior Specialist, Rehabilitation Medicine, Member of the Sydney LHD Wound Prevention and Management Committee
Dr Indu Nair	Senior Staff Specialist, Rehabilitation Medicine, Member of the Sydney LHD Wound Prevention and Management Committee
Spinal Outreach Service	Members of the multidisciplinary team including medical, nursing, physiotherapy, occupational therapy, dietetics, social work, Royal Rehabilitation Centre Sydney
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Rebecca Hudson	Occupational Therapist, Spina Bifida Adult Resource Team, Northcott Disability Services
Jan Newland	Transition Advisor, GPNSW
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Rebecca Harrington	Dietitian, Royal Rehabilitation Centre Sydney
Helen O' Grady	NSW Kids and Family
Rehabilitation Team	The Children's Hospital at Westmead
Derene Anderson	General Manager, Greater Newcastle Cluster, on behalf of clinicians from Hunter New England Local Health District
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Lewis Kaplan	Chief Executive Officer, General Practitioners New South Wales
Vahid Saberi	Chief Executive Officer, Medicare Local, Mid North Coast
Debbie Schwebel	Mid North Coast Local Health District

Marianne Lackner	Murrumbidgee Local Health District Manager Aged Care and Rehab Services
Clair Ramsden	District Director of Nursing & Midwifery, Nepean Blue Mountains Local Health District
Dr Eva Pilowsky & Trish Boss	Health Service Planning and Investment Branch, NSW Ministry of Health
Kim Field	Director Primary and Community Health, Northern Sydney Local Health District (input from community, child and family health)
Marsha Ben	Senior Physiotherapist, Royal Rehabilitation Centre, Sydney
A/Prof Steven Faux	Director of Rehabilitation, St Vincent's Hospital
Andrew Bernard	Director of Operations, South Eastern Sydney Local Health District
Mark Zacka	Director Clinical Governance, South Western Sydney Local Health District
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16. APPENDIX 3

What Health Services can do to Support the Individual with a SCI/SB to Prevent and or Manage Pressure Injury

	HEALTH CARE SERVICE STRATEGIES TO SUPPORT THE INDIVIDUAL WITH A SCI/SB IN THE PREVENTION AND OR MANAGEMENT OF PRESSURE INJURY
Self-management	Health care services should consider the following:
	• Clinicians have knowledge and understanding of the importance of supporting the individual with a SCI/SB to develop skills and confidence in self-management techniques and/or in directing their carers/family members in their care and activities of daily living.
	 Clinicians are supported to attend education on self-management motivational techniques. Clinician / patient interactions focus on assessment of the individual's capacity to self-manage or guide their care and develop pressure injury prevention management plan.
	 The individual's ability and capacity to self-manage and direct their care is acknowledged and their involvement and participation in their planning of care is supported and encouraged.
	• Clinicians request information from the person with a SCI/SB and or their carers regarding their regular routines and management of their personal care, in particular bowel, bladder, diet, equipment, assistance and mobility requirements and incorporate these in the plan of care during their hospitalisation.
Assessment of risk	Health care services should consider the following:
of pressure injury	• Ensuring they have well established local policies and procedures for the timely assessment, identification of level of risk for PI, prevention, early intervention and management of pressure injuries.
Management of	Health care services should consider the following.
skin integrity &/or pressure injury	• The individual with a SCI/SB and their carers/family are supported to develop skills and knowledge in the assessment, prevention and early intervention strategies to protect the skin from pressure injury.
	• Clinical champions are identified and promoted as key resource people with knowledge and understanding of the special needs of people with a SCI/SB, their identified risks and strategies for the prevention, early intervention and management of pressure injuries.
	 Information about and timely access to available spinal specialist pressure injury services, advice, support and referral is available.
Care / support	Health care services should consider the following:
	• The attendant care and support needs of individuals with a SCI/SB are regularly reassessed, in particular at times of increased risk for or development of pressure injury.
	• An attendant care/support plan is developed, implemented and updated.
	 The role, responsibility and knowledge of carers/family in the prevention and management of pressure injuries, is acknowledged and supported.
	Table continues on page 7

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Table continued from page 70 HEALTH CARE SERVICE STRATEGIES TO SUPPORT THE INDIVIDUAL WITH A SCI/SB IN THE PREVENTION AND OR MANAGEMENT OF PRESSURE INJURY Information and help is provided to the individual / carers to seek and obtain increase in Care / support (continued) support and attendant care at times of increased need. • Timely referral is made to Commonwealth Respite and Care, Home Care, ComPacks (where eligible), Attendant Care, Community Options services and programs to support increased care needs during pressure injury management period. The impact and support needs of carers and family during management of pressure injury is acknowledged and assessed. • Alternative options for supported accommodation/ transitional care are available for individuals who require extended bed rest and gradual return to seating following surgical management of pressure injury. Health care services should consider the following: Equipment Information is available about the supply, review, replacement (purchase/hire), or repair of specialist equipment required by the individual with a SCI/SB to prevent and/or manage pressure injury. Referral to spinal specialist seating services for assessment and review are made in a timely manner. • A well-stocked emergency loan pool with pressure relieving equipment for short term loan to individuals with a SCI/SB during their acute and rehabilitation inpatient stay and or in the community, with clear eligibility criteria and loan procedures and regular equipment maintenance plan, is available. Management of Health care services should consider the following: general health Information and help is provided to individuals with a SCI about registration, maintenance and regular use a personally controlled electronic health record. • Seamless communication pathways and processes across health and government sectors are available to ensure a coordinated approach to the support and health care provision for an individual with a SCI/SB to prevent and manage pressure injury in a timely manner. • Local GPs with knowledge and understanding (or with access to spinal specialist information / advice) of the health care needs of the individual with a SCI, are identified and available. • The individual with a SCI/SB: o Receives an annual general health check and review. o Is referred to spinal specialist multidisciplinary team for an annual review. • The development, implementation/utilisation and regular review of a health management plan to communicate health care and support requirements is supported. Referral pathways to ongoing case management for identified individuals are established. Access to Health care services should consider the following: community based Information about and access to local community based clinicians is available. clinicians Timely referral occurs to community based clinicians with the aim of optimising health (eg RN, maintenance, physical and psychological health, nutritional status, and community access OT, physio, and independence. psychology, Timely referral to community nurse who can take on care coordination role for individuals dietitian) at high risk of deterioration and who has access to decision support system and specialist services for advice. Timely referral to psychology and drug and alcohol services for individuals identified at moderate or high risk occurs.

Table continues on page 72

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	HEALTH CARE SERVICE STRATEGIES TO SUPPORT THE INDIVIDUAL WITH A SCI/SB IN THE PREVENTION AND OR MANAGEMENT OF PRESSURE INJURY	
Peer support	Health care services should consider making available information about and referral to local peer support programs for people with a SCI/SB.	
Spinal and	Health care services should consider ensuring the following are available:	
pressure injury management specialist services	 Information about and access to available spinal specialist services, advice, support and referral. Access to spinal specialist pressure injury decision support tools and resources. Well established clinical and referral pathways to spinal specialist services. Timely referral to spinal specialist pressure injury services. Annual referral for multidisciplinary spinal specialist review and assessment. Spinal specialist advice and recommendations provided in transfer of care plans at discharge from specialist services are enacted by local health services to ensure continued improvement, prevention of recurrence of pressure injury, and a successful transition and return to community living. Dedicated theatre time is available to allow for day of surgery admission (DOSA) / day only admission (DOA). 	
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