NSW ACI Pain Network & NSW State Spinal Cord Injury Service

Chronic Pain & Spinal Cord Injury Project
Report 2: Clinician Needs Analysis
Report 2: The following report summarises the findings of the clinician needs analysis for the Chronic Pain and Spinal Cord Injury Project. This project is being conducted through the NSW Agency for Clinical Innovation (NSW ACI) with financial support from the NSW Lifetime Care and Support Authority (NSW LTCSA).
# TABLE OF CONTENTS

1. **BACKGROUND & INTRODUCTION**  
   
2. **METHODOLOGY - CLINICIAN NEEDS ANALYSIS**  
   2.1 INTERVIEWS WITH KEY STAKEHOLDERS  
   2.2 SURVEY DESIGN, MARKETING AND DISTRIBUTION  
   2.3 CLINICIAN FOCUS GROUPS  

3. **RESULTS**  
   3.1 DEMOGRAPHICS  
   3.2 ASSESSMENT TOOLS & OUTCOME MEASURES  
   3.3 RESOURCES  
   3.4 HEALTH SERVICES  

4. **SUMMARY**  

5. **FUTURE PLANNING**  

6. **REFERENCES**  

7. **APPENDICES**  

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1. BACKGROUND

Pain is defined by the International Association for the Study of Pain (IASP) as “an unpleasant sensory and emotional experience, associated with actual or potential tissue damage, or described in terms of such damage”. Chronic pain is defined as pain lasting longer than 6 months duration and chronic pain after spinal cord injury (SCI) is particularly refractory to treatment, which often leads to high levels of distress and impacts on quality of life.

The Lifetime Care and Support Authority (LTCSA) have funded a project being conducted through the NSW Agency for Clinical Innovation (ACI) to develop a resource for people with SCI who experience chronic pain, by improving opportunities for timely access to specialist pain services as well as the development of a series of internet based resources which focus on self-management for chronic pain.

Report 1 detailed the analysis of 45 responses to the consumer online survey. A further 27 consumers were consulted during a series of focus groups at Illawarra and Tamworth Spinal Cord Injuries Australia regional centres, 20 more consumers have contributed to the online survey and an additional 8 consumers have been interviewed over the past 2 months. Data obtained from these groups has now been added to Report 1, version 2 (attached) summarising the results of consultation with a total of 100 consumers thus far.

Figure 1 represents the schedule for project planning & key phases of the project, and progress against the project plan is highlighted;

- Stakeholder engagement
- Needs analysis of key stakeholders
- Service model development
- Trial of service model at Greenwich Hospital pain clinic
- Development of resource and resource testing
- Project evaluation

Now the diagnostic phase of the project is largely completed, focus will turn to the development and testing of the online resource package and the Greenwich SCI Pain Management service model.
INTRODUCTION

This report is dedicated to outlining the results of the clinician needs analysis. Primary care and specialist clinical services were engaged using a variety of strategies including interviews, online surveys and focus groups to explore dimensions of service provision and to establish resource needs.

Clinicians were included in this consultation phase if they were considered to play a role in the care of individuals with a spinal cord injury either during inpatient care, outpatients or community care. The results presented in this document represent the opinions of primary care clinicians, specialist clinicians from the multidisciplinary pain and spinal cord injury settings, private practitioners, LTCSA coordinators and case managers with both metropolitan and rural services represented.

It is important to acknowledge that this needs analysis has been an iterative process, with each interaction informing the next phase. Hence consultation on each key topic may have been explored with different numbers of clinicians. Throughout the document, the numbers of clinicians consulted per item, will be presented in brackets, for example (N=43) and the key figures will be presented as a percentage to allow more direct comparison.
2. METHODOLOGY – CLINICIAN NEEDS ANALYSIS

The process of clinician engagement employed three main strategies, as outlined Figure 2 below.

1. Semi-structured interviews with individual key stakeholders via phone or in-person to explore currently available services & resource utilisation. These meetings also helped to inform future survey design and focus group planning.

2. Online clinician survey to obtain a large volume of responses from a multidisciplinary perspective.

3. Targeted small focus groups to establish detailed data from a multidisciplinary perspective.

Figure 2: The process of Clinician Engagement
2.1 INTERVIEWS WITH KEY STAKEHOLDERS

Initial meetings with key stakeholders were undertaken to increase awareness of the project and to provide opportunities for services to engage during the planning and development phase. Key stakeholders were defined as services with experience in contemporary practice of SCI pain management in Tier 2 and 3 level pain clinics as well as within the services of the NSW State Spinal Cord Injury Service. Forty-three individual staff participated in interviews during this phase of the project.

The key services and agencies that were engaged included:

- Lifetime Care & Support Authority (LTCSA)

- State Spinal Cord Injury Services (SSCIS):
  - Royal Rehabilitation Centre Sydney Spinal Injury Unit (RRCS SIU)
  - Prince of Wales Hospital Spinal Injury Unit (POWH SIU)
  - Spinal Outreach Service (SOS)
  - Rural Spinal Cord Injury Service (RSCIS)
  - Royal North Shore Hospital (RNSH) - pending
  - Hunter Spinal Cord Injury Service (HSCIS)

- Pain Services
  - ACI Pain Network representative
  - Royal North Shore Hospital Pain Management Service
  - Prince of Wales Hospital Pain Clinic
  - Royal Prince Alfred Hospital Pain Clinic
  - St Vincent’s Hospital Pain Clinic
  - Orange Health Service Pain Clinic
  - Tamworth Integrated Pain Service
  - Hunter Integrated Pain Service
  - Greenwich Pain Management Clinic

- Non-government Agencies
  - ParaQuad NSW
  - Spinal Cord Injuries Australia (SCIA)
2.2 SURVEY DESIGN, MARKETING & DISTRIBUTION

It was determined that an online survey was the most effective method to obtain information from a large number of clinicians representing a range of geographical areas and clinical expertise. In total, 110 clinicians contributed to the online survey between August 7th 2013 – November 12th 2013. The survey was hosted on Survey Monkey, an online survey tool facilitating design, collection & efficient analysis of data. The survey is located at the following URL:

https://www.surveymonkey.com/s/SCIPainClinicianSurvey2013

The clinician survey consists of 21 questions in a variety of formats including – multiple choice, multiple answer, rated/ranked questions & open ended questions. The survey questions examined the following domains: demographics; assessment tools & outcome measures; resources; health services. The survey domains are detailed in Figure 3, and a full copy of the survey questions may be found in Appendix 1.

Figure 3: Online clinician survey – domains

In order to gain a broad representation of respondents to the survey, the link to the online survey was distributed widely including the Agency for Clinical Innovation Pain Network members, the NSW State Spinal Cord Injury Service and the Lifetime Care and Support Authority. The survey link and information about the project was also distributed to non-government organisations (NGOs), case management networks, professional associations and primary care clinicians, and was actively publicised at the Australia New Zealand Spinal Cord Society (ANZSCOS) conference. It was essential to engage a large number of
clinicians from diverse backgrounds to accurately reflect the range of services individuals with a spinal cord injury engage with. Figure 4 provides a summary of the services that supported the clinician survey, with staff representatives completing the survey as well as where appropriate, distributing the details of the online survey via email, e-newsletter, print media, and word of mouth.

Figure 4: Survey marketing and distribution

2.3 CLINICIAN FOCUS GROUPS

After some preliminary outcomes were analysed from the online survey, clinician focus groups were arranged with key groups to further explore service gaps and resource needs.

Focus groups were conducted with the following teams:

- **POWH SIU focus group** (N = 19)
- **RRCS SIU focus group** (N=17)
- **SOS focus group** (N=14)
- **RSCIS focus group** (N=6)
- **SCIA PT & EP focus group** (N=22)

A further series of focus groups is planned to workshop the evolving service model, referral pathway and resource development involving the following staff groups:

- **LTCSA coordinators**
- **LTCSA approved case managers**
- **Primary care clinicians**
- **RNSH SIU team**

The clinicians’ focus group meetings have incorporated an educational presentation on chronic pain after SCI, as well as exploring the resource and service needs of this group.
The KP1 Audience Response System software was used in consumer and clinician focus
groups thus far to gauge real-time audience opinions during the meetings. Questions for this
system were delivered as a 5 point Likert Scale, and were designed to promote interactivity
and discussion and to provide immediate feedback during the session.

Results of these three phases of engagement are outlined in the following pages and
resource development will evolve in accord with the combined results of the consumer and
clinician consultation.

3.0 RESULTS

Overall, there was strong response from clinicians, with a total of 242 total responses using
the various methods of consultation detailed above. A breakdown of this data demonstrates
the following contributions;

- Patient Experience Trackers at ANZSCOS (N = 27)
- Interviews with key stakeholders (N = 43)
- Online clinicians survey (N = 110)
- Focus Group attendance (N=62)

3.1 DEMOGRAPHICS

The majority of survey respondents provided clinical services in both rural and metropolitan
regions, with 48.6% respondents covering both geographic areas. 30.3% exclusively
covered metropolitan or urban areas, and 21.1% worked in the rural sector only.

The respondents represented a range of professional disciplines as outlined in Table 1.

<table>
<thead>
<tr>
<th>Professional Discipline</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiotherapist</td>
<td>27.9%</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>26.9%</td>
</tr>
<tr>
<td>Nurse</td>
<td>16.4%</td>
</tr>
<tr>
<td>Doctor – Specialist</td>
<td>10.6%</td>
</tr>
<tr>
<td>Social Worker</td>
<td>8.7%</td>
</tr>
<tr>
<td>LTCSA Coordinator</td>
<td>6.73%</td>
</tr>
<tr>
<td>Doctor – GP</td>
<td>2.9%</td>
</tr>
</tbody>
</table>
The respondents represented a diverse cross-section of the clinical community with interest in SCI and pain. The highest representation came from public hospital inpatient spinal injury unit (34%), followed by community health (19.8%), community outreach (18.9%) and public hospital non SIU (18.9%). Of the total respondents, 12.2% were staff of the LTCSA, solo private practitioners represented 8.5% & group practice private practitioners formed 4.7% of the sample. Smaller numbers of survey respondents were from private hospitals, private pain management centres, other insurance providers, NGOs and research organisations.

Clinical expertise in SCI demonstrated two peak trends among survey respondents, with 45.8% reporting that people with SCI formed 80-100% of their caseload, while 44% had less than 30% of their case load made up of individuals with a SCI. This was highlighted as a significant issue for respondents at both ends of the spectrum – with some feeling competent to manage SCI patients in general, but not SCI patients with chronic pain, while others felt under-resourced to address both SCI general and SCI chronic pain issues that arise. Indeed, 81.13% of respondents advised that they felt inadequately resourced to manage patients with post-SCI pain in the community or outpatient setting.
This high level of clinician uncertainty raises a number of issues including:

- **The need to improve clinical support and education regarding SCI pain.**
- **The importance of providing a freely available resource on an easily and frequently accessed host platform to optimise clinician access to and engagement with resources.**
- **The importance of providing clear and easy to understand resources that increase the capacity of primary care clinicians to assess and provide treatment.**
- **To provide a range of clinical support tools that can assist the client to develop effective self-management plans for chronic pain after SCI, in line with chronic disease management principles.**
- **The importance of providing clinical education tools, practical assessment and planning tools and a decision support tool for clinicians—mindful of their differing levels of experience in the areas of SCI and pain.**
- **The importance of promotion and advertising of the resource so all clinicians are aware of the resources’ content and location for use when needed.**
- **The importance of providing access to appropriate specialist service for referral and the need for clearly defined referral pathways.**

Resource needs were further explored during targeted focus groups. Clinicians’ contributing to the needs analysis describe the competing needs of adequate time and resources and the difficulty to prioritise and allocate these resources for such a small portion of their case load.

“As SCI is such a small component of my work - access to specialised advice is important”
“No one on staff has any experience with pain management. We feel that we cannot provide a service without some training (funding and resources). We are hesitant to provide sub-par pain management service and feel that this is a significant risk, given our lack of experience....”

“Lack of specialist knowledge in this area is a problem as we see these clients infrequently. We can also only see these clients for 8 weeks maximum which is a drop in the ocean compared to their needs.”

3.2 ASSESSMENT TOOLS & OUTCOME MEASURES

Felix et al (2007) suggests that in the SCI population, chronic pain is typically not one entity but often many types of pain, each with its own set of pain-generating and pain-maintaining mechanisms. Survey respondents identify a range of significant pain affecting their patients:

- At level neuropathic pain (71.3%)
- Below level neuropathic pain (88.9%)
- Musculoskeletal pain (84.7%)
- Visceral pain (38%)

Most clinicians believed that neuropathic pain is the most problematic, with 65.1% reporting below level neuropathic pain and 36.8% reporting at level pain as the most distressing symptom for their clients.

These different types of pain may occur independently or they may co-exist at any one time. It is important for the clinician to have an understanding of the pain types informing the overall clinical presentation, and thus a system of classification for SCI pain has been endorsed by a panel of international experts. Bryce et al (2012) developed the ISCIP Classification system for SCI pain, further developing the earlier work of Siddall & Middleton (2006). The ISCIP Classification provides a method to describe nociceptive and neuropathic elements depending on pain location and the level of SCI, and then further defines pain type using specific criteria. It is important to accurately classify SCI pain in order to devise suitable treatment plans and to identify early who is appropriate for the proposed intervention or who needs further referral. In addition, simple alert systems that flag underlying complications (ie ‘red’ and ‘yellow’ flags) where pain is an early sign would be of benefit.
The use of appropriate assessment tools and outcome measures is an essential element in the clinical management of chronic pain after SCI. They assist in defining symptoms, completing the SCI pain classification, assist with clinical decision making and informing SMART goals and giving structure to treatment plans.

Survey respondents were asked to nominate which assessment tools they were aware of and what tools they regularly used in clinical practice. A summary of the responses in descending order of awareness is located in Table 2.

<table>
<thead>
<tr>
<th>Name Of Assessment Tool / Outcome Measure</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual Analogue Scale (VAS)</td>
<td>64%</td>
</tr>
<tr>
<td>Depression and Anxiety and Stress Scale (DASS 21)</td>
<td>52.8%</td>
</tr>
<tr>
<td>Body Chart Diagram</td>
<td>52.8%</td>
</tr>
<tr>
<td>Numerical rating scale (NRS)</td>
<td>40.5%</td>
</tr>
<tr>
<td>SF – 36</td>
<td>38.2%</td>
</tr>
<tr>
<td>Pain Self Efficacy Questionnaire (PSEQ)</td>
<td>25.8%</td>
</tr>
<tr>
<td>Wheelchair Users Shoulder Pain Index (WUSPI)</td>
<td>25.8%</td>
</tr>
<tr>
<td>Brief Pain Inventory</td>
<td>23.6%</td>
</tr>
<tr>
<td>International SCI Pain Classification (ISCIP)</td>
<td>18%</td>
</tr>
<tr>
<td>International SCI Pain Basic Data Set (ISCIPBDS)</td>
<td>18%</td>
</tr>
<tr>
<td>Moorong Self Efficacy Questionnaire (MSEQ)</td>
<td>15.7%</td>
</tr>
<tr>
<td>Pain Catastrophising Scale (PCS)</td>
<td>14.6%</td>
</tr>
<tr>
<td>Neuropathic Pain Scale (NPS)</td>
<td>14.6%</td>
</tr>
<tr>
<td>International Association for the Study of Pain (IASP) Classification</td>
<td>13.5%</td>
</tr>
<tr>
<td>BPI – Modified</td>
<td>7.9%</td>
</tr>
<tr>
<td>Multidimensional Pain Index (SCI version) MPI- SCI</td>
<td>4.5%</td>
</tr>
<tr>
<td>Leeds Assessment of Neuropathic Symptoms and Signs (LANSS)</td>
<td>4.5%</td>
</tr>
<tr>
<td>DN4</td>
<td>1.1%</td>
</tr>
<tr>
<td>Bryce-Ragnarsson</td>
<td>1.1%</td>
</tr>
</tbody>
</table>

Despite knowledge of available assessment tools, a narrow range of assessment tools were employed for pain assessment, with the exception of a few respondents. The majority of respondents used the Visual Analogue Scale (VAS) 33.3%, the Numerical Rating Scale (NRS) 20.5% and the Depression and Anxiety Stress Scale (DASS 21) 13%. However, 22% of respondents did not use any specific outcome measures or assessment tools when assessing their client with post SCI pain.

With the international consensus on SCI pain classification and the recent development of the International Spinal Cord Society Pain Basic Data Set (Widerstrom-Noga et al 2008), it is timely to introduce a method of systematic assessment of SCI pain in NSW. This concept with the capacity to change practice was further explored in the clinician focus groups.
Kennedy et al (1997) in a longitudinal study examined individuals in the United Kingdom who had sustained a spinal cord injury, following them up for 12 months. It was found that perceived pain at 6 weeks was the most predictive factor, above psychological and functional variables, of pain at 1 year post hospital discharge. This would suggest that mandatory screening for post SCI pain prior to discharge may identify individuals at risk of developing pain related complications. In this circumstance it may be beneficial to commence an integrated pain management plan in preparation for discharge home. When surveyed during SCI clinician focus groups representative of both inpatient and community workers and including responses from over 40 clinicians, 100% of respondents agreed/strongly agreed in principle with pre-screening for SCI pain prior to or at the point of discharge. The logistical challenges of how to develop and implement this screening tool will be further explored as part of this project.

“I am truly surprised at the number of tools available”

“Participating in the survey has taught me about the tools and resources out there – I didn’t know about these before!”

### 3.3 RESOURCES

Clinicians were asked to explore their reports that they felt on the whole under-resourced to provide comprehensive pain management for people with SCI and chronic pain.

Clinicians discussed barriers to the implementation of best practice such as resource limitation (staffing, time & cost), insufficient knowledge of clinical practice guidelines and insufficient high quality evidence in the field of SCI in general. From the online survey, 75.7% of individuals reported being unaware of clinical practice guidelines for chronic SCI pain to guide clinical decision making, and few were aware of evidence summaries such as the Spinal Cord Injury Research Evidence (SCIRE) Pain Management document or the NSW SSCIS document “Managing Pain for Adults with a Spinal Cord Injury”.

Clinicians also highlighted patient factors such as personal motivation, patient expectations, lengthy personal care routines impacting attendance & travel as complicating issues when providing comprehensive care for individuals with SCI and chronic pain.

When asked what would improve clinician confidence to manage SCI pain, 60.4% of respondents indicated that an online interactive clinical pathway/treatment algorithm would
be a helpful decision support tool, and this was supported by 96% of focus group attendees (N=55) who agreed/strongly agreed with this option.

Other suggestions for resource development include access to pain and SCI educational resources for clinicians & consumers (83%) and access to specialist pain management service with specific clinical experience in SCI management for phone support and referral (60%). The importance of access to appropriate SCI pain assessment tools, was also highly rated among clinicians in the online survey (N = 110, 77.14%) to inform clinical decision making and assessment of outcomes.

Professional development opportunities were explored, with particular attention on methods of education delivery. Survey respondents were asked to rank in order of preference a number of options, and particular attention is paid to their 1st and 2nd preference. Respondents demonstrated an overall preference for smaller group sessions (73.8% ranked 1st or 2nd), followed by self-study options (48.9% ranked 1st or 2nd) and larger group sessions (40.2% ranked 1st or 2nd). Remote delivery of clinical education via online seminars/webinars or via teleconference/video conference, also rated strongly - particularly with rural clinicians.

In consensus with the previously documented consumer needs analysis, the internet was voted by far the preferred host for an information resource, with 82% rating this as their first or second preference for accessing resources. An online video resource detailing personal experience of SCI pain management was voted unanimously by the focus groups as an essential resources for the website (N=62).

Also, a comprehensive written text such as a consumer book specifically written about SCI pain was suggested as a desirable reference (84%), as was a smartphone/tablet App (75%) which could be used as an educational reference as well as an interactive device to record pain information and engage with pain management plans.

The complex aetiology of pain after spinal cord injury, and the varied level of clinician experience must be acknowledged when planning for resource content development. Assessment tools to assist pain classification, clinical decision support tools and care pathways, as well as resources to develop knowledge and skill at every stage of multidisciplinary care is essential. Options for resource content development were ranked in order of importance for individual respondents, summarised in Table 3:

“Usually I am so busy with my general case load that I need in-services (and access to resources) at my workplace”
Table 3: SCI Pain – Resource Content

<table>
<thead>
<tr>
<th>Resource</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral pathway for SCI Pain</td>
<td>71%</td>
</tr>
<tr>
<td>Exercise for pain management after SCI</td>
<td>71%</td>
</tr>
<tr>
<td>CBT for pain management after SCI</td>
<td>67.3%</td>
</tr>
<tr>
<td>Goal setting for pain management after SCI</td>
<td>64.5%</td>
</tr>
<tr>
<td>Mechanisms causing pain after SCI</td>
<td>62.6%</td>
</tr>
<tr>
<td>Medication for pain after SCI</td>
<td>58.9%</td>
</tr>
<tr>
<td>Stress management for pain after SCI</td>
<td>57%</td>
</tr>
<tr>
<td>Pacing strategies for pain management after SCI</td>
<td>52.3%</td>
</tr>
<tr>
<td>Relaxation strategies for pain management after SCI</td>
<td>51.4%</td>
</tr>
<tr>
<td>Sleep hygiene for pain management after SCI</td>
<td>50.5%</td>
</tr>
<tr>
<td>Upper limb preservation strategies for pain management after SCI</td>
<td>49.5%</td>
</tr>
<tr>
<td>Equipment prescription for pain management after SCI</td>
<td>48.6%</td>
</tr>
<tr>
<td>Environmental adaptation for pain management after SCI</td>
<td>46.7%</td>
</tr>
<tr>
<td>Meditation strategies for pain management after SCI</td>
<td>43.9%</td>
</tr>
<tr>
<td>How to accommodate patient with SCI in a group pain program</td>
<td>42.1%</td>
</tr>
</tbody>
</table>

The above resources will help to complement a range of multidisciplinary clinical interventions to promote education and tools to promote self-management, with the goals of supporting patient education and shared decision making as essential components of improved self-efficacy and positive health behaviour change.

Survey respondents also highlighted the importance of involving the patient in the development of comprehensive pain management plans and 89% of focus group attendees (N = 55) supported the development of such a tool.

Survey respondents reported wide use of simple patient handouts/information flyers, with 68.8% of respondents using these tools. Of the focus group attendees, 95% agreed or strongly agreed with development of downloadable pdf client flyers from a web-site as a desired resource, and there was an emphasis on use of clear and simple language to communicate these concepts.
“Clients need to own and drive the management plan by selecting the strategies that work for them, rather than being “prescribed” with (generic) strategies”

“A variety of credible, well recognised and accepted resources that can be accessed on several occasions over the span of a person’s life with upgrades and new information as it becomes available.”

“I think that a one off information service is never enough - rather people need a range of support services including written information, internet access or app sources as well as access to specialists and education of GP because it takes time to accept firstly that you have had an injury which is going to be permanent and secondly that the pain may be long term without any answers or magical cures. This is particularly so when the person is back home and their acute rehab has finished”
**RED FLAGS:**

There are instances where pain after spinal cord injury may be an indication of an underlying medical complication (highlighted through use of a ‘red flag’ alert system). Indeed, neuropathic pain has been said to be a diagnosis of exclusion and any new or changing neuropathic pain requires thorough medical investigation for potentially treatable causes such as a post-traumatic syrinx, a Charcot joint, kidney stones, heterotrophic ossification, hardware failure, fractures or herniated disc.

Survey respondents were asked to describe possible signs and symptoms of ‘red flags’, and these items are listed in Table 4. A relatively small number of responses were obtained for each item, and it is not clear if this was due to the assessment burden of the free text response or lack of awareness of the possible ‘red flags’.

**Table 4: SCI - PAIN red flags**

<table>
<thead>
<tr>
<th>Neurological deterioration</th>
<th>Increased spasticity</th>
<th>Bladder and bowel functional change</th>
<th>Autonomic dysreflexia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pressure injury</td>
<td>Fracture</td>
<td>Urinary tract infection</td>
<td>Fever</td>
</tr>
<tr>
<td>Unexplained weight loss</td>
<td>Change in pain</td>
<td>Functional impact of pain</td>
<td>Psychosocial factors</td>
</tr>
<tr>
<td>Medication misuse</td>
<td>Pain affecting sleep</td>
<td>Pain affecting transfers</td>
<td>Pain affecting relationships</td>
</tr>
</tbody>
</table>

It is evident that education regarding identification of spinal specific ‘red flags’ is an essential component of the online resources. Assessment tools and educational and clinical resources will be developed as part of the resource package, and red flag identification and clinical work up will form a component of the interactive clinical algorithm/decision support tool.

“Low mood, drug and alcohol habits ...sleep habits ....catastrophic thinking ...relationship impact... family withdrawal....community participation withdrawal......prolonged time in bed......disengagement from health services.......Then What Do You Do About It?!?!?!?”
3.4 **HEALTH SERVICES**

The current scope of health services for management of chronic pain after spinal cord injury was explored via stakeholder interviews, online survey and focus groups.

Survey respondents were asked to describe their current options for referral for clients with SCI presenting with persistant pain as detailed below. The majority of respondents indicated that they would preferentially refer to spinal specialist (79.8%), followed by pain specialist (67.3%), multidisciplinary pain clinic (59.6%) then individual allied health disciplines (Physiotherapy 56.7%, Psychologist 51.9%, Occupational Therapist 26%) and General Practitioner (33.7%) and case manager or Rural Spinal Cord Injury Service Coordinator (25%). A smaller number of respondents referred to nurses, social workers, outreach workers, community health, NGOs, peer support officers, surgeons, neurologists and the emergency department.

Consumers responding to the consumer survey indicate that in 91.1% of occasions they would discuss their pain management with their General Practitioner as a first line option, followed by their spinal specialist 71.1% and 26.7% had been referred to a multidisciplinary pain clinic.
These results indicate that in the majority of cases, SCI pain is managed by the Spinal or rehabilitation physician or the GP. When this concept was explored further during interviews and focus groups, it was identified that spinal physicians have a high level of confidence when providing medication management of post SCI neuropathic pain whilst also having a thorough understanding of other physical and functional elements of the SCI and this level of expertise is highly desirable. Spinal specialists also often have access to a team of allied health professionals and they refer to physiotherapists and occupational therapists in their networks for management of mechanical pain such as pain arising from shoulder overuse, poor posture or task specific activity. It was established that pain clinic referral was sought predominantly in three circumstances;

1. **Situations where complex medication was required in addition to the medications for neuropathic pain favoured by most SCI clinicians as first line treatment.** Such circumstances may include the need to consider opioid therapy or the consideration of medication infusions or pumps.

2. **Situations where 'yellow flags' had been identified that were contributing to the pain presentation.**

3. **Chronic neuropathic pain that was particularly refractory to standard treatment.**

In a small number of cases referral was made to pain clinics for attendance at group pain management programs and often this was when patients had a very incomplete spinal cord injury and could more easily be accommodated in the standard group program. Unfortunately some clients have reported being refused entry to various pain management groups due to their physical needs despite the clients themselves identifying the potential benefit of being involved in a group pain management program.

The gold standard for chronic pain management as published in the literature is participation in a therapeutic group program which provides medical, physical and psychological support. Results of studies by Norbrink et al 2006 & Nicholson-Perry et al 2010 have examined the benefits of individuals with SCI and persistent pain, participating in a group pain management program including specific SCI content. These studies indicate that pain interference and suffering can be significantly reduced despite ongoing neuropathic pain with the implementation of a pain management program. Quite substantial logistical challenges have hindered research efforts in this area and these challenges also currently form a barrier to implementation of these programs in standard practice. Difficulties such as recruiting adequate numbers to participate in a group program at any one time, transport/travel cost, scheduling of sessions and accommodating for personal care timetables make implementation
challenging. Specific needs of individuals with SCI regarding mobility, activity pacing, exercise and medication management also need to be considered in addition to standard issues such as time off work and family commitments that may impact on participation in a program.

However, the fact remains that individuals with SCI and chronic pain regularly experience severe and constant pain which is functionally limiting, refractory to conventional treatments and > 6 months duration and thus it would seem reasonable to advocate for a multidisciplinary pain service for individuals with SCI towards implementation of best practice. The development of a spinal cord injury specific pain management program is being explored at the Greenwich Hospital Pain Management Centre. Technology solutions such as telehealth and webinars are being investigated as a means of offering a supportive environment whilst overcoming geographic barriers. Program intensity, duration and the diverse needs of rural and urban dwelling individuals are being considered. The concept of travelling multi-disciplinary pain clinics for pain management was suggested by a number of survey respondents but these are currently unrealistic from a funding perspective.

The importance of communication with the primary care team and local service providers has been raised in the online survey. Primary care clinicians requested increased input into discharge planning and direct interaction with the specialist teams to facilitate a smoother transition to the community. Many primary care clinicians have cited the lack of feedback and collaborative support from tertiary centres as hindering their ability to engage with the client’s care plans when they return home and this needs to be proactively addressed in future service planning.

*Communication is important… “we need feedback from the pain clinics instead of the clients trying to explain what they have interpreted as the new treatment”*

*“If the generalist community nurse in the home country towns that are caring for the client be invited / involved more with the plans from the big city clinics.”*
“Rural clinics across State with MDT to assess for chronic pain and commence pain management program, plus online resources/phone follow up with a case manager or contact person from this team.”

“would be good to at least have access to these type of resources to be able to discuss with case manager and / or participant”

“Greater access to information for clinicians where their area does not have specialised services present - ie. Central Coast NSW. Increased access to Chronic Pain Management Teams - currently very long waiting lists due to minimal staffing.”

Chronic pain and SCI is a specialist area in its own right. Our current SCI resources for outpatients treat goal-specific rehabilitation and excludes ongoing management of pain purely due to limited resources/time. These issues are managed by generalist physiotherapists or the Chronic Pain Unit.
4. SUMMARY

A range of strategies were employed to engage clinical services to investigate service system and resource gaps for individuals with spinal cord injury and persistent pain including interviews, online surveys and focus groups. Clinicians were included in this consultation phase if they were considered to play a role in the care of individuals with a spinal cord injury either during inpatient care, outpatients or community care and thus results represent the opinions of primary care clinicians, specialist clinicians from the multidisciplinary pain and spinal cord injury settings, public health (non-SIU) services, private practitioners, LTCSA Coordinators and case managers.

It was established that of clinicians working with individuals with SCI and persistent pain, the majority described feeling under resourced to manage this issue, in some cases despite a high level of expertise in general spinal cord injury care.

It would appear from these results that an accessible and comprehensive resource is required that has the flexibility to cater to a variety of levels of clinician skills and expertise. Clinicians report that spinal specific pain management content would be of benefit including information about mechanisms of pain after SCI, education regarding specific medication management, exercise, activity pacing and equipment/environmental modification, as well as specific information regarding sleep, thought management & relaxation strategies. The majority of respondents advocated for access to a specialist pain service with experience in SCI for advice and referral as well as the benefit of accessing pain specific resources at a variety of intervals along the continuum of care.

A series of resources will be developed in line with the results of the consumer and clinician consultation. Testing or the resources will be conducted with groups of volunteers (consumers and clinicians) who have participated in the surveys and focus groups thus far and have requested ongoing involvement in the project.

The development of a spinal cord injury specific pain management program is being explored at Greenwich Hospital Pain Management Centre. The use of telehealth options are being considered in addition to traditional clinical care to address the significant logistical challenges of distance, travel and care. Specific attention is being paid to the needs of individuals with spinal cord injury to increase access opportunities to the multidisciplinary pain clinic environment and this work will be presented in future reports.
5. FUTURE PLANNING

The next phase of the project is to progress to development of nominated resources which will then be tested with groups of interested consumers and clinicians sourced through the previous survey and focus group activity.

Service model planning at Greenwich Hospital Pain Clinic will continue, detailing the process of referral; pre-assessment; triage; pre-appointment planning; program intensity, duration & monitoring; and follow up plans. Telehealth options, remote monitoring, and webinar group education & support options are all currently being considered.

Further stakeholder engagement will occur with LTCSA approved case managers & coordinators, primary care clinicians from Community Health, NGO and private practice and inpatient, outpatient and community care to finalise resource planning and development.

The first meeting of the Project Advisory Committee will be held on the 25th November 2013 and will include representation from all key stakeholders. The work of the Project Management Team is ongoing and will direct the development of project outcomes.
6. REFERENCES


Norrbrink, C, Kowalski, J, & Lundeberg, T (2006) **A comprehensive pain management programme comprising educational, cognitive and behavioural interventions for neuropathic pain following SCI.** Journal of rehabilitation medicine 38, 172-180


7. APPENDICES

Appendix 1: Clinician Survey Questions

Appendix 2: Experience Tracker results – ANZSCOS Conference 2013
Appendix 1: Clinician Survey Questions

### Chronic Pain and Spinal Cord Injury - Clinician Survey

The purpose of this survey is to examine the needs of clinicians working with individuals with a spinal cord injury and chronic pain. Pain is frequently reported after spinal cord injury. It may begin early after injury, or many years later. For the purposes of this project, pain is defined as “chronic pain” when the symptoms persist for a period of time greater than 6 months.

The Lifetime Care and Support Authority (LTCSA) are supporting a project being run through the NSW Agency for Clinical Innovation (ACI), to develop resources and improve service systems for people with spinal cord injury and chronic pain.

The NSW ACI has a key role as the primary agency in NSW for engaging consumers and clinicians to develop clinical resources and new models of care.

This survey should take no more than 5 minutes to complete. Your participation in the survey will help to establish further pain management services in NSW and inform the content of a series of pain management resources that will be freely available on the internet.

We are currently organising a series of Focus Groups for clinicians. If you wish to participate in a Focus Group to further explore this topic, and contribute to resource development, please contact the Project Officer Lyndall today at lyndall.kato@aci.health.nsw.gov.au or Ph: 0428 834 874.

Thank you for participating in the survey.

1. **What is your professional background? (tick all that apply)**
   - Doctor - Specialist
   - Doctor - GP
   - Nurse
   - Occupational Therapist
   - Physiotherapist
   - Exercise Physiologist
   - Social Worker
   - Other (please specify)

2. **What setting/s do you work in? (tick all that apply)**
   - Public Hospital – Spinal Injury Unit (SIU)
   - Public Hospital – non SIU
   - Public Hospital – Pain Management Centre
   - Private Hospital
   - Private Pain Management Centre
   - Private Practice – solo
   - Private Practice – group practice
   - Community Health
   - Community Outreach
   - Case Management Service
   - Lifetime Care & Support Authority
   - Insurance Provider
   - Non Government Organisation
   - Research
   - Other (please specify)
3. What geographic area do you cover? (tick one)
- Inner Urban
- Rural
- Both

4. Of your clinical workload, what % of people have a spinal cord injury? (tick one)
- 0
- <10%
- 10-25%
- 25-49%
- 50-99%

5. Pain after spinal cord injury can occur in many forms. What types of pain do your clients describe? (tick all that apply)
- All-level Neuropathic Pain - described as burning, electric, sharp or shooting pain in a region of sensory disturbance.
- Neuropathic Pain - often described as dull, aching pain in a region of sensory preservation, often related to activity and relieved by rest.
- Venous pain - dull, cramping abdominal pain.
- Don't know

6. Which type of pain do your clients report as the most distressing type of pain?
- All-level Neuropathic Pain
- Neuropathic Pain
- Venous pain
- Don't know

7. Are you aware of any clinical practice guidelines for persistent pain after spinal cord injury?
- Yes
- No
- Please specify

8. Can you list barriers to implementing evidence-based practice in the clinical practice setting?

9. Do you feel adequately resourced to manage patients with SCI and chronic pain?
- Yes
- No

10. What would make you feel better resourced to manage patients with SCI and chronic pain? (tick all that apply)
- Access to Pain & SCI education resources for clinicians
- Access to Pain & SCI education resources for patients
- Access to outcome measures to assess SCI Pain
- Access to spino multispeciality team for advice
- Access to specialist pain management service for advice
- Access to self-help pain management services with specific clinical experience in SCI management
- Other (please specify)

11. How do you prefer to access resources? (rate in order of preference 1-6)
- Personalised phone/email support
- Internet/web-based resources
- Books
- Journal Articles
- Smartphone/Tablet Apps
- Face-to-face

12. How do you prefer to learn about a topic? (Rate in order of preference)
- Self-directed study options (eg. reading journals, online study)
- Larger group sessions (eg. lectures, conferences)
- Smaller group sessions (eg. workshops, tutorials, seminar)
- Tutorials/Conference
- Online Survey / Videoconference
- Other (please specify)
13. Do you have any other comments or suggestions about accessing SCI Pain resources or education?

14. Considering your knowledge of available resources, what aspects of pain management after spinal cord injury would you like more information about? (Tick all that apply)
- Mechanisms causing pain after spinal cord injury
- Medication for pain after spinal cord injury
- Exercise for pain management after spinal cord injury
- Pacing strategies for pain management after spinal cord injury
- Oral Setting for pain management after spinal cord injury
- Relaxation Techniques for pain management after spinal cord injury
- Meditation Techniques for pain management after spinal cord injury
- Cognitive behavioural therapy for pain management after spinal cord injury
- Sleep hygiene for pain management after spinal cord injury
- Stress Management for pain management after spinal cord injury
- Upper limb preservation strategies for pain management after spinal cord injury
- Equipment prescription for pain management after spinal cord injury
- Drug and alcohol information
- Environmental adaptation for pain management after spinal cord injury
- Advice on how to accommodate patients with spinal cord injury in a group pain program
- Appropriate referral pathways for people with SCI and Pain

Other (please specify)

15. Which Outcome Measures and Pain assessment tools are you aware of?
- International Association for the Study of Pain (IASP) SCI Pain Classification
- IASP - International SCI Pain Classification
- International SCI Pain Basis Data Set (ISCI)
- Disc Pain Classification
- Catterall Pain Classification
- Skalstein-Pagman Pain Taxonomy
- DASS - Depression and Anxiety and Stress Scale
- DAIQ - Discoid Arthrosis Index
- DASS - Leading Assessment of Neuropathic Symptoms and Signs
- WUSP - Washington University Shoulder Pain Index
- NPS - Neuropathic Pain Scale
- MPQ - Multidimensional Pain Inventory - Spinal Cord Injury Version
- SF-36 - Medical Outcome Study Short Form 36
- BPI - Brief Pain Inventory
- BPI Modified - Brief Pain Inventory (modified for use in clinical populations)
- MSQOL - Multidimensional Quality of Life Questionnaire
- VAS - Visual Analogue Scale
- NRS - Numerical Rating Scale
- NPR - Neuropathic Rating Scale
- Body Chart Diagram
- PCS - Pain Chronicity Scale
- PSEQ - Pain Self-Efficacy Questionnaire

Other (please specify)

16. What pain assessment tools/outcome measures do you regularly use in clinical practice?

17. What Red Flags do you look out for when assessing a client with spinal cord injury and persistent pain?

18. If one of your clients presents with persistent pain after spinal cord injury, but you believe they would benefit from additional support - where or to whom would you refer them? (Tick all that apply)
- Medical/Spinal Specialist
- General Practitioner
- Pain Specialist
- Physiotherapist
- Occupational Therapist
- Psychologist
- Rural Spinal Cord Injury Service Coordinator
- Other (please specify)

Other (please specify) / Comments
19. Below is a list of examples of educational resources for people with spinal cord injury and/or chronic pain. Which resources would you use with your clients with SCI and Chronic Pain? (tick all that apply)

- Insulin Pump Injury Unit - Patient Education Sessions
- Books: "Manage Your Pain" by Prof. Michael Nicholas, Dr Allen Molloy, Lee Tainlin, Lee Seaton
- Books: "Explaining Pain" by Prof. Loimara Moseby & Dr. David Butler
- Books: "The Pain Book" by Prof. Philip Goodall, Rebecca McCan, Dr. Melvin Murray
- Books: Other (Please provide details below)
- Handouts/Eyepacs
- Journal Articles
- Press Articles
- Pain Management Workbooks
- Consumer Organisation Magazine (eg. Paraplegic News or Access)
- Consumer Organisation Website (eg. Paraplegic NSW or Spinal Cord Injuries Australia)
- Consumer Organisation App (eg. Parapass NSW or Spinal Cord Injuries Australia)
- Peer Support Sessions
- Queensland Spinal Cord Injury Service (QSCIS) Website & Fact Sheets
- NDIS Website: NDIS Website: "Managing Pain for Adults with a Spinal Cord Injury - Targeting Health Professionals"
- Paralyzed Veterans of America / Consortium for Spinal Cord Medicine Clinical Guidelines/Resources
- International Spinal Cord Society Website / Resources (ISCoS)
- American Spinal Injury Association Website / Resources (ASIA)
- Spinal Cord Injury Research Guidance Website / Resources (SCIERS)
- Spinal Hub Website / Resources
- Spinal Cord Injury Network Website/Resources (SCIN)
- Craig Hospital Website & Fact Sheets
- Chronic Pain Australia Website
- Pain Australia Website
- Pain Health Website
- Australian Pain Management Association Website
- Other (Please specify)

20. Specific resources for SCI Chronic Pain are being developed. What types of resources would be most helpful to assist you to manage your clients with SCI and pain? (tick all that apply)

- Book packs: selection of pain management books
- Web: text only
- Web: includes up videos of patient interviews, interactive resources
- Smartphone/Tablet App
- SCI Pain Assessment Tool Package
- Other (Please specify)

21. Do you have any suggestions how to improve services for clients with spinal cord injury and chronic pain in NSW? Thank you for your participation in the survey - your ideas are truly appreciated.
Appendix 2: Experience Trackers (PETS) administered during the Australian and New Zealand Spinal Cord Injury Annual Scientific Meeting 2013.