Final Project Report

Name of project: The Chronic Pain and Spinal Cord Injury Project

LTCSA reference number:

Project start date: 3rd June 2013

Project completion date: 6th March 2015

Date of final report: 23rd April 2015

1 Introduction

1.1 Description of project

Pain presents a major challenge to those with a spinal cord injury and subsequently to those involved in their care (Siddall, 2009). Chronic pain, defined as pain persisting for more than 6 months, is common after spinal cord injury (SCI) affecting 65-85% of individuals with 30% reporting the pain as severe (Siddall et al 2003). Research demonstrates that individuals with SCI experience a number of different types of pain (Siddall and Middleton, 2006). The most common types of pain include a neuropathic pain described as burning, electric shocks, icy cold or pins and needles affecting the front of the torso, buttocks or lower limbs, and musculoskeletal pain described as “aching” often affecting the neck, back and shoulders in particular (Mehta et al 2014). It has been reported that over 50% of individuals experience neuropathic pain after spinal cord injury (Bonica et al 1991 cited in Mehta et al 2014), 73% of individuals using a manual wheelchair experience shoulder and/or wrist pain with prolonged use of a manual wheelchair and performing body-weight transfers (Subbaro et al 1995) and after 15-20 years of manual wheelchair use, 100% of individuals will experience shoulder pain at some stage (Gellman et al 1988).

In accordance with the National Pain Strategy 2010, the Pain Management Taskforce Report and the NSW Pain Management Plan 2012-2016, chronic pain is best managed by a dedicated and coordinated multi-disciplinary team approach, providing a program of supported self-management. However, access to services with expertise in the management of chronic pain as well as an understanding of SCI specific health conditions was limited. Additionally, there were inadequate resources and educational materials for consumers with chronic SCI-related pain available, and clinicians were also largely under-resourced to provide comprehensive assessment and pain management plans for individuals with SCI pain due to lack of available resource material.

The NSW Lifetime Care and Support Authority funded a project conducted through the NSW Agency for Clinical Innovation (ACI) Pain Management Network to develop additional capacity in this area. The Chronic Pain and SCI Project was established to examine the needs of consumers and clinicians in relation to SCI pain management and to develop a series of resources and an innovative strategy for service system improvement for people with chronic SCI-related pain.
1.2 Objectives

The objectives of the Chronic Pain and Spinal Cord Injury Project are outlined below:

1. To provide access to a range of evidence informed, engaging and accessible consumer resources to assist self-management of chronic pain after SCI.

2. To provide resources to assist clinicians to access high quality and evidence based material to aid clinical decision-making, treatment and management of SCI-related chronic pain.

3. To increase capacity in specialist pain services to address the needs of individuals with SCI by education and promotion of the available online resources to tertiary pain services in NSW.

4. To develop and pilot a specialist SCI Pain Clinic at Greenwich Hospital, to improve access to both rural and metropolitan participants of the Lifetime Care and Support Scheme.

2 Executive summary

The Chronic Pain and Spinal Cord Injury Project, funded by the NSW Lifetime Care and Support Authority and conducted through the NSW ACI Pain Management Network was established to improve support to individuals with chronic SCI-related pain in the community.

The Chronic Pain and SCI Project commenced in June 2013 with the early diagnostic phase of the project focused on engaging with a community of practice dedicated to developing a greater understanding of knowledge and resource gaps and the needs of health services to better address chronic SCI-related pain. This involved extensive involvement from a core SCI Pain Project Management Group, consisting of A/Prof James Middleton (Rehabilitation Specialist, Director NSW State Spinal Cord Injury Service - SSCIS), Prof Philip Siddall (Pain Specialist, Director Greenwich Hospital Pain Management Service), A/Prof Kathryn Nicholson Perry (Clinical Psychologist), Jenni Johnson (Manager, Pain Management Network NSW ACI), Frances Monypenny (Manager, NSW SSCIS) and Lyndall Katte (Project Officer, NSW ACI), with monthly meetings to drive the development of resources. The SCI Pain Project Advisory Committee was also convened with multidisciplinary representation from the NSW spinal injury units - both rural and metropolitan services, community non-government organisations, consumer representatives and the NSW LTCSA, and met on four occasions with additional contact to develop, refine, distribute and ultimately endorse resources among representative organisations.

From the results of our needs analysis with information obtained through an online survey, a series of focus groups for both consumers and clinicians, as well as published qualitative works examining the health information needs of individuals with chronic SCI (Burkell et al 2006) and chronic SCI-related pain (Norman et al 2010), an online pain management resource was developed and embedded within the NSW Agency for Clinical Innovation Pain Management Network website www.aci.health.nsw.gov.au/chronic-pain/spinal-cord-injury-pain.

Norman et al (2010) reported on six main themes regarding questions that individuals with SCI have regarding chronic pain; cause, communication, expectations, getting information, management and others experience of pain. This was consistent with our findings through the survey process and five consumer films integrating information from consumers with lived experience of chronic SCI-related pain and expert clinicians from the field of pain medicine, rehabilitation medicine and clinical
psychology were created. The films and webpages address the following topics: “Introduction to Spinal Cord Injury Pain”, “Understanding Pain After Spinal Cord Injury”, “SCI Pain, Physical Activity and Exercise”, “SCI Pain and Medications” and “SCI Pain, Thoughts and Feelings” with complementary written resources to accompany each consumer film and additional resources to provide SCI-specific information on “Getting help from your Healthcare Team”, “Pain, Lifestyle and Nutrition” and “Pain and Sleep”.

From the needs analysis it was discovered that >80% of clinicians surveyed reported feeling under-resourced to manage chronic SCI-related pain in their clinical practice. This was consistent with the findings of Norrbrink et al (2012), where up to 87% of clinicians confident with managing other secondary conditions experienced by people with SCI described a knowledge or resource gap for managing chronic pain after SCI. The local needs analysis explored the resource needs of clinicians and an interactive online tool with guidance for screening, assessment and treatment planning as well as links to additional evidence based recommendations and a downloadable pain management plan was developed [http://www.aci.health.nsw.gov.au/chronic-pain/spinal-cord-injury-pain/sci-pain-navigator](http://www.aci.health.nsw.gov.au/chronic-pain/spinal-cord-injury-pain/sci-pain-navigator).

It has been established that classification of pain types is an essential first step in designing a successful treatment program (Siddall and Middleton 2006). Recent publication of the International Spinal Cord Injury Pain Classification (Bryce et al 2012) and the SCI Pain Basic Data Set (Widerstrom Noga et al 2014) are significant milestones in the area of SCI-pain assessment and classification, and contemporary resources and research efforts should be compatible with these works, and the SCI Pain Navigator refers directly to these key resources.

A tertiary pain management service for individuals with chronic pain after spinal cord injury has been developed at Greenwich Hospital. This service has been set up to provide specialist multidisciplinary pain management consultation and support to individuals with persistent SCI-related pain. Through the needs analysis process it was identified that individuals with chronic SCI-related pain were not routinely referred to multidisciplinary pain management services, despite presenting with a range of symptoms that would ordinarily indicate referral to these tertiary level services. Symptoms included pain persisting for > 6 months, complex co-morbidities, polypharmacy, and pain interfering significantly with daily life (eg: sleep, mood and activity). Access barriers to pain management services were explored in greater detail during the diagnostic phase of the project and a number of common factors such as personnel, resource and logistical barriers were identified. The SCI Pain Clinic at Greenwich Hospital aims to address both the logistical barriers of access and engagement, whilst providing a high-quality and contemporary pain management program with SCI specific content. The clinic utilizes an innovative service design and model of care that incorporates both physical attendance/s at clinic as well as pre- and post- clinic activities performed via tele-health to reduce the burden of travel and provide more equitable and convenient service for participants.
3 Outcomes and outputs

3.1 Project evaluation

Feedback has been sought from within the community of practice through each stage of resource development and testing, from the early diagnostic phase to the current phase of dissemination and implementation of the work. The needs analysis included responses from over 100 consumers and over 200 clinicians from the online survey, interviews and focus groups. SCI Pain education sessions and focus groups to workshop resource development were held around NSW 2013-2014, including at Prince of Wales Hospital (POWH) Spinal Cord Injury Unit (SCIU), Royal Rehab SCIU, Royal North Shore Hospital (RNSH) SCIU, Spinal Outreach Service, Hunter Spinal Cord Injury Service, Rural Spinal Cord Injury Service, Tamworth Integrated Pain Service, Hunter Integrated Pain Service, Orange Base Hospital Chronic Pain Clinic, the NSW Lifetime Care and Support Authority (Parramatta branch, Sydney branch and online via webinar, Spinal Cord Injuries Australia (Tamworth regional service, Illawarra regional service and national meeting of Walk On staff). Further to this, individual interviews were undertaken with key staff representing the spinal cord injury units and tertiary pain services at RNSH Pain Management and Research Centre, Illawarra and Shoalhaven Pain Clinic and Rehabilitation Department - Port Kembla Hospital, St Vincent’s Hospital Pain Clinic, POWH SCIU and Pain Management Department, Hunter Integrated Pain Service, Hunter Spinal Cord Injury Service, Spinal Cord Injuries Australia, ParaQuad NSW and the Spinal Outreach Service/Rural Spinal Cord Injury Service.

Website usage data is being examined using Google Analytics and demonstrated 17 000 “hits” within the first three months of the website launch (October 2014 – February 2015). A four question feedback tool is embedded into the webpages from the pre-existing Pain Management Network website, with valuable consumer and clinician feedback received thus far. In addition, a feedback questionnaire has been posted on Survey Monkey with a link from the website for more detailed responses for the purposes of iterative evaluation into the future: https://www.research.net/r/SCI-pain-project-website-evaluation

There are nineteen tertiary pain centres statewide and during phase one implementation of the project (February – March 2015), onsite education sessions were offered at each pain clinic. Fifteen of the nineteen pain services participated in these sessions including: Tamworth Integrated Pain Service, Illawarra Shoalhaven Pain Clinic - Port Kembla Hospital, Hunter Integrated Pain Service, Port Macquarie Hospital Chronic Pain Clinic, the Pain Clinic Gosford Hospital, Prince of Wales Hospital Pain Management Department, Westmead Hospital Chronic Pain Service, Nepean Hospital Pain Management Unit, Liverpool Hospital Department of Pain Medicine, St Vincent’s Hospital Pain Clinic, St George Hospital Pain Management Unit and Orange Base Hospital Chronic Pain Clinic, with further sessions planned for Concord Repatriation General Hospital Multidisciplinary Pain Clinic and Lismore Hospital Multidisciplinary Pain Management Clinic in the near future. A presentation was also given to the NSW ACI Pain Network annual workshop, and the website was also promoted during national workshops for the Australian Pain Society conference March 2015, and the Australian College of Rural and Remote Medicine November 2014.

Further active dissemination of the completed resource package has included a consumer forum held in Tamworth with assistance from Spinal Cord Injuries Australia and a clinician and consumer
forum in Newcastle with assistance from ParaQuad NSW to provide education, showcase the resources and obtain feedback.

Thus far, feedback responses have been obtained from 96 individuals from the education sessions, as represented in the graph below:

Of this combined group 84% agree or strongly agree the resources are easy to access online, and 82% believe there is a good range of resources, with 90% reporting they will use the resources again in future. Clinicians report they will use the resources for the purpose of self-education (15%), as a resource for students (22%), to share with colleagues (27%) and give to clients (27%), and consumers reported planning to use the resources for self-education, to manage their pain and to give to their carers.

A further roll out of the resources will occur through the services of the NSW SSCIS in the coming months as part of the second phase of implementation and knowledge translation research being conducted through the John Walsh Centre for Rehabilitation Research, Kolling Institute, University of Sydney.
3.2 Outcomes

The objectives of the Chronic Pain and Spinal Cord Injury Project as previously described were:

1. To provide access to a range of evidence informed, engaging and accessible consumer resources to assist self-management of chronic pain after SCI.

2. To provide resources to assist clinicians to access high quality and evidence based material to aid clinical decision-making, treatment and management of SCI-related chronic pain.

3. To increase capacity in specialist pain services to address the needs of individuals with SCI by education and promotion of the available online resources to tertiary pain services in NSW.

4. To develop and pilot a specialist SCI Pain Clinic at Greenwich Hospital, to improve access to both rural and metropolitan participants of the Lifetime Care and Support Scheme.

1. To provide access to a range of evidence informed, engaging and accessible consumer resources to assist self-management of chronic pain after SCI.

The project has resulted in the development of an online toolkit of resources for individuals with chronic pain after SCI. The consumer resources are based around key topic areas identified to be of importance to people seeking information to assist self-management efforts. It was important to host the information online as 74% of respondents from the needs analysis identified the Internet as their preferred method of obtaining healthcare information. This allows people to access high quality evidence based information on an ‘as needed’ basis and mindful of principles of adult learning theory, information must be considered intrinsically important and presented in a way that appeals to the consumers preferred learning style eg: kinaesthetic, visual or auditory. By providing engaging and accessible information presented using film, visual and auditory stimulation, downloadable education flyers and assessment forms / questionnaires, an interactive clinician’s tool and with animated graphics to explain complex concepts, learning and retention is optimised. The website may be viewed at www.aci.health.nsw.gov.au/chronic-pain/spinal-cord-injury-pain

2. To provide resources to assist clinicians to access high quality and evidence based material to aid clinical decision-making, treatment and management of SCI-related chronic pain.

The SCI Pain Navigator has been developed as an online interactive clinician decision support strategy to guide users through the process of screening, assessment and developing a pain management plan for their patients. The tool allows rapid access to relevant research findings, assessment tools, patient resources, a screening process for SCI pain red flags, links to further information and referral options. The tool saves entered data into a pain management plan document that may be printed out as a summary of the session, saved and developed over time as the patient progresses. The pain management plan is labelled with a unique code of letters and numbers and no further identifying features are captured to preserve patient confidentiality when using the tool.
3. To increase capacity in specialist pain services to address the needs of individuals with SCI by education and promotion of the available online resources to tertiary pain services in NSW.

As detailed above, the first phase of implementation has involved an active dissemination strategy, whereby 15 of the 19 tertiary pain services in NSW have engaged with a SCI Pain and website education session. Additionally, they were provided with a hard copy of all the downloadable material from the website, and a USB with soft copies of the documents and the consumer films in case of problems with internet access/connection issues. These resources were presented in a personalised folder to each service and the resources were very well accepted. A book has also been produced during the course of the project – *The SCI Pain Book*. The book is a collaborative work between the Greenwich Hospital Pain Clinic team and the Chronic Pain and SCI Project Management group, with support from the NSW ACI. The book will be distributed to all NSW Pain Clinics and also NSW public libraries during National Pain Week July 2015, as a further strategy to increase capacity in specialist pain services to address the needs of individuals with SCI-related pain.

4. To develop and pilot a specialist SCI Pain Clinic at Greenwich Hospital, to improve access to both rural and metropolitan participants of the Lifetime Care and Support Scheme.

A tertiary pain management service for individuals with chronic pain after spinal cord injury has been developed at Greenwich Hospital. This service has been set up to provide specialist multidisciplinary pain management consultation and support to individuals with persistent SCI-related pain. In order to optimise accessibility of the program on a state-wide level, novel methods of service delivery have been implemented, including telehealth as an integral component of the model of care. The service model has been tailored to accommodate the special requirements of individuals with SCI, and strives to provide a patient centred approach. During the pilot phase of the clinic Feb 2014 – Dec 2014, seven patients were seen in the clinic and provided feedback on the structure of the clinic and also on ways to optimise the model for future patients. The model of care currently includes a pre-clinic telehealth appointment where the participant is screened for red flags and pain history is discussed. If the client is from a rural area, a care plan is also completed during this stage to assist planning for travel and accommodation if a visit to Sydney is required. For both rural and metropolitan clients, it is recommended that the case manager participate in the pre-clinic telehealth appointment and if feasible, it may also be of benefit for the case manager to attend the clinic sessions - this is particularly important if there are associated diagnoses such as traumatic brain injury or if the individual is having difficulty with short term memory perhaps secondary to pain or medication (or both). Support from the case manager has been found to be of great importance and assists the client to make the necessary changes in their own area and with local support. The clinic session involves a multidisciplinary appointment followed with individual medical, physiotherapy and psychology assessment, then multidisciplinary case conference, and a series of afternoon appointments to set goals and develop the physiotherapy, psychology and medical treatment plans. It is essential the client be given a summary of the day’s session, as there is much covered in a short time period. To this end, a pain management plan template has been included in the hard copy resources, and linked to each of the web pages. Additionally, a SCI Pain Workbook has been created for use in the SCI Pain Clinic at Greenwich Hospital as a patient-centred resource.
### 3.3 Outputs

There are a number of tangible outputs for the project, these include:

- **SCI Pain Website**
  - 5 new SCI – specific consumer films, with more than 1 hour of screen time covering the following topics:
    - Introduction to SCI and Chronic Pain
    - Understanding Pain after SCI
    - SCI Pain: Physical Activity and Exercise
    - Medications for SCI Pain
    - SCI Pain: Thoughts and Feelings
  - 15 spinal cord injury specific downloadable information flyers summarising the key content from each of the films, plus an additional three topic areas:
    - Getting help from your Healthcare Team
    - Pain: Lifestyle and Nutrition
    - Pain and sleep
  - Tools including the Spinal Cord Injury Pain Questionnaire which combines questions from the International Spinal Cord Injury Pain Basic Data Set and the International Spinal Cord Injury Pain Classification. These questions are put into a format that can be easily completed by consumers as tested during the project, and can be used as a communication tool with the individual’s healthcare team.
  - A downloadable pain management plan that links to each topic covered in the webpages and films to assist in practical goal setting and active learning process.
  - Links to over 60 additional online resources

- **SCI Pain Navigator**
  - An online clinician decision support tool to guide the clinician through the phases of screening, assessment and treatment planning, with links to further assessment tools, online resources and a downloadable pain management plan.
• SCI Pain Clinic at Greenwich Hospital
  o A multidisciplinary SCI Pain Clinic was developed, tested and implemented incorporating both telehealth sessions and on-site clinic attendance. Documentation has been developed to support the clinic including checklists for roles and responsibilities of staff and patients, a care plan, red-flag checklist and initial assessment form and a SCI Pain Workbook to complement the SCI Pain Book.

• The SCI Pain Book
  o *The SCI Pain Book* has been written by the Greenwich Hospital Pain Clinic team in collaboration with the Chronic Pain and SCI Pain Project Management group during the course of the project as an additional resource.

• Reporting:
  o Report 1: Consumer Needs Analysis
  o Report 2: Clinician Needs Analysis
  o Report 3: Development of the SCI Pain Navigator
  o Report 4: Development of the SCI Pain Online Toolkit
  o Report 5: Development of the SCI Pain Clinic at Greenwich Hospital

• Poster Presentation:

• Conference Presentations:
  o GP 14: Assessing and managing chronic pain after spinal cord injury – a new tool for GPs and Practice Nurses (October 2014, Adelaide)
  o Australian College of Rural and Remote Medicine (ACRRM): Assessing and Managing Chronic Pain after Spinal Cord Injury (November 2014, Sydney)
  o Australian Pain Society Conference: Mix and Match – Meeting the needs of people with chronic pain (March 2015, Brisbane)

• Presentations:
  o Lifetime Care and Support Authority – Sydney Office
  o Lifetime Care and Support Authority – Parramatta Office
4 Immediate or future impact

The immediate and potential long-term impact is to build capacity in the area of chronic pain management after SCI. The online SCI Pain Toolkit is freely available with a range of engaging consumer and clinician resources and tools to support people in the community with chronic SCI–related pain. The resources are evidence-based and have been reviewed and endorsed by the major stakeholder groups in NSW, including consumer organisations. Active dissemination of the resources and education has been provided to the tertiary pain services throughout NSW and via the
NSW ACI Pain Management Network, and further work regarding knowledge translation and implementation science is being conducted in collaboration with the University of Sydney.

Additional resources are also available for a fee including The SCI Pain Book and the SCI Pain Clinic at Greenwich Hospital, with LTCSA codes and costing of the model of care completed as part of the pilot phase of the clinic. By utilising a combination of on-site clinic attendance and remote access via telehealth, the model is accessible to people residing in both metropolitan and rural NSW. It is hoped these diverse methods of addressing identified knowledge, resource and service gaps may help to provide long term and sustainable solutions.

5 Discussion about conduct of the project

5.1 What worked well?
Throughout the project, active stakeholder involvement was encouraged to ensure clinician and consumer groups were thoroughly engaged in the resource development process. This has provided a strong foundation for the project and a sense of investment in and ownership of the resources across a wide variety of settings from public health/hospitals, LTCSA Case Managers and Coordinators and also community and non-government organisations. The resources appear compatible in a variety of environments and the consumer experience endorsed in the films, webpages, downloadable flyers and the SCI Pain Book are the core strength of the resources. The resources provide a conduit for sharing both evidenced based research but also the lived-experience of chronic pain and practical management strategies to support individuals who experience persistent pain after SCI.

5.2 What were the barriers you encountered?
The major barrier yet to be adequately addressed is engagement with the primary care sector. Despite widespread advertisement of the online survey through primary care publications and organisations including Medicare Locals (Central Coast, Went West, South Western Sydney, Western, Northern Sydney, North Coast, Illawarra Shoalhaven), Royal Australian College of General Practitioners, GP NSW, Australian College of Rural and Remote Medicine and non-government organisations such as Pain Australia, Chronic Pain Australia and the Australian Pain Management Association, only 3 General Practitioners (GPs) responded to the online survey. Although occasional informal consultation was achieved with 2-3 GPs, it was not possible to establish GP representation on the project Advisory Committee for the duration of the project. A workshop for the Australian College of Rural and Remote Medicine annual conference provided the best opportunity to obtain feedback from a small group of GPs attending a workshop on SCI Pain and the use of the SCI Pain Navigator. As a result of feedback from this session, modifications have subsequently been made to the tool to improve acceptability of the tool for use in primary care. Further engagement with primary care is planned during the knowledge translation/implementation science work in collaboration with University of Sydney.

5.3 What were the strategies you used to address the barriers?
Please refer to 5.2.
6 Recommendations

The Chronic Pain and Spinal Cord Injury Project has resulted in the development of a series of resources including a freely available online toolkit for consumers to promote health and wellbeing through supported self-management. The resources may be used independently but will be optimally effective when combined with support from a qualified health professional with experience in chronic pain management. Resources for clinicians also feature on the website to provide a guide to evidence based screening, assessment and treatment planning for individuals with chronic SCI-related pain. During the course of the project the SCI Pain Clinic has been established at Greenwich Hospital under the directorship of Professor Philip Siddall. This clinic provides specialist chronic pain management service with expertise in SCI-related pain and incorporates medical, physiotherapy and psychology follow-up. The model of care incorporates an on-site clinic visit with pre- and post- clinic telehealth sessions to improve access to the clinic and reduce prohibitive logistical barriers as identified in an earlier needs analysis. The Chronic Pain and SCI Project was established to develop capacity in the area of chronic pain management for individuals experiencing chronic pain after SCI. The diverse range of resources is targeted to address specific knowledge, resource or service gaps as identified in the needs analysis, with an emphasis on sustainability.

Note: Final payment approval is based on a satisfactory final report, financial report and tax invoice.

I, the undersigned, being the person duly authorised by the grant recipient organisation, certify that:

(a) the above information is true and complete;
(b) the expenditure of the grant received to date has been solely on the project;
(c) there is no matter or circumstances of which I am aware, that would constitute a breach by us or, if applicable the end recipient, of any term of the Funding Agreement between us and the LTCSA that has not been notified to the Authority

Please sign the declaration below:

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