

# **RURAL SPINAL CORD INJURY PROJECT (RSCIP)**

## **“DEVELOPING SPINAL NETWORKS”**

**2003-2005 PHASE TWO**

### **FINAL REPORT**

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## EXECUTIVE SUMMARY

### **Introduction:**

The Rural Spinal Cord Injury Project (RSCIP) is a pilot project funded by the Motor Accidents Authority of NSW to examine ways to improve the provision and coordination of services for people with a spinal cord injury (SCI) in rural and remote regions of NSW. The first phase of the project involved performing a needs analysis, developing specialised educational resources and providing education and support to rural health professionals, clients with SCI and their care providers. Based on the results and recommendations from the first stage of this project<sup>1</sup>, a second phase (RSCIP 2) proposed to implement and then evaluate a model for developing sustainable spinal networks between local rural health professionals/care providers and metropolitan specialised SCI units/services. It was anticipated that this would lead to improved coordination of care and service provision to people with SCI, as well as advocacy, educational and professional support in rural and regional NSW. This report is a summary of the aims and objectives, methods, key findings and recommendations of the RSCIP 2.

### **Purpose, Aims and Objectives:**

The overall purpose of RSCIP 2 was to establish integrated spinal networks in rural areas of NSW for enhanced service coordination and provision of ongoing education and professional support. The project aimed to determine the efficacy of a local “spinal coordinator” or Rural Net Worker (RNW) as a way of establishing the feasibility and sustainability of the spinal network model and to use this experience to determine an appropriate model to further develop and sustain rural spinal networks in the future.

The primary objectives of the project were:

- To develop integrated service provision amongst rural and metropolitan medical and health professionals,
- To provide peer and professional support to medical/health staff and consumers in rural regions,
- To provide systemic advocacy for people with SCI and professionals living and working in rural regions,
- To raise awareness amongst rural medical/health professionals of the health needs of people with SCI, and
- To continue to develop appropriate education resources, training and skill development.

### **Model Implementation:**

RSCIP 2 was undertaken from 2003-2005 and involved the employment of a rural clinician (RNW) one day per week in six NSW rural and regional area health services (Macquarie, New England, Northern Rivers, Mid North Coast, Hunter and Illawarra) with ACT Health also participating. A project officer was employed to coordinate the project who was based in Sydney. As part of developing an integrated approach to service provision within the region, and providing support to consumers and local service providers, the RNWs facilitated the provision of health care and other services for people with SCI, both for those who were being transitioned back to a rural area following discharge from a metropolitan spinal unit (including those with newly acquired SCI and also for those after being readmitted), and for SCI clients living in rural communities. Through this process, the RNWs facilitated a continuum of care, promoting access to appropriate services and determining the needs of rural people with SCI, their carers and service providers, with development of local networks.

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<sup>1</sup> N Flamborous (2003) Educating Rural Communities. Final Report. Motor Accidents Authority Sydney NSW

## **Data Collection**

The RNWs were provided with an orientation and training session in Sydney and the project officer visited all RNWs in their areas during the project. Data collection consisted of completing activity logs, service maps, and descriptive reports. RNWs undertook individualised goal planning with each client at initial contact utilising a modified version of the Canadian Occupational Performance Measure and completed the Self Efficacy scale on appropriate clients. The data measures provided a mechanism of reporting issues in rural areas, primary RNW activity and client issues. RNW activity was essentially client related and client issues were predominantly health related.

## **Evaluation**

An independent evaluation was undertaken to assess effectiveness of this pilot model. Several performance measures were utilised. Key rural and metropolitan personnel in the network were surveyed, RSCIP 2 clients were invited to take part in the evaluation via telephone interview (following organisational ethics approval) and the evaluator conducted two focus groups with the RNWs via teleconference, and examined descriptive data in relation to their activity logs and service maps.

## **Findings**

Feedback provided by consumers, rural and metropolitan clinicians and the RNWs strongly endorsed the need for increased support for clients with SCI, health professionals and service providers in rural areas. Through a combination of direct client contact, liaison/coordination activities and service mapping, the RNWs played a key role in: increasing our understanding of key rural issues and knowledge of available local resources/service gaps, developing better working relationships with improved links between local service providers, and building/extending networks between rural health care providers and metropolitan SCI services. This report and the evaluation demonstrate that the RSCIP 2 model of service delivery was well received and provide evidence that there is a need for it be continued and enhanced with greater resources and support through expansion of the SSCIS to include a rural component.

Eighty rural clients with SCI participated in RSCIP 2, with most clients in the sample (83.7%) having sustained a traumatic injury. Client goals most frequently related to resolving health issues, functional mobility, community participation, accommodation, personal and other goals. Participants with SCI in the project reported a broad range of health issues impacting upon their health status, including: pressure ulcers and other skin-related issues, urinary tract infections, gastrointestinal problems, pain, psychosocial and other health-related issues. Negative health events were reported by 51% of the RSCIP 2 sample and were more frequent in persons with tetraplegia than paraplegia and clients with an established rather than with a newly acquired SCI. Access to mobility and other equipment, functional changes associated with aging (and consequently changing care and equipment needs) and issues impacting on community participation such as transportation were also reported. It was clearly demonstrated during the project that many of the challenges faced by rural people with SCI are health related. Issues needing to be addressed were particularly those associated with medical, nursing and occupational therapy. Psychosocial themes and inter-disciplinary issues were also frequently reported.

A review of RNWs activity logs revealed that their pattern of activity was primarily related to clients' health needs, with a majority of time spent on liaison with, and providing information to, clients and service providers, in addition to making referrals to other health professionals and service providers. Activity also frequently related to issues such as seating, equipment, PADP,

driving and home modifications. These activities achieved the objectives of improving integrated service provision, of providing peer and professional support to consumers and care providers and raising awareness of the health needs of clients with SCI within local communities. A major challenge of the project was that the RNWs reported a blurring of boundaries between a clinical and networking role, that they became the contact for all clinical SCI issues in their areas, and that their primary role took on a direct client focus. They reported that they filled a gap in clinical and case management in some cases as these gaps were unable to be filled elsewhere. These issues highlight the need for local networking and support for rural people with SCI.

Factors that hindered the RNWs achievement of all of the project objectives included time constraints (6-8 hours per week in the position), large geographic distances to cover, role delineation with usual clinical duties, lack of resources/systems to follow-up long-term clients with SCI, suitable assessment tools and reporting mechanisms. Within this context, service mapping proved a difficult task requiring more resources than were available; however, it was identified during the project as a very useful adjunct to the delivery and networking of services. If adequately resourced, service mapping has the potential to add to specialist service capacity and efficiency.

Other challenges reported included; discharge planning from metropolitan areas to rural regions, access issues such as those to; rural specialists and diagnostics (such as rehabilitation specialists, urologists, pain specialists and services such as video urodynamics) , equipment, client reviews, and general practitioners. The management of pressure areas, geographic distances and transport were also identified as significant challenges through the duration of RSCIP 2.

### **Future Directions and Recommendations**

Requests for ongoing regular rural clinics including specialist medical and multidisciplinary reviews are a recurring theme throughout RSCIP Phase 1<sup>2</sup> and 2. Many rural clients are aging with a spinal cord injury and their health needs will potentially multiply in the future. A health maintenance model needs to be pursued to prevent deterioration in health status. People with spinal cord injury who have an alteration in their health status face difficulties participating in the community.

The project demonstrated that a co-ordinated approach is required to ensure that rural people with SCI are not lost to follow up, are linked with appropriate professionals and have the capacity to follow a health maintenance model. Complex community clients who are aging with a SCI were found to be the greatest utilisers of the RNWs resources and the most challenging. Ensuring that this client group had equipment reviewed, rescripted and delivered highlighted the difficulties related to equipment provision and the challenges facing rural therapists, who lack experience in the management of people with SCI. Linking clients to appropriate medical specialists, including connecting them back into a health system, which the person had not accessed for many years, highlighted the need for a mechanism of following up clients in the community. This client group were found to have indications for medical and diagnostic reviews related to changes in their health status and required a co-ordinated approach to facilitating relevant interventions.

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<sup>2</sup> N Flambouras (2003) op, cit.

To address some of these challenges local coordination is required to empower the local network to provide specialty services for this population, to take ownership of issues and to give consumers confidence in their local providers. A rural spinal network can operate successfully when local participants are able to operate in partnership with metropolitan specialist support. Local providers require support through education, networking and communication, service provision and advice from specialist services within the State Spinal Cord Injury Service (SSCIS) and other specialist providers. RNWs indicated that increased use of technology, such as telemedicine, had the potential to provide better communication and support.

**Recommendations:**

1. The State Spinal Cord Injury Service (SSCIS) should be expanded by NSW Health to include a rural component in collaboration with Rural Area Health Services to establish a State Wide Rural Spinal Cord Injury service in an ongoing capacity.
2. The role of the rural net workers should be expanded to full time clinical coordination roles in all NSW rural referral hospital areas in collaboration with rural area health services.
3. A central rural spinal co-ordinator role should be established in a full time capacity to coordinate rural activities of the SSCIS and ensure a planned approach.
4. A medical spinal specialist rural outreach clinic model, with the support of a multidisciplinary team (SSCIS rural outreach service) should be established in an ongoing capacity.

**Rural Spinal Cord Injury Project Rural Net Workers \***

Bronwyn Dalton, (Hunter Area Health Service)  
Elizabeth Keith (Mid North Coast Area Health Service)  
Michelle Ellis (Northern Rivers Area Health Service)  
Robyn White (New England Area Health Service)  
Suzanne Johnston (Macquarie Area Health Service)  
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Raelene McNaughton (ACT Health)

**Rural Spinal Cord Injury Project Steering Committee\***

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\* Position and title at time of participation in RSCIP Phase Two.

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- The Motor Accidents Authority for funding the second phase of this project and continuing to acknowledge and highlight the needs of rural people with spinal cord injuries.
- The Rural Net Workers in each of the participating Area Health services for the dedication and enthusiasm they brought to the position, often in challenging circumstances.
- Rural people with SCI for agreeing to participate in the project.
- The Spinal Outreach Service (Sydney) for their support of the rural net workers, rural people with spinal cord injuries and rural service providers and clinicians. A particular acknowledgment of their commitment in providing multidisciplinary consultation through rural clinics and education sessions\* to rural clinicians, in addition to telephone, electronic and tele health support in an ongoing capacity. A special acknowledgment to the program manager for her support to the project officer.
- The spinal specialists from the spinal injuries units of the Prince of Wales Hospital (POWH), Royal North Shore Hospital (RNSH) and Moorong (Royal Rehabilitation Centre Ryde) for their time and expertise in the provision of clinics for people with spinal cord injuries in rural areas, education sessions for rural clinicians, and education for rural general practitioners throughout the duration of this project\*. The time constraints and additions to their significant workload are much appreciated, as is their support in highlighting the issues for people with spinal cord injuries in rural areas.
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- Rural clinicians and service providers for embracing the project in their areas, for supporting and attending education sessions\*, for liaising with, and guiding the project when needed, for their hospitality and willingness to assist when required.
- The authors of the RSCIP fact sheets, both for the review of the original, and creation of the new. These time consuming tasks have resulted in an important resource that is, and will continue to be, utilised across a wide community, clinical and geographic population.
- Staff of the spinal injuries units of the Prince of Wales Hospital, Royal North Shore Hospital and Royal Rehabilitation Centre (Moorong) including those of the specialised Seating and Plastics/Spinal Pressure Services.
- The NSW State Spinal Cord Injury Service (SSCIS) for hosting Phase Two of the project and for promoting and highlighting rural issues related to the care of people with spinal cord injury in an ongoing capacity.

\*Clinics for clients with SCI, and education sessions for medical, allied health and nursing staff were held at seven sites throughout rural NSW in 2004-05. These clinics were a collaborative process between three projects/programs the RSCIP, the Spinal Outreach Service (SOS) and the Medical Specialist Outreach Assistance Program (MSOAP). Each project/ program was financed by its funding body individually to participate in the process.



## **SECTION ONE: PROJECT INTRODUCTION**

### **1.1 INTRODUCTION AND PROJECT TITLE**

The following document reports on the second phase of the Rural Spinal Cord Injury Project (RSCIP 2) 2003-2005 titled “Developing Spinal Networks”. This report seeks to outline issues facing rural people with spinal cord injury (SCI) identified through RSCIP 2, and suggest ways that they may be supported in rural areas.

It is acknowledged that there are many issues relevant to rural people with SCI, their carers and service providers not addressed in detail in this report, though they have been identified, highlighted and canvassed throughout the duration of this project. Issues such as accessibility for people with SCI in rural areas, home modifications and accommodation, telehealth, the provision of care and care providers. Rural and regional inpatient services; and the need to target and provide them with education and support regarding the management of rural people with SCI, and the challenges of accessing psychological support services in some rural areas. The contribution that community and non government organisations make and the enormous role they play in rural communities, and the advocacy role provided by many rural people within their own local community in supporting people with SCI through means such as local fundraising. It was not within the scope of this report to discuss the many issues facing rural people with SCI, their carers and service providers however it is recognised that there are many different factors impacting upon this population.

### **1.2 PROJECT DESCRIPTION**

A clinician or rural net worker (RNW) was employed in seven area health services and the ACT for one day per week for the duration of the project. The RNW was the link between metropolitan and rural services and one of their aims was to be the local connection in developing spinal networks.

The primary goals of the RSCIP 2 were to determine and develop networks in rural areas, to identify services and service providers related to the provision of care to clients with SCI who live in those rural areas, and to determine the effectiveness of the role of a local coordinator or rural spinal net worker (RNW) in facilitating the receipt of health and other services for rural people with spinal cord injuries.

### **1.3 START DATE, DURATION AND MAA FUNDING OF PROJECT**

The RSCIP 2 was a community based project of which \$430, 000 (\$215, 000 per annum) was approved for two years, commencing in 2003 and concluding in 2005. The Motor Accidents Authority (MAA) funded Phase One of the Rural Spinal Cord Injury Project in 2000-02. This project involved a needs analysis of consumers with SCI, carers and clinicians and also involved the delivery of education models related to SCI in four Area Health Services (AHSs) (Mid West, Greater Murray, Mid North Coast and New England). As a result of the findings of Phase One of the RSCIP<sup>3</sup> the MAA approved funding for two years to focus entirely on network establishment in eight rural health services.

Seven NSW AHSs commenced the RSCIP 2 in February 2004 and the ACT (funded through ACT health) commenced in September 2004. In January 2005 there was a merger of the NSW AHS from eight rural areas (including those of the Hunter and Illawarra areas that both had a rural and metropolitan component) to four. For the purpose of RSCIP 2 and this report, the original areas were considered for the duration of the project.

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<sup>3</sup> N Flambouras (2003) op cit.

## 1.4 BACKGROUND

Almost a quarter of the people in NSW live outside the three major cities of Sydney, Newcastle and Wollongong. The total NSW population (projected) in June 2004 was 6,731,295 with a median age at June 2003 of 36.4 years<sup>4</sup>. Rural NSW has a projected population for 2011 of 1,561,240.<sup>5</sup>

Rural NSW is characterised by its diversity, it being made up of major regional centres and coastal cities, small towns and remote communities.<sup>6</sup> Reports have shown that Australia's remote and rural populations have poorer health than their metropolitan counterparts, they have higher mortality rates and as a result lower life expectancy, and they also experience higher hospitalisation rates for some causes of ill health.<sup>7</sup>

Injury and suicide rates in males have been found to be higher in rural areas. Analysis of morbidity and mortality data, health resources, risk factors and socio economic measures using the Rural, Remote and Metropolitan Area (RRMA) zone classification, has indicated that differences in mortality, morbidity, health service usage, and socio economic disadvantage increase with distance.<sup>8 9</sup> Factors such as isolation and distance, delays in definitive care, a higher incidence of single vehicle crashes, road and environmental conditions, driver competence and fatigue, and compliance with preventative measures such as alcohol, seatbelts, helmets and speed have been found to be significant in rural trauma.<sup>10</sup>

From a socio demographic perspective, life expectancy has been reported to vary with geographic location. Those living in capital cities can expect to live longer than those living in a remote zone and to a lesser extent those living in rural areas.<sup>11</sup> Hospitalisation rates for injury have been shown to be much higher in the rural and remote zones compared to the metropolitan zones.<sup>12</sup>

Rural people face many barriers such as isolation, unemployment/poor job prospects and limited career paths, distance to access services and transport, and higher fuel and food prices. These barriers are heightened when a person has to deal with catastrophic injury such as SCI. SCI is sudden and unexpected. It can be devastating and costly in human and social terms.<sup>13</sup>

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<sup>4</sup> ABS (2003/4)3218.0 Regional Population Growth, Australia and New Zealand. Preliminary Local Government Area (LGA) populations (at June 2004) and revised median ages (at June 2003) <http://www.abs.gov.au/Ausstats/abs@nsf/1020492cfcd63696ca256811002477b5/58c>.

<sup>5</sup> NSW Department of Health .The NSW Health Report (2002) The report of the Rural Health Implementation Coordination Group. NSW Government Action Plan, Sydney. <http://www.health.nsw.gov.au/rural/ruralreport.pdf>

<sup>6</sup> NSW Health (2002) op cit.

<sup>7</sup> Australian Institute of Health and Welfare (1998).AIHW Cat no.PHE 6. Health in rural and remote Australia. Canberra:AIHW

<sup>8</sup> NSW Health (2002) ,op.cit

<sup>9</sup> NSW Health (2002) ,op.cit

<sup>10</sup> Neurosurgical Society of Australasia. (1999) 'The management of acute neurotrauma in rural and remote locations. A set of guidelines for the care of head and spinal injuries' *Journal of Clinical Neurosciences* 6 (1),8593

<sup>11</sup>NSW Health (2002) ,op.cit

<sup>12</sup>NSW Health (2002) ,op.cit

<sup>13</sup> RA Cripps (2004) AIHW Spinal Cord Injury 2002-03. Injury Research and Statistics Series Number 22.Adelaide:AIHW (AIHW cat no.INJCAT 64)

The age adjusted incidence rate of SCI in the financial year 2002-03 was estimated to be 12.4 new cases per million population.<sup>14</sup> Through the Australian Spinal Cord Injury Register (ASCIR) it is possible to identify the areas where the person was living when they had their SCI (if they were admitted to a spinal unit), through collection of data on admission. The ASCIR in 2002-03, was in its ninth year of operation and has about 10,800 cases of persisting SCI registered.<sup>15</sup>

The incidence of SCI in rural populations recorded by the NSW State Spinal Cord Injury Service (SSCIS) is consistent with population distribution figures, with 25% of new spinal cord injuries returning to rural communities after acute metropolitan treatment.<sup>16</sup> It is important to note that some rural rehabilitation services report new cases of SCI that are not treated in the metropolitan spinal units. These cases are most often of a non-traumatic aetiology, however aetiology has no bearing on service provision and incidence and prevalence figures should be considered as lower estimates. A feature identified through RSCIP Phase One and RSCIP 2 was the significant number of people with SCI seeking services that were not linked to either the SSCIS or any other health service, further underestimating the prevalent SCI population.

Life expectancy has increased significantly for people with a SCI (estimated to be between 70% and 90% of the normal life expectancy); consequently the total number of people living in the community with a SCI is growing. It is estimated that there are between 3,500 and 4,500 people living in NSW with a SCI. If an assumption is made that there is no distribution differences between rural and Greater Metropolitan Region SCI prevalence, then the rural SCI prevalence is 700 – 900 cases or 58 - 64 cases per 100,000. A defining feature of people with established SCI is their high utilisation of health and community services and the significant potential for negative health events and complications.<sup>17</sup>

Rural people with SCI have been found to encounter barriers to health care and other subsequent problems.<sup>18</sup> Fewer health care providers, particularly those with expertise in SCI or rehabilitation, transportation limitations, attitudinal restraints and lack of knowledge about the specific needs of people with SCI have been reported.<sup>19</sup>

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<sup>14</sup> Cripps (2004) op cit

<sup>15</sup> Cripps (2004) op cit

<sup>16</sup> D Andrews (2006) Personal Communication

<sup>17</sup> D Andrews (2006) op, cit.

<sup>18</sup> K Hagglund and D Clay (1997) 'Rural Healthcare Initiatives in Spinal Cord Injury' *Archives American Rehab.* <http://www.ed.gov/pubs/AmericanRehab/spring97/sp9702.html>

<sup>19</sup> Hagglund and Clay (1997), op.cit

## SECTION TWO: PROJECT OVERVIEW

### 2.1 PROJECT AIMS

The RSCIP 2 aimed to build on the achievements of Phase One<sup>20</sup> by focusing on developing spinal networks across rural and regional health services in NSW. Seven NSW AHSs and the ACT participated in the project, with the employment of a clinician for one day per week for the duration of the project.

The aim of RSCIP 2 was to determine networks or services in rural areas relating to the provision of care to clients with SCI who live in those areas, and to develop those networks. In addition, RSCIP 2 has aimed to determine the efficacy of a regional coordinator “spinal rural net worker” in facilitating the receipt of care and services to people with SCI in rural areas, and have developed integrated service provision and coordination as part of that network development. Findings from phase one suggested that rural network development was required, in addition to rural people with SCI being able to access rural clinics for specialist medical review and follow up, multidisciplinary review, and ongoing education for rural service providers and clinicians.

### 2.2 PROJECT OBJECTIVES

1. To develop integrated service provision and coordination amongst rural and metropolitan medical and health professionals.
2. To provide peer and professional support to medical/health staff and consumers in rural regions.
3. To provide systemic advocacy for people with spinal cord injuries and professionals living and working in rural regions.
4. To raise awareness amongst rural medical/health professionals of the health needs of people with spinal cord injuries.
5. To continue to develop appropriate education resources, training and skill development.

### 2.3 PROJECT IMPLEMENTATION

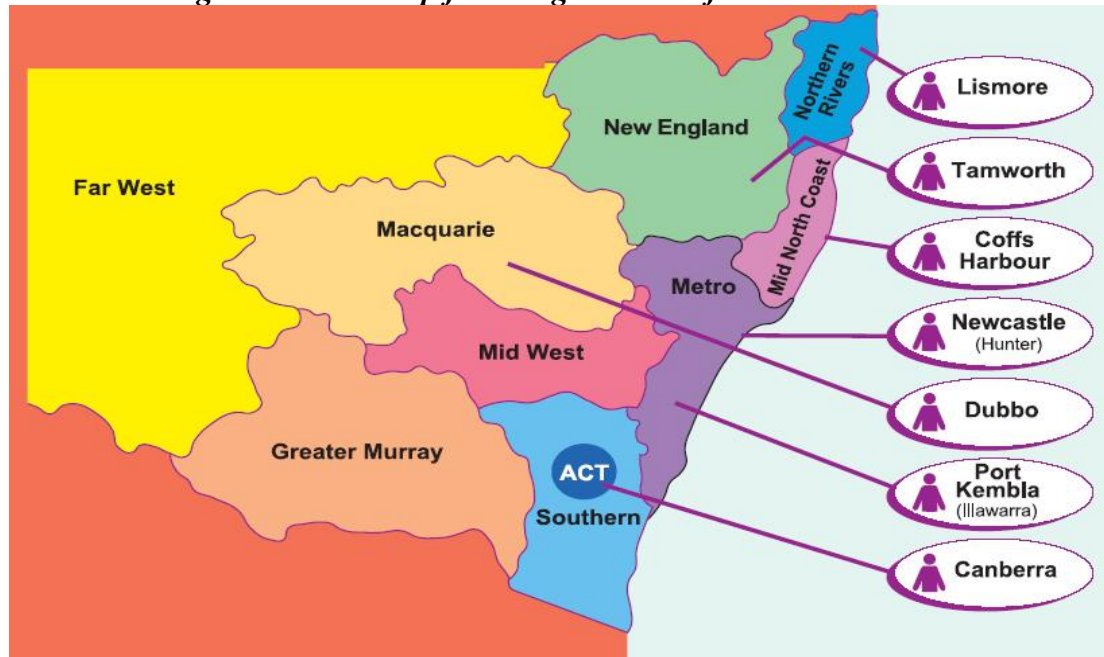
Each NSW rural/regional AHS (with the exception of the Far West Health Service) was invited to participate and to nominate a RNW in their AHS. Two AHSs did not participate in the project, Mid Western and Greater Murray. One AHS (SAHS) completed six months of the project only.

The RNWs were employed six to eight hours per week depending on their clinical classification. Their disciplines comprised of a physiotherapist, two registered nurses (one a clinical nurse consultant in rehabilitation) and four occupational therapists. A project officer was employed to coordinate the project and was based primarily at the Spinal Outreach Service (SOS), Royal Rehabilitation Centre Ryde, and the Prince of Wales Hospital with the SSCIS. Project RNWs were based with the Brain Injury Rehabilitation Program and/or Rehabilitation service teams in Tamworth, Coffs Harbour, Lismore, Dubbo, Newcastle, Port Kembla and Canberra. (See Figure 1).

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<sup>20</sup> Flambouras (2003) op cit.

**Figure 1: NSW Map featuring location of RSCIP 2 RNWs \***



At the commencement of RSCIP 2, the project’s Steering Committee determined that the most relevant way to understand, promote and document existing networks in each of the rural areas was for the RNWs to facilitate the transition of a limited number of clients back to their rural area / community from the Sydney metropolitan spinal units. Through the transitioning process, and by following clients up in their own rural communities, networks would be developed, there would be more integrated service provision between rural and metropolitan areas, services (including gaps in service provision) would be identified, and the needs (both health and community) of rural clients with SCI would be recognised and “triaged” to the appropriate provider. Pathways could also be determined, for example, how do clients and care providers access health care systems and other relevant community organisations?

As the project progressed in some areas, the RNWs also received community referrals via their local service providers. These referrals came from a variety of sources; community nurses, community occupational therapists, regional ParaQuad and SCIA representatives, clinical nurse consultants (CNCs), GPs, clinicians and others, who were noted informally, to be part of the local rural networks. Those considered to be part of the network were those that had previously cared for clients with SCI, (and therefore had the capacity to) were currently caring for clients with SCI, or were considered to be an essential component of the provision of long term care (for example community nursing and urology services.)

As the project progressed it became clear that the RNWs were dealing with multiple complex clients and their related issues, and that the allocated time in the position was not sufficient to meet the demands of the role. The numbers of clients with SCI returning to rural areas from the metropolitan spinal units were such that in some areas, community clients were not the primary focus, however in other areas the RNWs reported that community clients were the greatest utilisers of their resources. Health, functional changes with aging and equipment issues in particular, together with rehabilitation and community participation were all actual client issues and concerns raised throughout the duration of this project.

\* Position at time of commencement of RSCIP Phase Two. Pre area health service mergers of January 2005.

## 2.4 PROJECT METHODOLOGY

### 2.4:1 DATA COLLECTION

Training was provided to the RNWs at a three day orientation program and initially electronic versions of the database were distributed, however they were unable to be supported in rural AHSs due to software compatibility issues. Data collection consisted of the RNWs completing monthly activity logs, descriptive reports and service mapping exercises. They also completed the modified COPM (Canadian Occupational Performance Measure) and the Moorong Self Efficacy scale (SES) (*see Appendices*) on appropriate clients. Information supplied by the RNWs was collated centrally by the project officer.

Rural clients being discharged from an in patient episode in one of the spinal units (Prince of Wales, Royal North Shore or Moorong) between February 2004 and August 2005 (either as a readmission or as a new acute injury) were identified by the case conference process through the three spinal units in collaboration with the SOS case conference representative. Clients who consented to the RSCIP 2 were linked to the RNW via the project officer and the SOS and the client was then followed up by the RNW in that rural area, by phone or home visit, depending on need, geographical distance and ability to travel to that area.

Monthly activity logs recorded data related to RNW activity and outcomes, issues the RNWs were dealing with (both client and non client related) and the proportion of time spent on activities such as education, network development, service mapping and operational issues (*see appendices*). Descriptive reports provided an avenue to raise issues that were not covered through other means, and a method of providing “snap shots” and case studies of relevant issues.

The service map was a tool designed to record services in rural areas that were relevant for rural people with SCI and to identify those service providers that make up the network. The aim of this exercise was to promote a better understanding of rural services and their capacity to be utilised by rural people with SCI, both from a local rural and metropolitan perspective. The RNWs were asked to identify key providers in their rural areas and to record any gaps in service provision (for example, were positions unfilled?). Key providers included, but were not limited to, rehabilitation specialists, urologists, neurologists, general practitioners, clinical nurse consultants, community nurses, occupational and physiotherapists, social work and counselling services, attendant care agencies, splinting and driving services, diagnostic services, seating and equipment review services, PADP and transport services, home modifications, and community support agencies and services.

The Canadian Occupational Performance Measure (COPM) is a client centred outcome measure developed in 1991 for use in occupational therapy practice and research<sup>21</sup>. A modified COPM was adopted by the Spinal Outreach Service (SOS) and utilised by the RNWs as a tool in identifying the needs of the client, and in quantifying change relating to intervention. The provided COPM was modified to include life domains other than the original self care, productivity and leisure and included additional domains such as accommodation, relationships and community<sup>22</sup>. Clients were able to nominate goals relative to the domains identified by the tool and related to accommodation, community participation, functional mobility, health, personal/relationships and other.

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<sup>21</sup> Law et al (1991) 'Canadian Occupational Performance Measure', Toronto, ON: CAOT Publications ACE. (cited by Yap 2005 personal communication)

<sup>22</sup>M Yap et al (2005) COPM presentation Personal Communication ,

The SES is a 16 item- scale rating confidence in performing everyday activities on a 7 point Likert scale<sup>23</sup>

The client data (both qualitative and quantitative) from a small sample of rural people with spinal cord injury is presented in this report as a method of outlining issues (both health and non health), demographics, injury information and other matters facing people with SCI in rural areas.

#### **2.4:2 EVALUATION**

An external evaluator who utilised several performance measures evaluated the project. The evaluation surveyed key rural personnel in the network, key metropolitan people in the network and invited RSCIP 2 clients to take part in the evaluation via telephone interview (following organisational ethics approval). The evaluator also conducted two focus groups with the RNWs via teleconference, and examined descriptive data in relation to their activity logs and service maps.

Some descriptive summaries are provided later in this document (*see section four*) and are intended as a snapshot of responses against the performance measures utilised in the evaluation.

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<sup>23</sup> J Middleton, R Tate and T Geraghty (2003) 'Self efficacy and Spinal Cord Injury: psychometric properties of a new scale'. *Rehabilitation Psychology*. Vol 48, No 4, 28-288

## SECTION THREE: PROJECT ACTIVITY

### 3.1 RSCIP 2 CLIENT DESCRIPTIONS

The RSCIP 2 was not a research study. It was a pilot project to provide descriptive data to inform the process and outcome of spinal network development in rural areas of NSW. The sample consisted of eighty clients (N=80) with a mean age at injury of 35.88 years (range 61 years) and a mean age at the time of commencing RSCIP 2 of 45.4 years (range 58 years). The mean years since injury were 9.95 years with a range of 53 years.

The data is a summary of that provided to the project officer by the RNWs. As noted throughout the report, the data is only related to the sample of RSCIP 2 clients. It does not represent the true numbers of rural people with SCI accessing any other existing service.

**Table 1: Number of clients participating in RSCIP 2**

Variable	Male	Female	Total
Number of clients	60 (75%)	20 (25%)	80
Number of Newly acquired injuries	28	14	42 (52.5%)
Number of readmissions or long term injuries	33	5	38 (47.5%)
Number of Complete injuries	32	8	40 (50%)
Number of incomplete injuries	25	11	36 (45%)
Incomplete injury data	3	1	4 (5%)

*Note: Data included was only that where data was received by the project officer and recorded and does not indicate the true numbers of people with SCI in rural areas. These figures represent only those clients who consented to be involved in the RSCIP 2 and do not represent the numbers of clients with SCI in any other existing service. Numbers of clients referred to the Hunter and Illawarra Area Health services as part of their existing services were not recorded.*

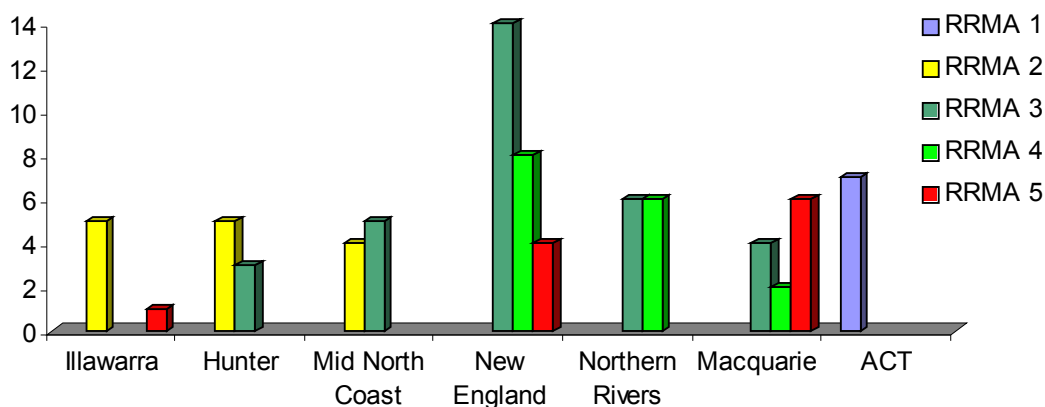
The Remote and Metropolitan Area classification (RRMA) system was developed in 1994 jointly by the Department of Primary Industries and Energy and the then Department of Human Services and Health.<sup>24</sup> It was used as a framework for analysing data for differing geographic zones based on population and an index of remoteness. The three zones are Metropolitan areas (which includes Capital Cities RRMA 1, and other metropolitan centre RRMA 2 population greater than 100,000, example Newcastle or Wollongong), Rural (which includes large rural centre RRMA 3 population 25,000 to 99,999; small rural centre RRMA 4 population 10,000 to 24,999; and other rural centre RRMA 5, population less than 10,000).

<sup>24</sup>.Australian Institute of Health and Welfare 1998.AIHW Cat.No.PHE 6.Health in rural and remote Australia.Canberra:AIHW



The third zone is the remote zone (RRMA 6, remote centre with a population of greater than 5000; and RRMA 7, other remote centre with a population of less than 5000).<sup>25</sup>

**Figure 2: RRMA classification and related RSCIP 2 clients**



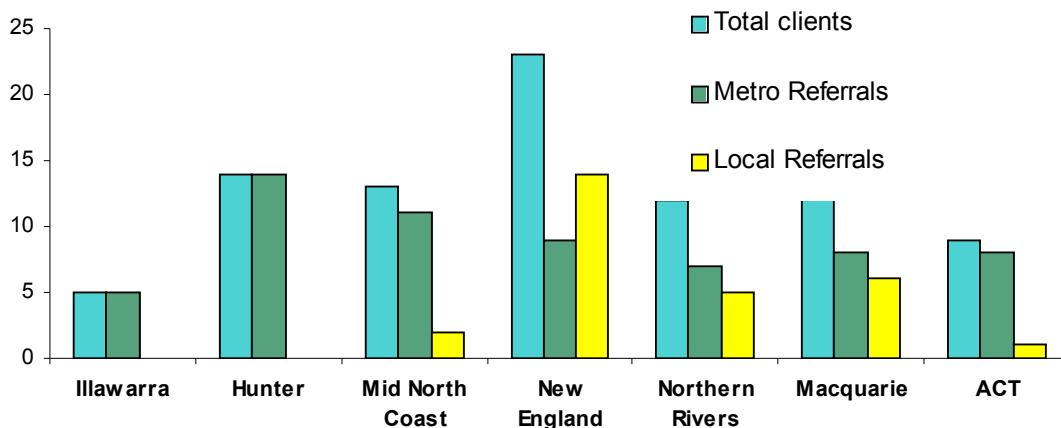
*Note: These figures represent only those clients in the RSCIP 2 and do not represent the numbers of clients with SCI in any other existing service. Numbers of clients referred to the Hunter and Illawarra Area Health services as part of their existing services were not recorded-only those who participated in the RSCIP 2.*

The RNWs in Macquarie and New England recorded the greatest number of rural clients (RRMA 5). The RNW in Macquarie also had client queries from the Far West AHS (though this area did not actively participate in the project) with classification zones of RRMA 6 and RRMA 7 (see Figure 2). There are several clients with SCI known to be living in this area. The vast geographic distances in these areas in particular, pose substantial transport challenges, both for the provider of services and for the consumer. The RNW in Macquarie did not have the capacity to see some of these remote clients given they were a four hour one way trip away by road in a one day a week position.

People living in rural and remote zones have less access to health care compared with those living in the metropolitan zone. Medicare data indicates that people living in rural and remote zones are using less services than those living in the metropolitan zones however, it has been reported that overall hospitalisation rates are highest for those living in the remote zone.

<sup>25</sup>Australian Government Department of Health and Ageing. The Rural, Remote and Metropolitan Area (RRMA) classification system <http://www.health.gov.au/internet/wcms/publishing.nsf/Content/health-workforce-bm...>

**Figure 3: Referral Pattern of clients to the RSCIP 2**



*Note: These figures represent only those clients in the RSCIP 2 and do not represent the numbers of clients with SCI in any other existing service. Numbers of clients referred to the Hunter and Illawarra Area Health services as part of their existing services were not recorded-only those who participated in the RSCIP 2.*

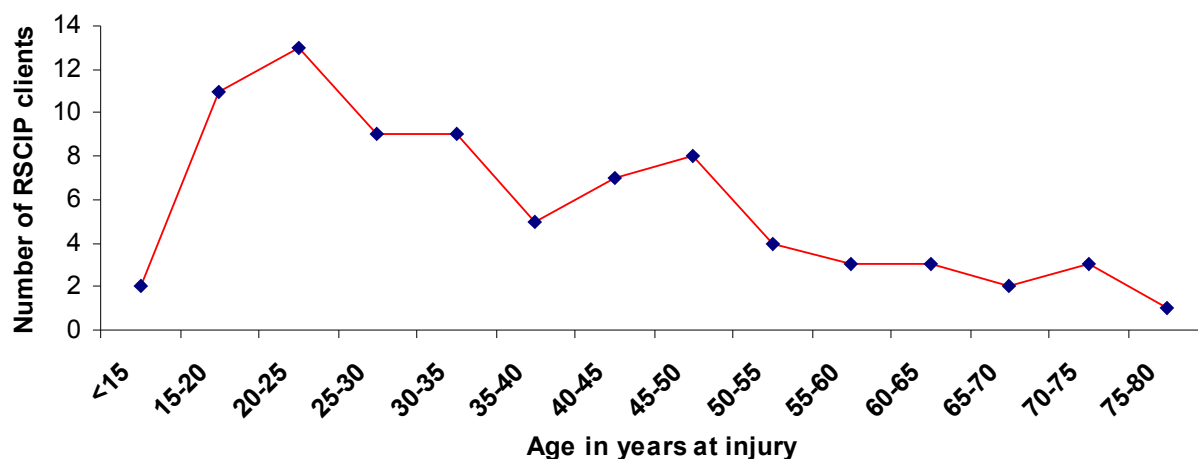
There were more metropolitan than local community referrals to the project, as was to be expected given that the project was not widely advertised in local communities (*see Figure 3*). The project did not aim to provide a clinical service to rural clients with SCI, but to facilitate the receipt of health and other services to those clients. In some areas, the numbers of clients and their complexity meant that the majority of the RNWs allocated project time was spent on client related issues and interventions, and there was often insufficient time to complete the other requirements of the project.

Community (that is clients with long term injuries living in the community) referrals were more prominent in the areas of Macquarie (MAC), Northern Rivers (NR) and New England (NE) than in the Mid North Coast (MNC), though MNC had the highest number of clients transitioning back to rural areas from the spinal units through the duration of the project. These figures relate only those clients in the RSCIP 2, and do not represent the numbers of clients with SCI in any other existing service. Numbers of clients referred to the Hunter and Illawarra Area Health services as part of their pre-existing rehabilitation services were not recorded.

Numbers of community client referrals were impacted upon by the prominence of the RNW in their other role and within their local community. Clients came to the attention of the RNWs through avenues such as their other positions in community rehabilitation; through in patient rehabilitation facilities, through community agencies and some clients came “out of the wood work” as they had “heard about” the project and may have perceived that they had someone to deal with their SCI related specific needs. Some of the RNWs reported that many of their community clients had not had a review of their spinal specific needs for many years.

The RNWs in Northern Rivers, New England and Macquarie in particular, noted that community clients consumed the largest proportion of their project time. Some of the RNWs reported that they were “concerned about a lack of formalised referral system for community clients.” They reported the “lack of services for people with long term injury was of great concern” to them. Other RNWs reported that they were unable to travel to other areas to see clients due to time and geographic constraints.

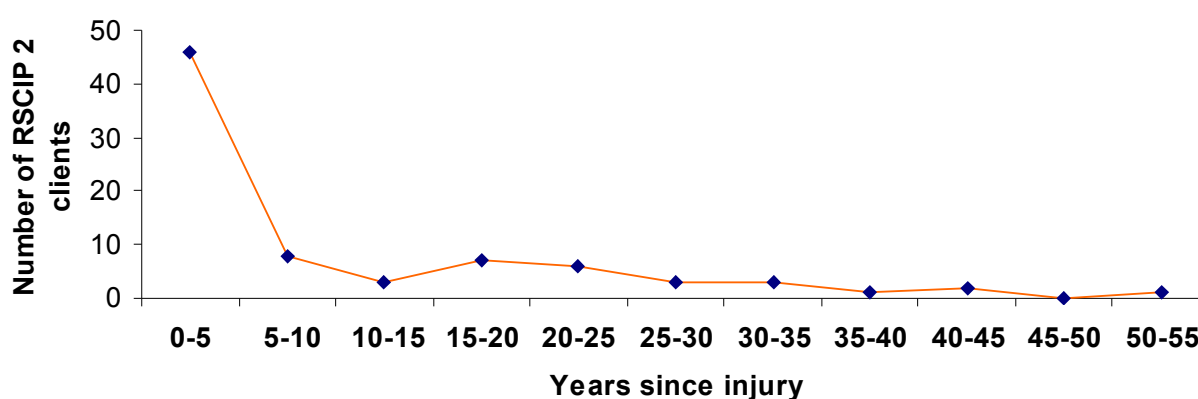
**Figure 4: RSCIP 2 clients' age at injury**



*Note: These figures represent only those clients in the RSCIP 2 and do not represent the numbers of clients with SCI in any other existing service. Numbers of clients referred to the Hunter and Illawarra Area Health services as part of their existing services were not recorded-only those who participated in the RSCIP 2.*

The age at injury distribution of cases from the RSCIP 2 (see Figure 4) sample show that the incidence of SCI at age 20-25 years (16.25%) was highest, followed by 13.75% in the 15-20 year age group with 25-30 years and 30-35 years of age recording the next highest incidences at 11.25% respectively (total 52.5%). Over half this sample had their SCI between the ages of 15 and 35 years. Another peak occurred at the 45-50 age range at 10%. This sample is typical for an SCI population. Cripps<sup>26</sup> recorded a similar age distribution with 46% of all traumatic cases in 2002-3 being in the 15-34 years age group.

**Figure 5: RSCIP 2 clients' years since injury**



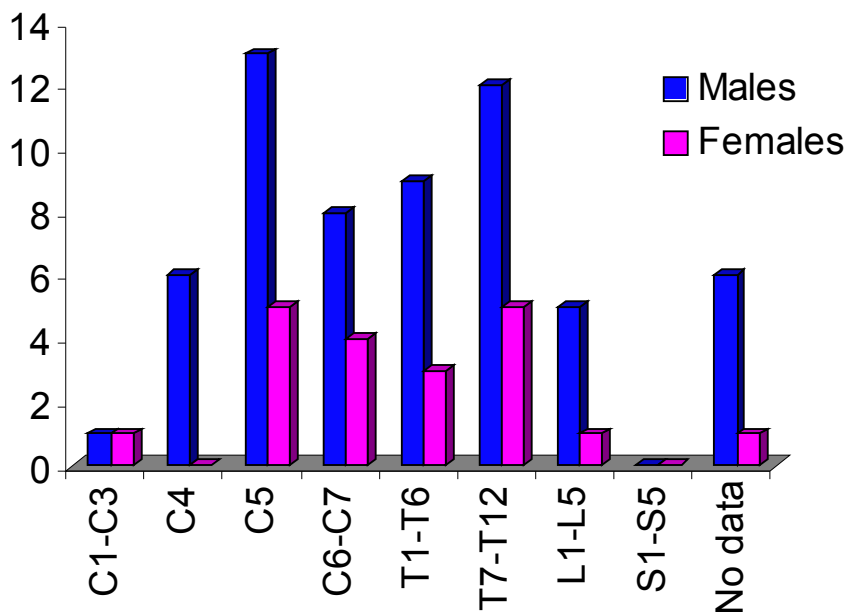
*Note: These figures represent only those clients in the RSCIP 2 and do not represent the numbers of clients with SCI in any other existing service. Numbers of clients referred to the Hunter and Illawarra Area Health services as part of their existing services were not recorded-only those who participated in the RSCIP 2*

<sup>26</sup> Cripps (2004) op, cit.

Just over half (57.5%) of the RSCIP 2 sample (total N=80) were less than 5 years post injury followed by 5-10 years (10%), 15-20 years (8.75%) and 20-25 years post injury (7.5%). Several clients were over 25 years post injury and one client was 53 years post injury (see Figure 5).

Aging with a spinal cord injury can present significant challenges. Complications related to the gastrointestinal, respiratory and genitourinary systems, infectious diseases, neoplasms, loss of motor or sensory function, cardiovascular conditions, fractures and dislocations have been found to increase in frequency with both age and years post injury. Furthermore, studies have found that functional decline with aging or decreasing physical independence was an adverse outcome of long term spinal cord injury<sup>27</sup>.

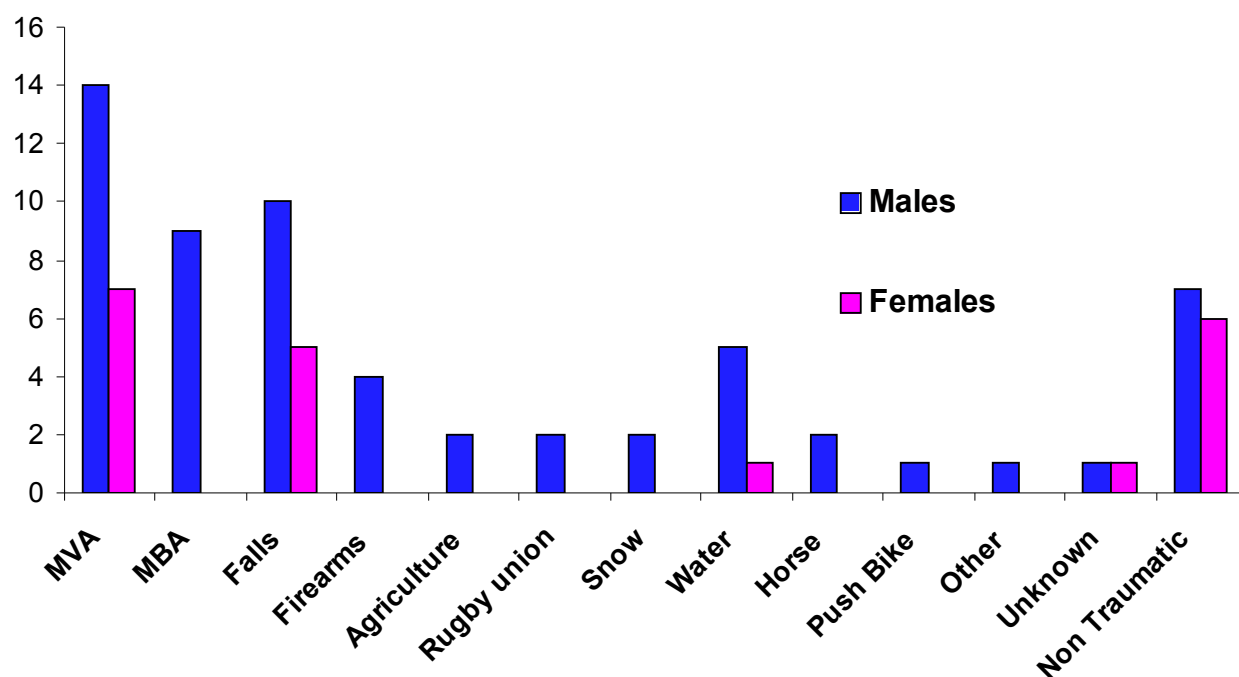
**Figure 6: RSCIP 2 clients' level of injury**



*Note: These figures represent only those clients in the RSCIP 2 and do not represent the numbers of clients with SCI in any other existing service. Numbers of clients referred to the Hunter and Illawarra Area Health services as part of their existing services were not recorded-only those who participated in the RSCIP 2*

<sup>27</sup> KA Gerhart, SW Charlifue, RR Menter, DA Wetzenkamp and GG Whiteneck (1997) 'Aging with a Spinal Cord Injury' *American Rehab* <http://www.ed.gov/pubs/AmericanRehab/spring97/sp9706.html> accessed on 08/06/2005

**Figure 7: RSCIP 2 clients' cause of injury**



*Note: These figures represent only those clients in the RSCIP 2 and do not represent the numbers of clients with SCI in any other existing service. Numbers of clients referred to the Hunter and Illawarra Area Health services as part of their existing services were not recorded-only those who participated in the RSCIP 2.*

The RSCIP 2 sample shown in Figure 7 showed that 83.75 % of the total client sample sustained their injuries traumatically. The traumatic injuries were related to motor vehicle accidents (31.3%), falls (22.3%), motor bike accidents (13.4%), sporting related (10.4%) and water related injuries (8.9%). Firearms, agriculture related, unknown/other made up the other causes of injury. Clearly motor vehicles, falls, motor bike accidents and sporting injury account for the majority of traumatic injury in males, and motor vehicle accidents and falls account for the majority of traumatic injury in females in this sample.

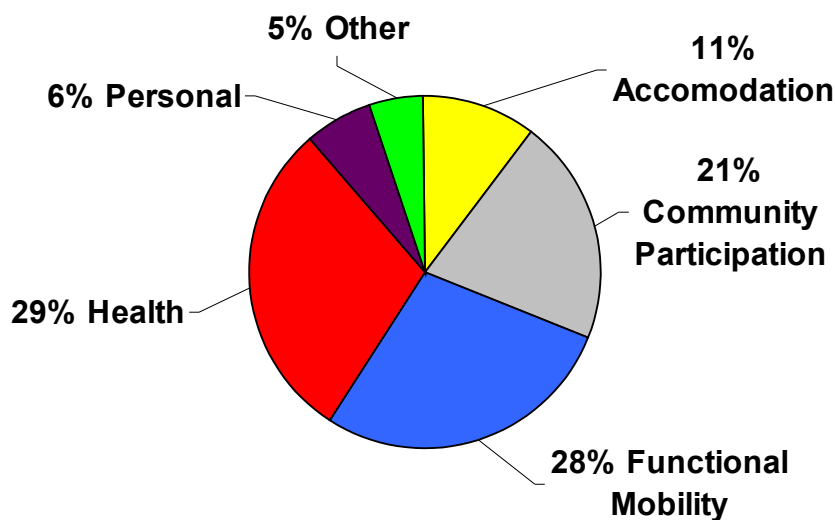
Non traumatic cause of injury (such as an epidural abscess) made up 16.25% of the total cause of injury in this sample. Cripps<sup>28</sup> recorded the incidence of cause of traumatic injury in 2002-03 as motor vehicle (22%), falls (34%) unprotected road users (motor cyclists and pedestrians) (23%), sporting related (6%), water related (7%) and other unspecified causes as (8%).

<sup>28</sup> Cripps (2004) op, cit.

## 3.2 RSCIP 2 CLIENT RESULTS

### 3.2:1: CLIENT GOALS

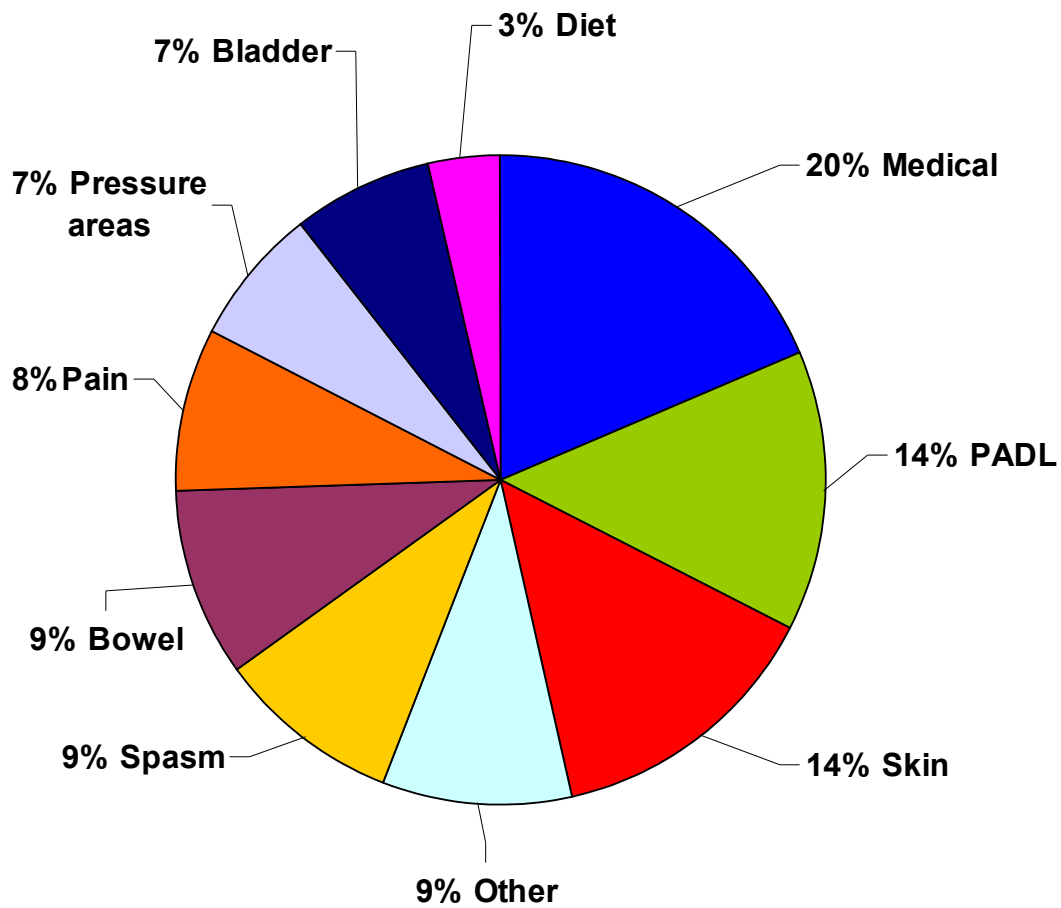
**Figure 8: Client Goal Domains and frequency recorded by RSCIP 2 clients**



Clients who completed COPMs with the RNW were asked to record their goals in relation to five domains (as shown in Figure 8). The domains were accommodation, community participation, functional mobility, health, personal/relationships and other. Within each domain, specific goals could be chosen. Of those COPMs that were completed (n=53) the most frequently recorded goals were related to health (29%), functional mobility (28%), community participation (21%), accommodation (11%), personal (6%) and other (5%). Goal attainment scaling<sup>29</sup> is recommended to rural and remote multidisciplinary health services because of its ability to summarise outcomes from heterogeneous service activities.

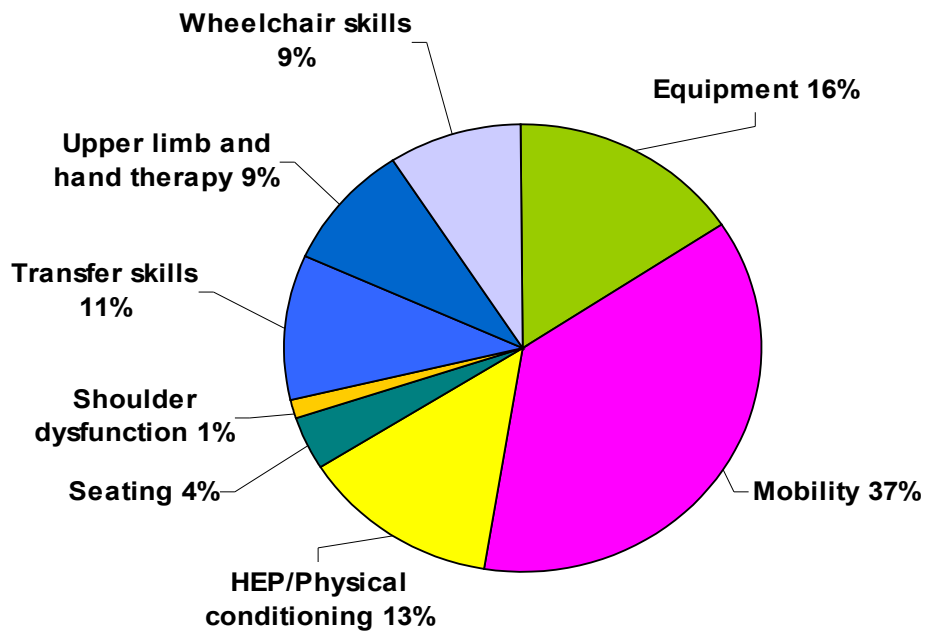
<sup>29</sup>R Cox and D Amsters (2002). Goal Attainment Scaling: An effective outcome Measure for rural and remote health services. *Australian Journal of Rural Health*. Volume 10 Issue 5 page 256

**Figure 9: Frequency of health goals reported by RSCIP 2 clients**

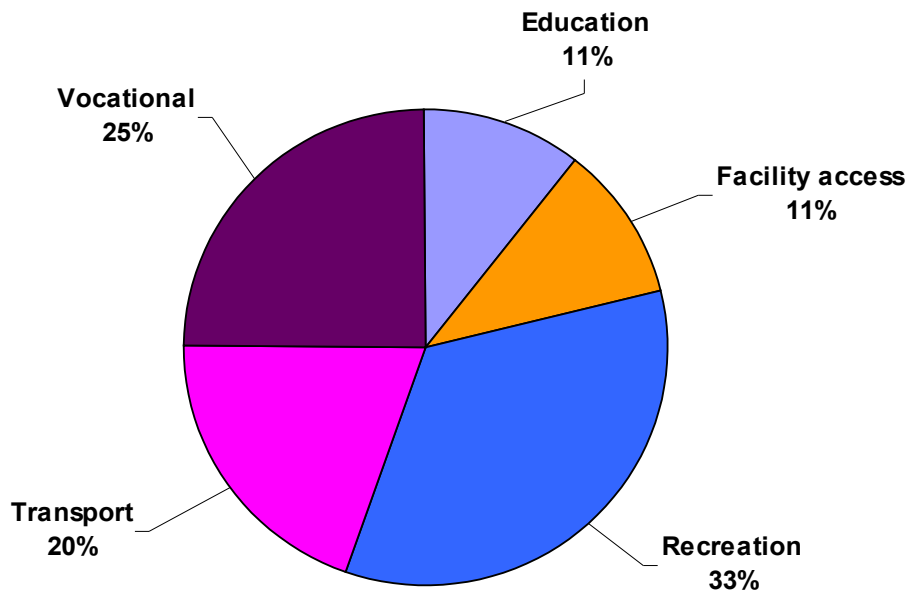


The most frequently recorded health goals shown in Figure 9 relate to issues including medical 20% ,Personal Activities Daily Living (PADL)14%, skin 14%, other 9% ,spasm 9% , bowel 9%, pain 8%, pressure areas 7%,bladder 7% and diet 4% .”Other” included issues such as medication and autonomic dysreflexia.

**Figure 10: Frequency of Functional Mobility Goals reported by RSCIP 2 clients**

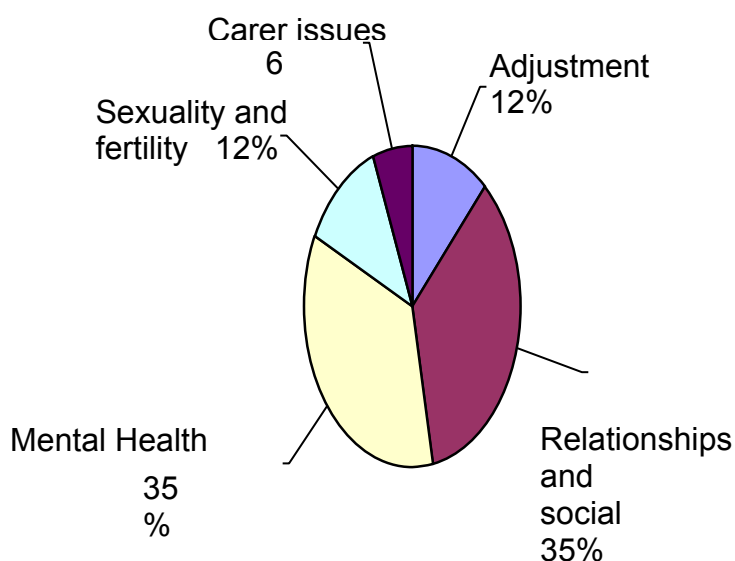


**Figure 11: Frequency of Community Participation Goals reported by RSCIP 2 clients**



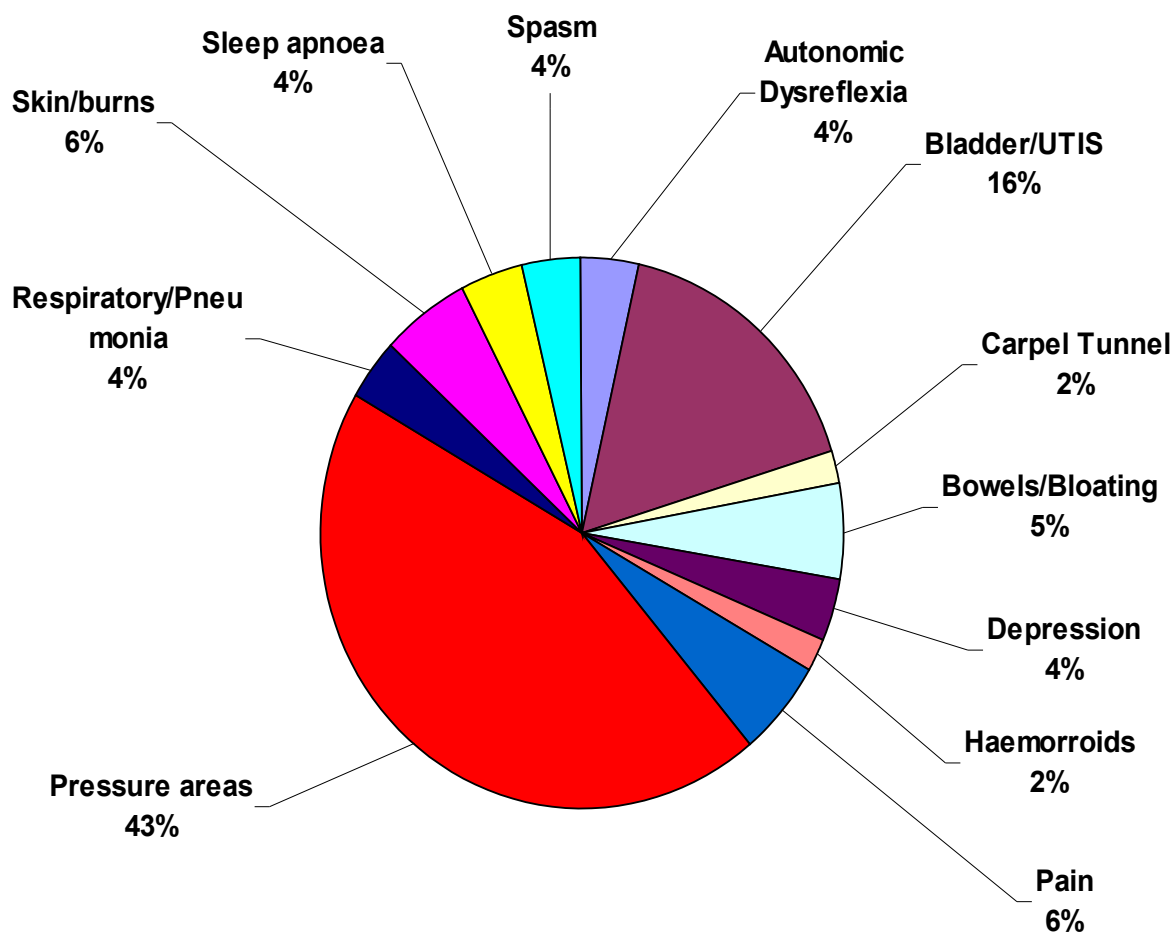


**Figure 12: Frequency of relationship/personal goals reported by RSCIP 2 clients**



As shown in Figures 10-12 the RSCIP 2 clients recorded many goals related to their functional mobility, community participation and relationship/ personal goals. The goals recorded indicate the multifaceted needs of people with SCI and highlight the multidisciplinary support requirements in addition to health and community support.

**Figure 13: Frequency of negative health events recorded by RSCIP 2 clients**



Negative health events were reported by 51% of the RSCIP 2 client sample. Negative health events are those health issues that arise as a result of a SCI and significantly impact on activities of daily living. (Negative health events related to co-morbidities were not recorded). The most commonly reported negative health events were related to pressure areas (43%) bladder/UTIS (16%), other skin (6%), pain (6%), bowels/ bloating (5%) sleep apnoea (4%), depression (4%), spasm (4%), autonomic dysreflexia (4%), respiratory (4%), carpel tunnel (2%) and haemorrhoids (2%).

Tetraplegia was slightly more common in those recording a negative health event (51.2%) than paraplegia (48.8%). Clients who were readmissions or long term injured recorded a negative health event more frequently (65.8%) than clients who had newly acquired injuries (34.1%). Thirty three males (80.5%) and eight (19.5%) females recorded a negative health event. These negative health events were only those that were recorded by the RNWs and do not take into account any episodes

that occurred before or after these episodes had been recorded. Additionally, some clients recorded more than one negative health event simultaneously, furthermore they do not take into account whether the negative health events were persisting (such as for a pressure area) or resolved.

Pairs of SES scores were recorded for 23 clients. The SES is an indication of feeling of self efficacy and an increase in SES could indicate an increase in feelings of wellbeing, whilst a decrease in SES score could indicate a decrease in self efficacy and feelings of wellbeing. There were 47.8% of the sample clients who recorded an increase in their SES score on the second recording, 43.5% of the sample who recorded a decrease in their SES score on the second recording, and 8.7% of the sample clients who recorded no change in their SES score. Of the clients with long term injuries 46.7 % recorded a decrease in SES, 33.3% recorded an increase in SES and the others remained unchanged. Of the clients that were transitioning with new injuries, 50% of them had a decrease in SES scores on their second recording.

Many of the RSCIP 2 clients who recorded a decrease in their self efficacy score recorded a negative health event in the intervening time between the first and second SES score being recorded. One client who recorded his second (and significantly lower) SES score of 39 had repeated pressure areas with resulting change in care regime and community participation, in the intervening time between the first and second SES scores being recorded. Psychological well being and the need for counselling for some of the rural clients were reported consistently through the duration of the project. Similar negative health issues as recorded by the RSCIP 2 sample were recorded in a study by Gerhart et al (1997) that showed that pressure areas and urinary tract infections were the most frequent diagnosis when recording morbidity, illness and complications in people with a SCI.<sup>30</sup>

Persons with tetraplegia were reported to be more likely to have problems with chest infections, spasticity, perceived abdominal pain and general malaise than those with paraplegia or incomplete injuries. They were also reported to have had twice as many procedures to remove bladder stones or catheter related procedures and accounted for the majority of urinary tract infections. Those with paraplegia reported more musculoskeletal problems like joint pain and stiffness, as well as more pressure sores, diarrhoea and constipation.<sup>31</sup>

A study by Middleton et al (2003) on the patterns of morbidity and rehospitalisation following spinal cord injury showed that the most frequent reasons for rehospitalisation were urinary tract infection, bowel problems, pneumonia, pressure sores, musculoskeletal complaints including overuse, pain and spasm, and the need for further rehabilitation. Pressure sores accounted for less than 10% of all readmissions, however contributed to a disproportionately high number of bed days (~ 30%)<sup>32</sup>. The study suggested that up to one third of all readmissions for causes such as pressure sores, urinary tract infection, chest infection and burns are potentially preventable.

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<sup>30</sup> Gerhart et al (1997) op. cit

<sup>31</sup> Gerhart et al (1997) op.cit

<sup>32</sup> J Middleton ,K Lim ,L Taylor ,R Soden and S Rutkowski (2003) 'Patterns of Morbidity and Rehospitalisation following spinal cord injury' *Spinal Cord* 42,359-367

Rural people with spinal cord injury, their carers, care providers, community agencies and clinicians should be the target of a sustained prevention and health promotion approach. In some rural areas where follow up is limited and existing risk factors are exacerbated by rurality, strategies need to be put in place to provide support to prevent long term complications, morbidity and acute hospital readmissions. A local clinical coordinator could facilitate a long term health maintenance model, through net working with local clinicians and metropolitan spinal experts, providing a link both to and between, local and metropolitan providers, and ensuring that rural clients with SCI are not lost to follow up, and that intervention occurs before preventable health crises arise. Multidisciplinary support and specialist medical reviews need to be part of any health maintenance model.

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### 3.2:2 RURAL NET WORKER (RNW) ACTIVITIES

**Figure 14: Issues dealt with most commonly recorded by RNWs on activity logs**

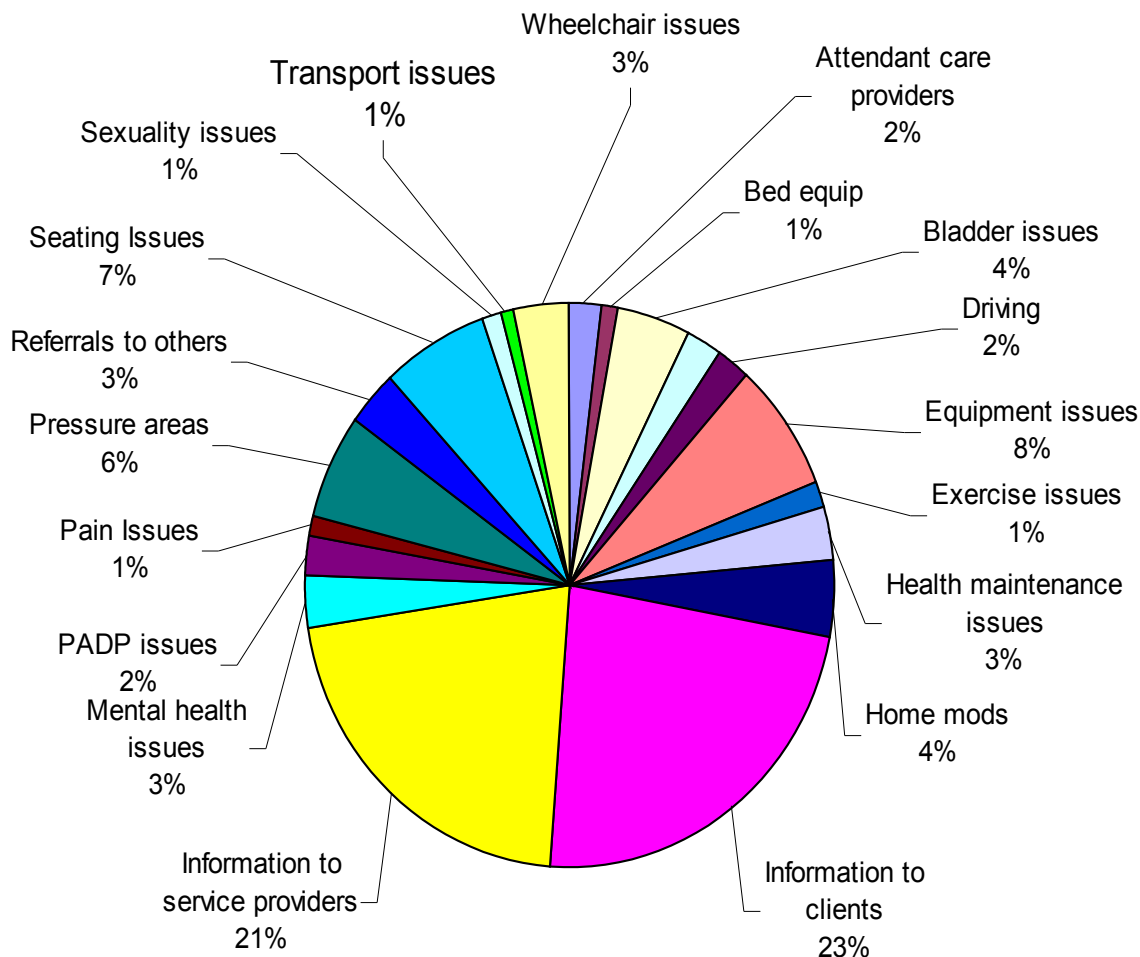


Figure 14 provides a “snap shot” or sample of what issues the RNWs were dealing with in their position as summarised from their activity logs. As can be seen, the issues recorded are multidisciplinary. The majority of the RNWs time was spent in liaison with clients and other service providers which was part of their role, as a facilitator to the receipt of health and other services. Many referrals to other agencies and service providers were also made. Nursing issues (such as bladder, bowel, pressure areas, sexuality, pain, mental health/counselling and health maintenance) and occupational therapy issues (such as seating, wheelchairs, driving, home mods, PADP issues and other equipment issues) were the most common of the multidisciplinary issues recorded. Other cross disciplinary issues such as transport, exercise and provision of care/ attendant care issues were also recorded.

From the snap shot of the activity of the RNWs, it can be seen that multiple issues were dealt with within a short time frame. The needs of people SCI are highlighted, through identification of the issues by clients (through completion of the COPM and SES). Issues were also identified by the RNWs through the liaison and net working role between themselves, the project officer and through liaison between local and metropolitan providers. Issues relating primarily to health and functional mobility, followed by community participation were repeatedly raised through the duration of the project.

### **3.4 CASE STUDIES: RNW ACTIVITY AND OUTCOME OF INTERVENTIONS**

The following case study summaries are provided as examples of some of the activities, interventions and outcomes that the RNWs were involved in and achieved through their net working positions. It was clear in some areas that the RNWs became the contact for all issues related to SCI regardless of their perceived role or their discipline. The “snap shots” highlight key issues including; advocacy, clients who are “lost to follow up”, clients requiring psychological intervention and clients aging with a SCI and accessing local services. Other key issues highlighted include the complexities of managing SCI with co-morbidities, and the successful outcomes possible when managing a client with a pressure area by working collaboratively with relevant providers in the local rural, and specialist metropolitan network. These case studies highlight the need for local support and networking support for rural people with SCI.

**Client A:**

*Background:* 14 years post injury. C5 incomplete injury. Client referred to RNW via local SCIA representative. Client was living on a mission and was not known to local health services. When seen by the RNW he was mobilising on the ground using his arms and his wheelchair tyres had been replaced by rope.

*Intervention:* RNW contacted local OT regarding wheelchair needs. Repairs were quoted on and approval was given to proceed. Letter of support was written together with the local SCIA representative regarding functional abilities and possible future needs to the Department of Housing. Client had been reported to have been on the priority waiting list for eight years.

*Outcome:* Client has now moved into a Department of Housing abode and has new equipment.

This case (client A) was an example of how the RNW were able to assist with the advocacy role. Through the utilisation of clinical skills to support the advocacy role, the RNW and the SCIA representative were able to work collaboratively to achieve a positive outcome for the client, after many years of the client not accessing services nor having any active intervention.

**Client B:**

*Background:* Client referred to RNW through community role. Client injured 38 years ago C4-5 incomplete tetraplegia. Client had managed his own health whilst living in Sydney and working full time, including self managing a persisting pressure area and had recently moved to a rural area.

*Intervention:* RNW provided GP with SCI information package and provided client with some general education and information as had not accessed any recent SCI information, then attempted to get client admitted to the nearest rehabilitation facility and referred client to local OT for complete review of equipment.

*Outcome:* some new equipment implemented. Pressure area improved and being monitored by GP and community nurses.

This case (client B) was an example of someone who had been “lost to follow up”. The client had not had regular health maintenance reviews or essential diagnostic tests, nor had he had his equipment reviewed and was not linked with any medical specialists.

The issue of how to get someone linked “back into the system” when they are geographically distant is one that is challenging and provides a rationale for the provision of a mechanism of following a health maintenance model. There is a need for periodic clinics in rural areas to implement a health maintenance model, which includes the capacity for medical and multidisciplinary spinal specialist review and a central and local coordinating ability to ensure that clients are monitored throughout their lifetime.

**Client C**

*Background:* Two years post injury (incomplete T7-T12) .Referral from daughter of client to RNW. Client reported panic attacks and anxiety.

*Intervention:* RNW referred client to local social worker for counselling.

*Outcome:* Client no longer reporting panic attacks after intervention from social worker and has returned to work part time.

This case (client C) highlighted a key need identified throughout the project. The need for psychological support and counselling for rural people with SCI, and the difficulties reported in accessing these types of services in some rural areas.

**Client D**

*Background:* 31 years post injury. C4 complete injury. Fifteen years since medical specialist and/or multidisciplinary review. Referred to RNW as persisting pressure area and general poor health.

*Intervention:* RNW referred to local OT, support of local OT for prescription decisions regarding new wheelchair and mattress, provision of written education resources to GP.

*Outcome:* Client has new wheelchair and mattress. Client having support from community agencies where he had not had any significant support or intervention in recent years.

This case (client D) highlighted the needs of those clients living in rural communities who have not accessed health or other multidisciplinary services for many years, and how aging with a SCI can impact on the health status of the client. A mechanism for following clients in the community and linking them to appropriate services provided is warranted.

**Client E:**

*Background:* T7-T12 complete injury. 15 years post injury- client with pre existing co morbidity of degenerative neurological disease and pressure area and referred whilst in local rural hospital lived in a remote centre. Client referred via treating physician in metropolitan area.

*Intervention:* RNW liased with nursing staff in the local hospital, contacted local OT regarding equipment and wheelchair, contacted speech pathologist regarding clients’ needs in this area, and contacted ACAT regarding future accommodation needs.

*Outcome:* This was a very complex case and required that the client be admitted to a nursing home.

The RNW in this case (client E) continued to visit and liaise with the nursing home and facilitated the prescription of a new wheelchair via the OT, and a referral to the wound CNC regarding review of the clients wound .This case highlighted the support needs (both staff and client) that are required for nursing homes, and the complexities of managing co-morbidities with a SCI.

**Client F**

*Background:* T7-T12 complete injury.22 years post injury .Client referred to RNW via local rehabilitation physician.

*Intervention:* RNW facilitated chair assessment, new cushion and reassessment of all equipment including mattress via local OT as client had not had his equipment reviewed since injury, and he had a pressure area which had not healed after four months of bed rest. RNW facilitated a referral to the local wound CNC and to the specialist metropolitan plastics and pressure services, she liaised with this service and facilitated the admission of this client for surgery through liaison with this service.

*Outcome:* this client had surgical closure of his wound, review and replacement of his old and outdated equipment and is now home in his local community.

This case (client F) was an example of how a network can function with the rural rehabilitation physician, community nurses, wound CNC and community OT working together with the local RNW as facilitator of the client's case, together with metropolitan specialist services working collaboratively for the client. The person locally is central to the network as they can act as the link between metropolitan and local services.



## SECTION FOUR: PROJECT EVALUATION

### 4.1: RSCIP 2: EVALUATION

The following section provides a sample of the responses against the key performance measures utilised in the independent evaluation. Key performance measures included surveys from key rural and metropolitan personnel, clients being invited to participate in a telephone interview, focus groups with RNWs and review of their activity logs and descriptive reports.

#### 4.1.1: IMPACT OF THE RNW/RSCIP 2 ON KEY RURAL SERVICE PROVIDERS

Key rural personnel were sent a survey regarding the impact of RSCIP 2 in their areas and were asked to suggest ways they may be supported. Results of the survey sent to key rural areas had an excellent response rate at 81%. All rural AHSs responded to the survey which indicated a high level of awareness of the project and the RNW at local level. Key rural personnel felt there was increased support for rural SCI clients and themselves as key rural service providers. Key rural personnel reported outcomes and positive impacts that occurred as a result of the RNWs interventions and the RSCIP 2. They were unanimous that the project hours were insufficient to meet the need, and all suggested that it needed to be made into a full time position. Key rural personnel suggested more education visits to rural areas, more hospital in reach capacity for the RNWs so they could expand their expertise to cover inpatient services, and that any future position would require nursing, occupational therapy and multidisciplinary input.

*Examples of comments made by respondents to the key rural personnel survey*

“Client with Grade 1V pressure areas who had not accessed any services beyond GP. The RNW facilitated the review and reassessment of his general condition, equipment and services and the outcome was a much improved quality of life”

“It is advantageous for clients to have a single contact for SCI issues, who is able to do home visits and prevent them from having to undertake long distance travel. Clients needs were identified and because the net workers had a good knowledge of local services and contact they could link clients into appropriate services efficiently”.

“As a result of a joint assessment with the RNW a client has had his bed and pressure care reviewed. A number of items have been purchased. Now looking into environmental controls. Prior to this he had not been reviewed for approx 15 years”

“The needs of SCI people are multifaceted and dynamic and this project ensures an integrated, comprehensive approach”

By having a local contact regarding SCI issues it provides resources /knowledge to those of us caring for these clients, which increases the level of support SCI clients would receive.

“This project has been hamstrung by the limited capacity of the outreach worker time wise. More hours (lots of them) are desperately needed to make any real difference

#### **4.1:2: IMPACT OF THE RNW/RSCIP 2 ON KEY METROPOLITAN SERVICE PROVIDERS**

Key metropolitan service providers were surveyed regarding the impact of RSCIP 2 and suggestions for the provision of SCI support to rural areas. Results of the survey sent to the key metropolitan personnel had a very good response rate at 70%. The majority of respondents reported that their level of awareness of the project was high; they highly agreed that rural clients had more support due to RSCIP 2 and they were able to provide increased support to their rural clients via the facilitation role of the RNW. Rural and regional SCI clients were viewed as disadvantaged by metropolitan personnel who responded to the survey, in relation to service provision issues. There were several suggestions for addressing these issues. Some of the respondents suggested increasing the provision of education to rural areas through all methods including telehealth, courses and outreach visits. Others suggested an increase in funding for resources, for the provision of equipment and for the establishment of clinics, both medical and multidisciplinary, and a formalisation of multidisciplinary teams for rehabilitation in rural areas through local hospitals and health centres.

*Examples of comments made by respondents to the key metropolitan personnel survey*

Newly injured and established clients were referred to RSCIP for follow up. Metro personnel reported that the “RNWS aided in the transition from inpatient to community living, they checked equipment and seating, they monitored pressure areas and skin management, they monitored and facilitated wound care skills, facilitated home modifications, provided clients with review and networked to link clients to local services such as appropriate carers and physiotherapists”

“It has been very valuable to have a specific clinician to refer on to. Without RSCIP worker our service will find it very difficult to identify clients that could benefit from our service”

“RSCIP provided a local who could visit, network, utilise my specialised expertise for her local clientele”

“The rural net worker has established contacts with and has worked with on a practical and professional level the various local disciplines and medicos”

“A full time staff member in each region is required. A few hours a week has achieved a lot in some areas, but is insufficient due to large distances”

#### **4.1:3 IMPACT OF THE RNW / RSCIP 2 ON CLIENTS**

Clients were invited to take part in the evaluation of the project. They were asked to return a consent form, and they were then contacted for telephone interview. The response rate of 40% was lower than expected, however it is acknowledged that clients with SCI are the subject of many surveys and projects and may have had some overexposure to interviews. RNWs expressed concern that clients may not be able to distinguish them from other providers. The data recorded many positive outcomes of the RNWs interventions and described the impact of that intervention on the clients involved. The client interviews captured the role of the RNW as providing education,

network and specialist support, assisting in discharge planning and continuity of care, and providing local expertise and knowledge. All clients interviewed reported the need for provision of similar support in an ongoing capacity.

*Examples of some of the RNW impact highlighted through the client interviews*

Clients reported that they saw the RNWs role in educating clients and other health professionals and providing resources as very important. They talked about how informative the RNWs were and how they provided literature which clients could use themselves or give to their GP.

A newly injured client said that his RNW came into the hospital before he came home and talked to him about his bodily functions, what to expect and to check if he needed anything. He found this very helpful, as he feels that the issue of bodily functions...is one of the biggest issues for SCI people.

RNWs were helpful in putting clients in touch with local resources and clients felt that it was good to have someone local for this reason, because they are more accessible and have more local knowledge.

One client wanted to do things to keep him self busy and was provided with useful information by his RNW on local community radio and volunteer work. Another client was looking for future job prospects and was put in contact by his RNW to his local TAFE where he is now doing a computer course.

A client reported that the RNW was helpful in referring him to PADP for equipment. She also facilitated his referral to a urologist. She also helped him with his application to his insurer for a new wheel chair.

#### **4.1:4 OUTCOMES FROM RNWs FOCUS GROUPS**

The RNWs participated in two focus groups via teleconference for the evaluation. The focus groups captured many positive outcomes as a result of the project and the RNW interventions, and recorded suggestions for ongoing sustainability for a model of rural service delivery for SCI clients. The evaluation captured some limitations of the project, primarily related to operational issues, some of which will be addressed later in this report. Some of the limitations related to resources and time constraints and suggestions to overcome some of these limitations will be discussed later in this document, however the limitations should not over ride the overall positive achievements of the RNWs and the project itself.

As the RNWs implemented the project at local level, it is relevant to consider their suggestions for future directions for the provision of a SCI support in their areas.

#### **Rural Networks:**

One rural net worker suggested that funding to bring specific allied health and other health education to local rehabilitation units would help rebuild confidence in their local service providers

RNWs would like to see regular reviews conducted on SCI clients in their areas by multidisciplinary teams and the Medical Specialist Outreach Assistance Program (MSOAP) with the flexibility to conduct home visits or at least at the local Community health centre.

RNWs felt that the development of strong links with local GPs, surgeons, local allied health services, community support agencies and private providers would enhance their position. This is also important to RNWs so that information on service providers can be constantly updated.

RNWs saw the maintenance of regular contact with local staff as an important step towards increasing the effectiveness of their own roles. RNWs wanted to be kept informed of staff changes and be contacted by the local hospitals when their SCI clients were admitted for procedures.

RNWs were unanimous in their agreement that one day per week was inadequate to provide a net working role in addition to being flexible enough to meet client needs. Part of the difficulty reported was due to the size of the area health service and there was the suggestion that the rural net workers be allocated to sectors within each of the area health services.

### **Service mapping:**

One of the aims of the service mapping component of the project was to determine if clients had a pathway that they could follow within their area relating to the management of their SCI, and to determine those services that make up the network. For example, is someone able to have a renal ultrasound in the rural area they live? Services that need to be determined as part of this pathway include a GP for the referral, a facility that has ultrasound capacity, a facility that is accessible to the client, urology services, and transport for the client to get there. The RNWs, through service mapping were able to identify services and service providers in their rural areas that a person with a SCI may need to utilise. Gaps in service provision were also noted. It is recognised that service mapping requires regular updating and that rural staff are transient, however the essential components of the services required by a person with a spinal cord injury as part of their health maintenance remain relatively static as part of a health maintenance model. The service maps aimed to provide an outline as to whether rural people with SCI were able to access services in their area, for example, could they have a new wheelchair scripted and supplied in their area? Did they have to travel to access this service?

Documentation of services in rural areas, whilst recognised as requiring time to attend and regular updating, is required in order to record those in the network and how networks operate. Networks are often noted informally, particularly local networks, so may not be able to be documented as a tangible resource. A greater knowledge of services and pathways in rural areas however, helps to facilitate a smoother discharge from metropolitan areas and also facilitates appropriate planning for elective admissions. Ensuring that databases are kept up to date, and ensuring that discharge planners are aware of services available or not available to the client on discharge, assists in the implementation of an achievable plan.

Updating of service mapping is required by local staff and needs to be filtered through the network to the metropolitan providers. This has been possible through the duration of RSCIP 2 through the RNWs and via the project officer. A coordinating link between rural and metropolitan areas should continue in an ongoing manner. This requires appropriate resources to attend. Identification, documentation and implementation of local pathways require an ongoing local presence to facilitate the rural aspect of the path way of a continuum of care.

## SECTION FIVE: REVIEW OF PROJECT OBJECTIVES AND THEIR ACHIEVEMENT

### 5.1:1 To develop integrated service provision and co-ordination amongst rural and metropolitan medical and health professionals

RNWs, key metropolitan and rural personnel all reported that there was a more integrated and co-ordinated service provision amongst rural and metropolitan medical and health professionals as a result of the Rural Spinal Cord Injury Project.

It is recognised that communication is one of the most difficult processes in integration, particularly for rural and remote patients and their primary health care providers<sup>33</sup> Through RSCIP 2 and the facilitation of communication and information via the net workers and the project officer, there has been a reported increase in awareness of the services available, and those key people that are in the local and metropolitan network and how to access them, which encourages greater integration and co-ordination.

#### *Sample of comments from rural personnel regarding integration*

“The liaison role that net workers took with other services was helpful, particularly between rural areas and the city. It was useful to have the RNW bridge the gap between Sydney and the remote areas. Liaison between the RNW and other service providers was seen as beneficial”

“I have been linked in to wider metropolitan and rural services-a more integrated and multidisciplinary team to support my provision of services”

“The RSCIP co-ordinator has been very supportive and understanding of the difficulties inherent in dealing with metropolitan units and trying to get them to understand the environmental and social issues of remote contexts”

Clients who were discharged to rural areas were identified by the SOS representative at the case conferences in the metropolitan spinal units and the RNW was made aware there was a client coming back to their area via the SOS and /or the project officer. That RNW was then able to co-ordinate local service providers and continue to liaise with metropolitan providers via the project officer who provided another link between rural and metropolitan services.

Despite challenges that occur with discharge planning, the objective was achieved, though could be further enhanced by full time dedicated positions and multidisciplinary spinal support for rural clients. Webber (2005) suggested the development of a system to flag rural patient’s files when they are an inpatient so that rurality is considered in the discharge recommendations. This, combined with the knowledge of the needs of rural communities could lead to services being provided in a more appropriate setting for the patient <sup>34</sup>Having a local facilitator/ co-ordinator with the support of multidisciplinary support locally and through metropolitan specialist spinal support, means that the needs of particular rural communities could be promoted.

<sup>33</sup> KM Webber (2005) , General Practice Hospital Integration in Rural and Remote Australia: Summary of Findings Australian Rural Health Education Network

<sup>34</sup> Webber (2005) op. cit

Melissa McCormick (2006). *Rural Spinal Cord Injury Project. ‘Developing Spinal Networks’ Phase Two 2003-2005. Final Report*

### **5.1:2 To provide peer and professional support to medical/health staff and Consumers in rural regions.**

Peer and professional support was provided to consumers by the RSCIP 2 RNWs and the project officer as documented through the client data (and their issues being highlighted and interventions occurring accordingly), by the summary of activity, the rural and metropolitan surveys and the client interviews. Medical and health staff were provided with professional and peer support through the net working process. Examples of this include the RNWs sending resources to general practitioners, and providing advice regarding which specialists and services to contact regarding specific issues. Service providers contacted the RNWs and the project officer directly with both direct and indirect queries related to their clients. Service providers were advised of the appropriate direction related to their queries, and issues were filtered through the SOS by the project officer and RNWs when required. An examination of the call register data base from the SOS<sup>35</sup> showed a considerable number of telephone calls and queries were taken by the SOS from the RNWs, rural clinicians and rural hospitals throughout the duration of the project.

Medical and health staff were provided with support through formal education during the project, and were also provided with support through the SOS, metropolitan spinal units and other speciality services (such as the spinal pressure care services) and non government organisations such as ParaQuad and SCIA.

Co-ordination of education was provided primarily through the project officer and the RNWs at local level, though was delivered by the SOS. Clinics for clients with SCI, and education sessions for medical, allied health and nursing staff were held at seven sites throughout rural NSW in 2004-05. These clinics and education sessions were a collaborative process between three projects/programs the RSCIP 2, the Spinal Outreach Service (SOS) and the Medical Specialist Outreach Assistance Program (MSOAP). Each project/ program was financed by its funding body individually to participate in the process. Education sessions and clinics provided a forum for medical and health staff and also provided an avenue for community clients to be reviewed. The challenge of providing this type of support from an operational perspective, without the backing of the other programs must be highlighted, as this objective would have been difficult to achieve if the project had functioned independently of this support.

These visits however are particularly resource intensive and remove the participants from their core activity. Specialist outreach programs have been reported to have been of great benefit in giving primary health care providers a network into metropolitan specialist networks, however it was preferable for the specialist to hand back care to the primary care provider with advice and support to enable the primary care provider to provide ongoing management of the patient<sup>36</sup>.

The experience gained through the RSCIP 2 (in collaboration with MSOAP and SOS) has highlighted the challenge of attending and following on from rural clinic and education visits. It has particularly highlighted the enormous amount of time spent in coordinating the visits and implementing recommendations on return. The co-ordination role for these visits was primarily carried out by the project officer, with support from the RNWs and local rural clinicians where possible, and therefore the significant time spent needs to be taken into account in the consideration of rural spinal service provision and a co-ordination role. Visiting specialist teams need to be appropriately resourced to provide pre and after services, and local primary and other health care providers need to have the capacity to provide ongoing management and follow up.

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<sup>35</sup> M Yap (2006) Report on the SOS' call register database. Personal Communication

<sup>36</sup> Webber (2005) op cit

**5.1:3 To provide systemic advocacy for people with spinal cord injuries and professionals living and working in rural regions.**

Systemic advocacy was provided through RSCIP 2 by the highlighting of issues relevant to rural people with SCI through; provision of information to area health services via external meetings (such as the regional occupational therapy meetings). Through dissemination of information to the SSCIS, and through communication to non government partners through involvement on the RSCIP Steering Committee.

**5.1:4 To raise awareness amongst rural medical/health professionals of the health needs of people with spinal cord injuries**

Awareness was raised amongst rural medical/health professionals of the health needs of people with spinal cord injuries in rural areas. This objective was achieved through the RNWs networking role, provision of education resources, linking to appropriate clinicians and service providers and referring to relevant clinicians. Formal education sessions, in collaboration with MSOAP and SOS also helped to raise awareness of the health needs of rural people with SCI.

**5.1:5 To continue to develop appropriate education resources, training and skill development**

The objective was achieved through the further development and distribution of the Rural Spinal Cord Injury Project fact sheets. These resources are now tangible resources that are available to a wide geographical and clinical population. RSCIP 2 saw the review of some of the original fact sheets (from Phase One) and the completion and implementation of three new fact sheets. The funding provided through the project enabled the fact sheets to be printed, and this provided a valuable education resource to support rural health professionals and general practitioners.

It should be noted that the fact sheets were written by spinal specialists, health and multidisciplinary professionals who gave generously of their time on a voluntary basis in addition to their normal work load. The project officer coordinated the reprinting and coordinated the distribution of the fact sheets, in collaboration with the SSCIS distribution of the fact sheets.

RNWs reported that they would have liked to have provided more education at local level, however given time constraints reported this was difficult to achieve, however the RNWs and project officer sent out many education packages to rural general practitioners and service providers. The project officer coordinated education visits, and followed up these visits with needs analyses for ongoing education. Requests for ongoing education were reported throughout the project, and this needs to be an ongoing objective for the provision of spinal services in rural areas. Provision for dedicated education to rural clinicians and service providers needs to be part of an implementation of a rural model.

## **SECTION SIX: DISCUSSION**

The RNWs reported many challenges to the project implementation, both from the perspective of developing the network in relation to their clients, and from an operational perspective. Reporting and discussion of some of these challenges aim to emphasise the complex nature of providing care and services to people with SCI who live in rural areas and to discuss ways of addressing them. Some of the challenges reported are not unique to rural people with SCI however rurality may be a confounding factor. Operational issues highlight the challenges of implementing a state wide project across multiple sites, however given that developing spinal networks was a pilot project, lessons learnt provide valuable information that may be utilised in the planning for future rural service provision.

### **CHALLENGES TO PROJECT IMPLEMENTATION AND SUGGESTIONS FOR FUTURE MODEL DEVELOPMENT**

#### **6.1: OPERATIONAL CHALLENGES TO PROJECT IMPLEMENTATION**

##### **6.1:1 DATA COLLECTION**

It is recognised that the data collection was challenging. The data collection process entailed hand writing considerable amounts of data, as some of the data required submitting on hard copy, and some of the RNWs did not always have computer access. It is noted that some of the RNWs did not achieve all the reporting requirements whilst other RNWs completed all reporting requirements consistently.

Reporting mechanisms should be clearly defined, piloted and tested prior to commencement of any project. Any reporting mechanism should be simple (to encourage accurate project reporting) but clearly related to the projects objectives, how they could be achieved and possible outcomes. It is challenging to set up a reporting mechanism once a project has already commenced.

The data recording mechanism, particularly in relation to RNW activity did not record in significant detail the complexity of the issues being dealt with by the RNW. Complex cases and the recording of the outcomes were often dealt with through electronic and telephone means, and through informal lines of communication, and therefore may not be entirely represented. The project officer took many phone calls and liaised with many rural service providers and the data collection process does not indicate the true nature of this co-ordination role.

The data collected however, was able to present a picture of client issues, the activity completed by the RNWs and the services and components that make up the networks in some of the rural areas. This data not only reiterates what was determined through RSCIP Phase One, but has also provided insight into previously undocumented areas. The issue of reporting mechanisms and systems, and the time available to achieve them, administrative and information technology support should be addressed in any future position of this nature.



### **6.1:2 CLINICAL ROLES**

A position that takes on a clinical direction in any capacity needs to ensure appropriate skills. Many nursing, occupational therapy and rehabilitation issues were identified throughout this project in addition to social work issues and those relating to community participation. As shown in Figure 14, the most frequently recorded issues were nursing and occupational therapy, but were also cross disciplinary. Any position of this nature requires a multidisciplinary approach. People with persisting spinal cord injuries require input from many disciplines and services across their life continuum; however health issues may exclude someone with spinal cord injury from participating fully in their community. Some of the RNWs reported feeling out of their depth in relation to the queries and requests coming from clients related to their health status. This emphasises two issues of primary importance—firstly that clients with SCI have health issues that require addressing in an ongoing capacity, and secondly that a clinician is required in the position to co-ordinate access to health services.

### **6.1:3 GOVERNANCE**

Some of the RNWs reported feeling isolated at times. A structure allowing for peer support and review of issues should be implemented in similar projects. This provides the capacity for positive reinforcement of achievements and encouragement to adhere to objectives. A structure where the project worker is aligned to one governance structure is preferred as it is more likely that adherence to reporting mechanisms and project plans is achieved.

### **6.1:4 TIME CONSTRAINTS**

RSCIP 2 demonstrated that the time available to the RNWs in the position was insufficient to meet the needs, both from clients, clinicians and service providers. RNWs felt that they were not able to fully develop networks in their areas due to time constraints. This included facilitating education to local service providers, developing networks in surrounding towns and regions and following up clients who were geographically isolated. RNWS also reported they were unable to co ordinate joint assessment times with other part time workers. Despite the time challenges, needs have been identified as a result of RSCIP 2 and strategies can be put in place to address the needs. Full time positions are required in rural areas in order to address the needs of rural people with SCI and need to take into account the geographical distances in many areas.

### **6.1:5 INFORMATION TECHNOLOGIES**

Any information technology issues need to be addressed prior to commencement of any project. Computer programs should be piloted for usability and any information technology problems addressed. It should be ensured that regional information technology systems can support the software due to be implemented as regional health services do not always have the information technology capacities that metropolitan areas do. It appeared that some rural areas were technologically disadvantaged related to their information technology services.

### **6.1:6 COMMUNICATION SYSTEMS**

If a project is to cover rural areas, it is imperative that the project workers have access to communication systems including computer and information technology support, electronic mail systems, telephone and mobile telephone.

### **6.1:7 TRAVEL**

A travel budget with capacity for road and air transport is imperative to any rural project. Accommodation and away from home allowance must also be considered.

## **6.2: EVALUATION CHALLENGES**

Aims and processes for evaluation clearly should be clearly defined prior to commencement of a project. Any project should have a plan for evaluation documented and its tools tested. It is challenging to change the evaluation process after a project has commenced. If a project has a clinical component, clinical background is essential in order to disseminate the clinical information particularly in relation to conducting client interviews.

## **6.3 CHALLENGES TO PROJECT IMPLEMENTATION REPORTED THROUGH RSCIP 2**

**6.3:1 Discharge Planning from Metropolitan to Rural areas:** Challenges arise when clients are discharged to rural areas, as inpatient units do not have the ability to do home visits prior to clients going home. Discharges must be planned over the phone, via documentation and liaison between metropolitan and rural health professionals. This means that discharges from inpatient units to rural areas must be thorough and timely, to ensure that local services have the ability to plan for the admission of the client to their service.

It has been evident through the project that having one point of contact when clients are going home facilitates more timely and accurate discharge planning, should that one point of contact have the time, ability and capacity to facilitate that discharge. Inpatient facilities do not have the time to be “tracking” individual relevant clinicians. If there was one point of contact, or a small group of key personnel locally to facilitate the discharge planning, it would be smoother, more relevant and timely. Some areas, particularly those in more isolated or smaller towns, have limited services and infrastructure, and may not have had exposure to, and therefore experience in, dealing with clients who have had a SCI. This means they need support to plan and implement care.

**6.3:2 Clients returning to isolated rural properties and regions:** Particular consideration needs to be given to those clients that are going home to isolated rural properties or remote areas. Clients who are going home to rural properties (for example those that are several kms from their nearest town/centre) need to be particularly considered in the discharge process. People who live on rural properties do not have the benefits of accessible neighbours, food, shops or emergency medical services. Transport is also a greater issue than the normal rural challenges, as standard transport will not go out to rural properties (for example taxis, that is if the town actually has a taxi service, and if so if that taxi service has the capacity to take a disabled client). Some rural community services do not offer a seven day a week service, so this population must be able to manage independently on weekends and some services such as meals on wheels do not go to rural properties, so planning and preparation for possible eventualities must be considered, particularly if there is limited family or carer support. Whilst it is acknowledged that local rural communities are excellent providers of support to people in their own communities, the particular challenges of returning to an isolated rural area need to be considered throughout the discharge process from inpatient facilities, and local communities need support to address these challenges.

**6.3:3 Limited rural client access to specialist testing and diagnostics:** Challenges were reported throughout the duration of this project in clients accessing some specialised testing and diagnostics. Tests such as neuropsychological tests were reported to be difficult to access in some rural areas. It was suggested that if this type of testing is indicated, it must be done whilst the client is an inpatient if possible. Local rural therapists who care for clients with challenging behaviours have suggested that it is very difficult to have any type of testing once the client is discharged, as there is a more limited availability of personnel specialising in this area in some rural areas. Whilst it is noted that there are some specialist services available in rural areas for this type of testing, the clients’ eligibility for utilising these types of services often needs to be determined at the inpatient rather

than the community level. Accessing specialised diagnostic tests such as video urodynamics was reported to be challenging in some areas, even those areas that were reported to have urology services. Specialised pain management services were also reported to be difficult to access in some areas.

**6.3:4 Equipment** Many equipment challenges were reported by the RNWs through the duration of this project. Despite the best efforts of the prescriber, equipment that has been prescribed whilst clients are inpatients has been reported to be not always suitable when the client goes home, particularly on rough surfaces/uneven terrain and rural properties. It was reported that sometimes clients are still waiting for their own equipment to arrive or be approved when they go home and are utilising loan equipment in the interim. Some of the RNWs reported that suitability of equipment to the environment would be more easily determined if there was the capacity to trial equipment when the client gets back to their home or place of residence. It was suggested that clients be admitted to facilities closer to their home as a “step down” and allow trial of equipment. Feasibility of this occurring warrants further investigation.

The rural client with SCI has often been in hospital for long periods, away from family and friends, and if they have a newly acquired injury, have a major period of adjustment. Potential utilisation or not of equipment, is often not identified until the client returns home. It is noted that it is very challenging for inpatient units to prescribe for every situation and eventuality, particularly when they have not been able to do a home visit.

As noted throughout the project, equipment issues were also particularly challenging for those clients with long term injuries that live in the community, who have not had their equipment reviewed for many years. The challenges of accessing specialised review and scripting of equipment and the process of receiving that equipment were reported to be significant.

Occupational therapists in rural areas are often called upon to follow up equipment that may sometimes require repair, adjustment or review from the company that manufacture that equipment and they then have to attempt to contact that company in an isolated rural area. It was reported that often the manufacturing companies may only do bi annual visits or not have a representative in that area. The cost of some companies going to rural areas was also reported to be beyond the means of some providers and clients.

Therapists in rural areas have multiple case loads and multiple settings, as well as covering a large geographic area, and some therapists were reported to have minimal experience in the management of people with SCI. Reviewing and re scripting equipment were reported to be predominantly difficult on complex SCI clients (particularly the long term injured). As previously noted in this report, occupational therapy and equipment issues occurred regularly through the duration of this project. Occupational therapists in rural areas have been noted to be eager for specialist education and the support of spinal specific expertise.

**6.3:5 Pressure area management.** As noted in section three (figure 13) pressure areas were recorded by a significant number of the RSCIP 2 clients. Pressure areas are a major complication of SCI and have a significant impact on quality of life for the person with SCI. The RNWs reported several challenges to the management of pressure areas in rural areas. The provision of specialised pressure care mattresses both at a local hospital, nursing home and at the community level, the issue of updating equipment in a timely manner to accommodate pressure area management, and the issue of changing care regimes to accommodate bed rest due to reported limitations of service provider resources. Education regarding the management of pressure areas, to rural clients and service providers alike were reported as priority areas, including a prevention and health maintenance approach. The cost of providing tertiary surgical services and the social impact of the

rural client having a long length of stay in hospital must be considered in the provision of SCI support to rural areas. Studies have shown the cost of treating pressure areas in the community to be astounding and have reported that innovative approaches are needed in the community to reduce a person's pressure ulcer risk.<sup>37</sup>

**6.3:6 Client reviews:** RNWs reported the need for clients to have the opportunity to access spinal specialist and multidisciplinary review. RNWs reported their concern regarding the long term injured population in their area who had not been reviewed for many years, and how to “get someone back into the system”. They reported the need for regular rural clinics, multidisciplinary review and up skilling of staff in their area. Spinal specific issues, for example, complex seating was reported to be challenging for some therapists with minimal experience in this area.

**6.3:7 General Practitioners:** The challenge of how to engage and provide SCI support to rural general practitioners was highlighted through RSCIP 2. Rural GPs form an integral link as part of the network and are an essential component of a health maintenance model. Rural GPs were noted in some areas to be transient, and in some areas waiting lists and surgeries that had closed their books due to a full capacity were reported. Accessible rooms, bulk billing capacity, facilities to examine clients and the ability to do home visits were reported to be barriers in some areas. Additionally some GPs may only have small numbers of SCI clients compared to clients with other conditions. How to best provide spinal specialist up skilling and education to GPs who are required to be multiskilled in rural areas, particularly where there is limited specialist and diagnostic support are ongoing questions to be addressed in future rural model development.

**6.3:8 Geographical Distances:** It was recognised throughout the project that the geographical distances in some of the area health services are vast. The capacity of the RNW to visit clients and to fully develop networks in surrounding regional areas, in one day a week was not achievable. The inland rural health services such as New England and Macquarie had clients who lived in more remote and sparsely populated areas, and were more dispersed into (and surrounding, for example on rural properties) the smaller towns rather than the larger regional centres. In Macquarie Area Health service, the RNW had client queries from remote areas such as Bourke and Brewarrina (a four hour one way trip by road from Dubbo) and Walgett. In New England, the RNW had clients in Moree, Narrabri and queries from Tenterfield. In Northern Rivers, the cluster of clients tended to be around the coastal and regional centres, however the vast distance back to the state capital from this area has proved challenging for clients requiring follow up. Mid North coast had two clusters of clients around the two largest regional centres, however was unable to travel to the lower mid north coast around Taree, where there were reported to be a number of clients with SCI. Similar issues were reported there to other rural areas.

The issue of distance is twofold and should be considered from two perspectives. One, from the perspective of the client in accessing services, and two, in planning strategies to provide services for clients with SCI. The perceived need and ability of the client to travel should be taken into account. Should a client with SCI travel ten hours by car from the Northern Rivers area for a routine review, or should these services be provided in their own area? Issues of transport, accommodation, cost, social impact, health impact (in particular the potential for pressure areas from sitting in the car too long) and rationale should be considered. Local services need to be able to provide basic routine review and health maintenance with the support of specialist services, and acute specialist spinal services should be retained for acute and complex management. In a study by Webber (2005)<sup>38</sup> remote and rural health care providers reported that their patients were often required to travel back

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<sup>37</sup> S Garber and D Rintala (2003) ‘Pressure ulcers in veterans with spinal cord injury: A retrospective study’ *Journal of Rehabilitation Research and Development*. Vol.40, No.5, Pages 433-442

<sup>38</sup> Webber (2005) op cit

Melissa McCormick (2006). *Rural Spinal Cord Injury Project. ‘Developing Spinal Networks’ Phase Two 2003-2005. Final Report*

to the distant hospital that they were admitted to for follow up care, that they felt could have been provided by them in the patients community.

Provision of staff for isolated areas needs to take into account the vast geographic distances in some areas and the ability of staff to get there. For example, is there a plane that the staff can access? Plane travel is often expensive and inflexible, the ability to take equipment on board, is limited. Hours of staffing and numbers of staff versus population, needs to take into account how sparsely the population in need is dispersed and the ability of staff to get there.

**6.3:9 Transport.** Despite significant efforts by Area Health and community services, through the duration of RSCIP 2, multiple transport issues were reported to have arisen relating to the provision of transport services for rural people with SCI. The normal transport challenges faced by people who live in rural areas are exacerbated for those with a spinal cord injury, as the availability of accessible transport has been reported to be limited in some areas.

NSW is comprised of 470 rural villages, towns and regional centres. 387 of these are without country link rail services, 110 are without country link coach services, 395 are without local route bus services and 336 are without local taxi service.<sup>39</sup> A significant number of people in rural NSW have difficulty getting to or from a health facility, whether to attend an outpatient clinic, to be admitted to hospital or to return home following discharge.<sup>40</sup> These people commonly do not own a car or are unable to drive, do not have friends or relatives able to assist them, and cannot make use of public transport. This may be due to mobility restrictions, affordability, or simply because they live in an area where there is little or no public transport when they need it<sup>41</sup>. Services, where available, have been reported to be limited. It has been found that the ageing demographics of rural and remote areas were having a major impact on the capacity of rural and remote communities to organise transport by private car.<sup>42</sup>

How to get to a medical appointment in a regional area, or how to return to Sydney for a specialist review have been concerns that have been raised through the experience of this project. For those clients that do not have access to a modified vehicle with driver, transport has been reported to be very challenging in some rural areas. Air ambulance does not have the ability to take a wheelchair on board as it only has the capacity for a 5kg limit on what can be taken. If an electric wheelchair is utilised, it must be brought by road. Cost of transport to hospital for non emergency procedures and accommodation before and after the procedures has been found to be significant for many rural patients and their families. Rules governing travel subsidy schemes that may force a patient to see the geographically closest specialist, though this may compromise the patient's continuity of care and prove difficult due to public transport constraints, have been raised by rural and remote primary health care providers<sup>43</sup> The impact of productivity lost by rural residents and their families when they leave their communities to seek care is unknown.<sup>44</sup>

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<sup>39</sup> S Olsen (2003) Transport for Health: Facilitating access to health services in rural communities. Paper from the 7<sup>th</sup> National Rural Health Conference [www.nrha.net.au/nrhpublic/publicdocs/conferences/7thNRHC/papers/general%20papers/olsen.pdf](http://www.nrha.net.au/nrhpublic/publicdocs/conferences/7thNRHC/papers/general%20papers/olsen.pdf).

<sup>40</sup> NSW Health (2002) op cit.

<sup>41</sup> NSW Health (2002) op cit.

<sup>42</sup> Council of Social Service of New South Wales (NCOSS) (2001) Transport to access health services in rural and remote NSW [www.ncoss.org.au/bookshelf/transport/submissions/NSWHealth\\_Hrt\\_policy.pdf](http://www.ncoss.org.au/bookshelf/transport/submissions/NSWHealth_Hrt_policy.pdf)

<sup>43</sup> Webber (2005) op cit.

<sup>44</sup> Webber (2005) op cit.

Considering and recommending a transport model is an issue beyond the scope of this project, however transport availability and accessibility has an enormous impact on how a rural client with a spinal cord injury may access health and community integration facilities. Transport issues have been highlighted elsewhere and are being addressed through various means.<sup>45</sup>

## **SECTION SEVEN: RESOURCES DEVELOPED**

### **7.1: NEW RESOURCES DEVELOPED**

Funding provided by the MAA for this project enabled two new fact sheets to be developed and enabled all fact sheets to be reprinted and distributed. A tangible and valuable resource is now available to a wide clinical and geographic population.

### **7.2: PRESENTATIONS**

Presentations describing RSCIP 2 its aims and implementation were made to the following by the Project Officer:

- Macquarie Area Health service (2004),
- Southern Area Health service (2004),
- Mid Western Area Health service (2004)
- Mid North Coast area Health service (2004)
- Northern Rivers area health service (2004)
- New England Area Health service (2005).

A presentation was also made at the:

- Spinal Outreach Service Forum (2004)
- Spinal Nurses Forum (2004).
- A poster was presented at ANZCOS (2005)

An article written for the Goulburn Local Paper (2004)

An article written for the SCIA magazine Accord (2005).

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<sup>45</sup> NSW Government (2002) NSW Government Response to the Report of the Rural Health Implementation Coordination Group Report

## SECTION EIGHT: CONCLUSION AND RECOMMENDATIONS

### 8.1: CONCLUSION

RSCIP 2 has demonstrated that a coordinated approach is required to ensure that rural people with spinal cord injury are not lost to follow up, are linked with appropriate health, other professionals and service providers and have the capacity to follow a health maintenance model. Prevention of adverse health events and poor outcomes must be ongoing. Health promotion must be a priority. Local coordination is required to empower the local network to care for the rural SCI population and to give rural consumers confidence in their local providers. Local providers must be supported to do this through the provision of specialist education, networking and communication, through spinal specialist advice and support. A rural spinal network will operate more effectively with local participants who are able to network with the support of a spinal specialist team.

RSCIP 2 has provided an opportunity to identify issues and barriers relating to the provision of services to rural people with SCI. It has provided an opportunity to examine a model of service provision to rural people with SCI and to recommend a sustainable rural spinal service model. This will improve community reintegration for rural people with SCI and ensure delivery of equitable specialist health services in rural NSW.

### 8.2: RECOMMENDATIONS

**1. The State Spinal Cord Injury Service (SSCIS) should be expanded by NSW Health to include a rural component in collaboration with Rural Area Health Services to establish a State Wide Rural Spinal Cord Injury service in an ongoing capacity.**

A State Wide rural spinal cord injury service would facilitate:

- The provision of support to all rural people with spinal cord injury in NSW –including those with newly acquired and long term spinal cord injury.
- The promotion of more accessible and equitable service provision to the rural population with SCI including strategies to cover geographic distances.
- A coordinated and planned approach to the provision of services and support to rural people with SCI.
- A health maintenance approach allowing greater community participation for rural people with spinal cord injury.
- Support for prevention of adverse health events and hospital readmissions
- More coordinated discharge planning for hospital discharges through metropolitan and rural coordination.
- The provision of support to rural clinicians and service providers.

**2. The role of the rural net workers should be expanded to full time clinical coordination roles in all NSW rural referral hospital areas in collaboration with rural area health services. –**

Coordination roles would provide

- Clinical coordination and consultation relating to rural SCI client management including the provision of some ambulatory services in partnership with primary care and hospital staff.
- Local rural hospital support
- Facilitation of a smooth continuum of care for rural clients transitioning from metropolitan spinal units, tertiary and rural referral hospitals.
- The implementation of a health maintenance model to rural community clients with SCI.
- Expert knowledge regarding local services and the ability to function as the local link between rural communities, local clinicians, service providers, the SSCIS and SOS.
- Coordination of SCI education in rural areas in consultation with rural outreach.
- Coordination and clinical support to rural Outreach medical and multidisciplinary visits, including facilitating the implementation of recommendations in collaboration with local clinicians and service providers.
- The capacity to cover geographic distances (such as funding for road and air transport, accommodation and away from home allowance).

**3. A central rural spinal co-ordinator role should be established in a full time capacity to coordinate rural activities of the SSCIS and ensure a planned approach.**

This coordination role would provide:

- A key link between rural coordinators, clinicians and service providers and metropolitan providers
- Monitoring of activity in rural areas to ensure equity of assessment and access
- Monitoring and documentation of pathways of care to specialised metropolitan and rural services for rural clients; in collaboration with rural coordinators, rural service providers, the rural and State Spinal outreach service and the SSCIS.
- Assistance to facilitate discharges to rural areas, and admission to metropolitan services in collaboration with rural coordinators, rural service providers, the rural and State Spinal outreach service and the metropolitan specialist spinal services.
- Monitoring and documentation of demand and utilisation, to facilitate appropriate planning in collaboration with rural coordinators, the rural and State spinal outreach service and the SSCIS.
- Central coordination for rural and metropolitan enquires regarding rural people with SCI and related issues to ensure a coordinated approach. (should include a centralised data base for clinicians, service providers and clients).
- Coordination of rural spinal education activities in collaboration with rural coordinators, rural service providers, the rural and State spinal outreach service and the SSCIS.
- Coordination of a medical spinal specialist (with support from a rural outreach multidisciplinary team) rural outreach clinic model.



#### **4. The SSCIS Spinal Outreach Service should be resourced to provide rural multidisciplinary support through a rural outreach service:**

This service would:

- Provide multidisciplinary support to rural clinicians and service providers managing rural clients with spinal cord injury
- Promote the development of local rural workforce skills ,confidence and ability to manage issues locally as able, in collaboration with rural coordinators , service providers and the SSCIS
- Support and promote the implementation of strategies to prevent adverse health events in partnership with rural and metropolitan clinicians and service providers.
- Provide multidisciplinary support to the medical spinal specialist rural outreach clinic model
- Allow equity of access to SCI expertise across all disciplines in rural areas
- Allow for the provision of dedicated education
- Provide support through onsite visits, tele health and provision of electronic and written resources.
- Allow for the development of resources for rural clinicians in collaboration with the SSCIS.

#### **5. A medical spinal specialist rural outreach clinic model, with the support of a multidisciplinary team (SSCIS rural outreach service) should be established in an ongoing capacity.**

This model would:

- Allow rural clients with SCI to access medical specialist and multidisciplinary review (both newly acquired injuries and those with long term injuries)
- Enable a health maintenance and health promotion model to be pursued
- Allow complex issues to be addressed at local level where possible and promote prevention of negative health events
- Reduce the need for rural clients to travel long distances to access metropolitan services
- Promote a holistic approach to provision of care to rural people with SCI
- Provide rural medical specialists with support and up skilling as required
- Support rural general practitioners in their SCI clinical practice
- Promote equity of access to specialist services
- Provide support to local clinicians and multidisciplinary team members by inclusion in the model, supporting and promoting clinical skills.

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**ACRONYMS:**

Aged Care Assessment Team.....	ACAT
Australian Spinal Cord Injury Register.....	ASCIR
Area Health Service.....	AHS
Brain Injury Rehabilitation Program.....	BIRP
Canadian Occupational Performance Measure.....	COPM
Clinical Nurse Consultant.....	CNC
Medical Specialist Outreach Assistance Program.....	MSOAP
Program of Appliances for Disabled People.....	PADP
Rural Net Worker.....	RNW
Rural Spinal Cord Injury Project Phase Two.....	RSCIP 2
Self efficacy scale.....	SES
Spinal Cord Injury.....	SCI
Spinal Cord Injuries Australia.....	SCIA
Spinal Outreach Service.....	SOS
State Spinal Cord Injury Service.....	SSCIS

**Modified COPM**

Date.....

COPM No: .....

				<b>STEP 1: IDENTIFICATION OF ISSUES</b>				<b>STEP 2: RATING IMPORTANCE</b>			
<b>PERSONAL CARE</b>											
Dressing, Bathing, Feeding, Drinking, Grooming, Bowel Management, Bladder Management, Skin Care, Equipment/Adaptive aids											
<b>HEALTH</b>											
Medication, Pain, Spasm, Diet, Energy, Fertility, Fitness, Autonomic Dysreflexia											
<b>FUNCTIONAL MOBILITY</b>											
Transfers, Wheelchair Skills, Walking, Standing, Equipment, Exercises, Shoulder Management, Splint, Orthotics											
<b>COMMUNITY ACCESS</b>											
Transport (Driving, Public Transport), Community Facilities (footpaths, shopping centres, gyms, surgery, etc)											
<b>EDUCATION/WORK (PAID/UNPAID)</b>											
Returning to Work, Finding New Employment, Volunteering, Technology/Equipment, School											

**LEISURE**

Hobbies, Reading, Crafts, Sports, Outings,  
Travel, Gardening, Visiting Friends, Parties.



very uncertain

very certain

6) I can have a satisfying sexual relationship.

1    2    3    4    5    6    7

very uncertain

very certain

7) I can enjoy spending time with my friends.

1    2    3    4    5    6    7

very uncertain

very certain

8) I can find hobbies and leisure pursuits that interest me.

1    2    3    4    5    6    7

very uncertain

very certain

9) I can maintain contact with people who are important to me.

1    2    3    4    5    6    7

very uncertain

very certain

10) I can deal with unexpected problems that come up in life.

1    2    3    4    5    6    7

very uncertain

very certain

11) I can imagine being able to work at some time in the future.

1    2    3    4    5    6    7

very uncertain

very certain

12) I can accomplish most things I set out to do.

1    2    3    4    5    6    7

very uncertain

very certain

13) When trying to learn something new, I will persist until I am successful.

1    2    3    4    5    6    7

very uncertain

very certain

14) When I see someone I would like to meet, I am able to make the first contact.

1    2    3    4    5    6    7

very uncertain

very certain

15) I can maintain good health and well-being.

1    2    3    4    5    6    7

very uncertain

very certain

16) I can imagine having a fulfilling lifestyle in the future.

1    2    3    4    5    6    7

very uncertain

very certain

**TOTAL SCORE :** \_\_\_\_\_



