

# Rehabilitation and Reintegration Outcomes Following Spinal Cord Injury in the UK

A thesis submitted for the degree of Master of Philosophy.

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## **Abstract:**

### **Background:**

Spinal cord injury (SCI) is defined as a low incidence, high cost condition, however there is little information in the UK regarding the incidence, prevalence or associated costs of SCI. Additionally there is little evidence identifying outcomes or issues associated with delays in referral, admission or discharge from an SCIC or the impact of delays in provision of resources on reintegration outcomes.

### **Research Aim:**

This novel study aims to determine factors and timings which may facilitate or limit successful rehabilitation and community reintegration for individuals with SCI. Map timescales and key indicators in the SCI injury and rehabilitation and reintegration pathways. Establish the impact of delays in provision of required resources on reintegration outcomes.

**Methods:** An observational longitudinal study, collecting data regarding individuals from injury to one year post-discharge.

Rehabilitation, reintegration and healthcare systems outcome measures to be evaluated were identified and included: community participation, quality of life, residential situation, readmission rate and vocational activity.

**Results:** Delays in accessing services occur for a variety of issues and can have lasting impact. Many issues can affect progress and may have a more profound effect at particular points of the injury and rehabilitation pathway. At one year post discharge some subjects have fallen short of the identified outcomes; potential reasons for this are discussed in addition to issues that may have facilitated improved outcomes in some subjects.

**Conclusion:** Some assumptions in SCI rehabilitation and reintegration have been challenged and some partially or fully supported. Novel findings have been identified in relation to physical social and psychological barriers or facilitators of outcomes following SCI.

Potential areas for further research to increase our knowledge of issues for SCI individuals, SCIC services, acute hospital services and community services are identified.

## Dedication

This thesis is dedicated to my mother Brenda Johnson. I miss you every day but know that the reason I could do this is because you are with me every day.

It is also dedicated to my husband and primary cheerleader, Rikki Khare. Thank you so much for your love, your kindness, your encouragement and your support over the years. I truly could not have done this without you.

*“Never confuse a single defeat with a final defeat.”*

F. Scott Fitzgerald

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## List of Abbreviations

AIS	ASIA Impairment Scale
C	Cervical
CCG	Clinical Commissioning Group
CHC	Continuing Healthcare
CSQ	Coping Styles Questionnaire
FIM	Functional Independence Measure
GP	General Practitioner
ICF	The International Classification of Functioning (ICF), Disability and Health
IDT	Interdisciplinary Team
ISNCSCI	International Standards for Neurological Classification of Spinal Cord Injury
IQR	Interquartile range
L	Lumbar
LOS	Length of Stay
LSCIC	London Spinal Cord Injury Centre
MDT	MultiDisciplinary Team
N	Number of Subjects
NHS	National Health Service
NSCIB	National Spinal Cord Injury Board
NSCISC	National Spinal Cord Injury Statistical Centre
NSF LTC	National Service Framework for Long-term Conditions
NTSCI	Non-traumatic Spinal Cord Injury
PCT	Primary Care Trust
PDB	Post Discharge Booklet
RTA	Road Traffic Accident
SCI	Spinal Cord Injury
SCIC	Spinal Cord Injury Centre
SCIM	Spinal Cord Injury Independence Measure
SOCQ	Spheres of Control Questionnaire
SSD	Social Services Department
T	Thoracic
TSCI	Traumatic Spinal Cord Injury
UK	United Kingdom of Great Britain
USA	United States of America

## Preface

Whilst working in a Spinal Cord Injuries Centre I became aware of the myriad of issues facing the newly injured SCI individual and the issues that they face when trying to resume their lives in the community. I also became aware of the scarcity of research (particularly in the UK) regarding optimal reintegration outcomes following SCI and factors which may facilitate or limit these outcomes. This then became the background and driver for this research. The aim of this thesis is to investigate outcomes in a cohort of spinal cord injured (SCI) individuals from the point of injury to one year post-discharge. In order to explain the issues that may face individuals following SCI, the optimal outcomes for them and why these issues are important the first three chapters will review the literature and research regarding SCI causes, management and outcomes.

**Chapter 1** will discuss the context of SCI. The causes, incidence and life expectancy of SCI will be discussed in order to clarify the size of the potential SCI population and its requirements. The need for appropriate management and the implications of inappropriate management will be discussed. Finally an overview of SCI rehabilitation approaches, services and standards internationally and in the UK will be presented.

In **Chapter 2** the relevant models of health and disability will be discussed. The potential healthcare systems outcomes as well as the rehabilitation and reintegration outcomes for the individual with SCI that will be examined in this thesis will be discussed and issues influencing their achievement discussed. **Chapter 3** will then examine research regarding potential contextual factors which may impact upon these outcomes. These contextual factors may be either internal or external to the SCI individual and may or may not be modifiable. Information regarding requirements for provision of resources such as accommodation, care and equipment as well as the impact of variation in provision will be examined where there is research available. Finally the gaps in research identified in this and the two preceding chapters will be discussed and proposed areas of investigation to be explored in this study will be formulated.

In **Chapter 4** the proposed methodological structure and process of this study discussed. Limitations of potential formalised measures will be discussed and the selected formal measures discussed along with the proposed survey tools. Methods of data handling and analysis will be presented. Outcomes from a pilot project and subsequent revisions to the data collected and project process will be presented.

Following this, three chapters of results will be presented which will identify results in relation to the relevant phase of the study. In **Chapter 5** baseline demographics from the point of injury will be presented along with information regarding rehabilitation outcomes and discharge disposition. Data will be presented and evaluated regarding the 'pathway' of the SCI individual from the point of injury to discharge, and the relevant healthcare system and rehabilitation outcomes will be identified and discussed.

**Chapter 6** will present data relating to outcomes at one year post-discharge. Changes in demographics will be discussed and outcomes will be evaluated in relation to the contextual factors identified from the literature reviews. Results for the outcome measure of QOL and the contextual factors of coping style and locus of control will be presented in **Chapter 7**. Relationships between these three factors will be evaluated. Finally the results previously discussed in Chapter 6 will be evaluated in relation to the potential to influence or be influenced by the psychological factors or QOL. The areas of investigation proposed in Chapter 1-3 will be discussed and evaluated in relation to the results presented.

The final chapter, **Chapter 8** will discuss the results presented in the three preceding chapters in the context of the proposed measures of successful rehabilitation and reintegration. The research project will be evaluated and the strengths and limitations of the project discussed. Potential implications or SCI and community services and service planners and recommendations for further research will also be discussed.

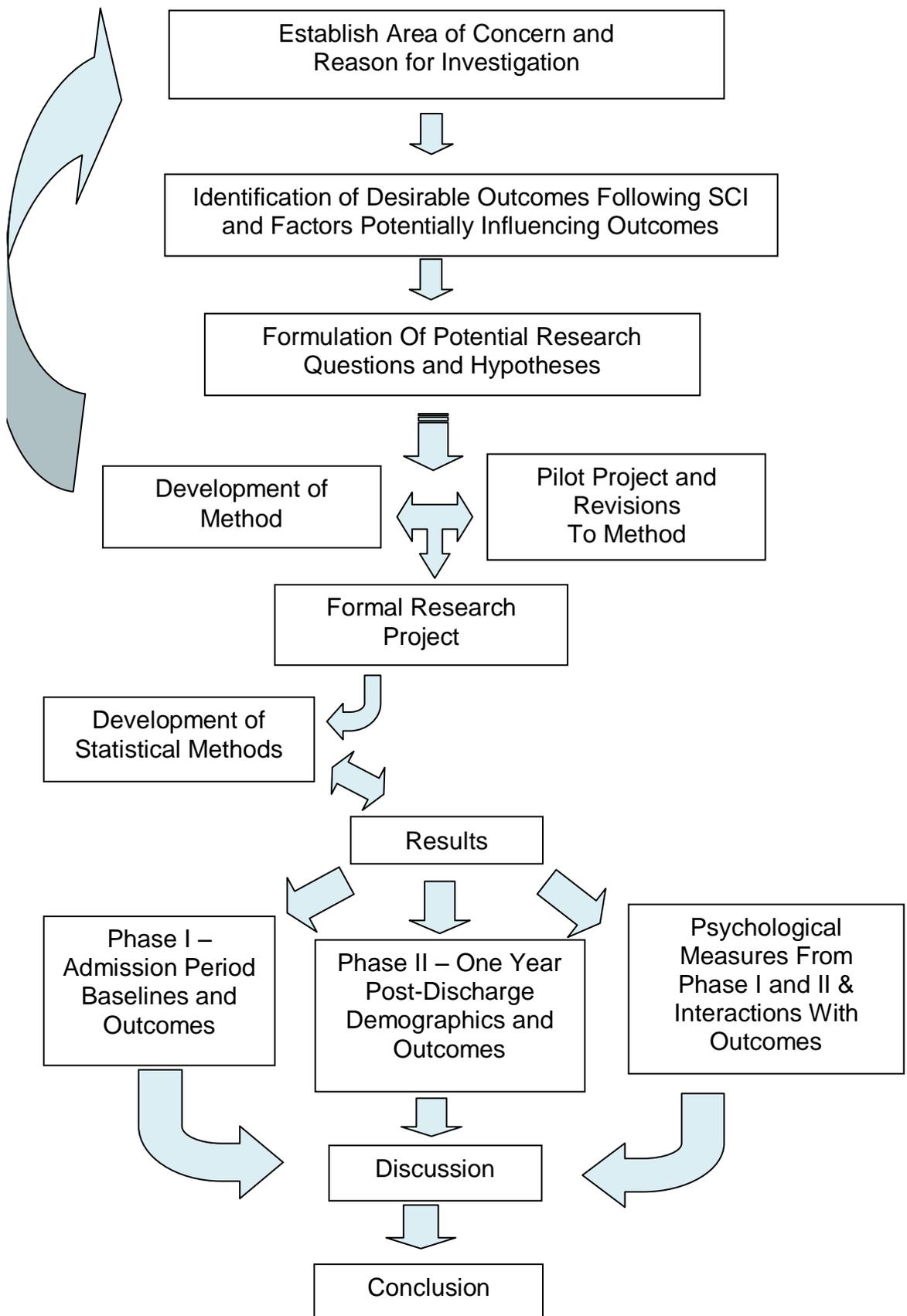


Figure P.1 Thesis Structure

## **CHAPTER 1: The Context of Spinal Cord Injury**

### **Overview**

Spinal cord injury (SCI) is noted to be a complex, low incidence condition with associated high costs. Despite this there is little information on the incidence and prevalence of SCI in the UK and a scarcity of research into outcomes following SCI in the UK. The focus of this thesis will be differences in outcomes in a cohort of SCI individuals and the factors which may have influenced these outcomes. This initial chapter presents the context for this research; it will focus on the presentation of SCI, the variety of impairments that may occur and the sequelae of SCI. The causes of SCI will also be discussed along with the clinical context of SCI. Information regarding potential incidence, demographics and the heterogeneity of the SCI population will be examined in relation not only to the potential impact on services but also on life expectancy post SCI.

An overview of SCI services and the structure and approach of SCI rehabilitation in the UK will be presented. The argument for the provision of specialist SCI management will be discussed along with potential issues that may occur if specialist input is not available or provision of this is delayed. Finally, potential areas for investigation that have been identified will be discussed.

## 1.1 Introduction

As with all other bones in the skeletal system the vertebrae can be subject to fracture which can result in damage to the spinal cord. Equally, damage can occur to the spinal cord without damage to the vertebrae through a variety of mechanisms. Each spinal nerve controls function (motor and autonomic) or sensation in a particular area of the body and is given a letter and number to indicate the area of the spine that it originates from. There are many excellent resources that describe both this and the neuropathology that occurs following spinal cord injury (SCI) in further detail if required (Kirshblum and Campagnolo, 2011; Somers, 2010; Lin, 2010).

## 1.2 Classifications and Grades of Spinal Cord Injury

An SCI can occur at any point along the spinal cord and result in a greater or lesser degree of damage. Both of these things can result in greater or lesser impairments, therefore it is necessary to have an objective classification of SCI through which it will be possible to identify the amount of impairment which occurs. The International Standards for Neurological Classification of SCI (ISNCSCI) incorporates both an assessment of neurological level of injury and the American Spinal Injury Association (ASIA) Impairment Scale (AIS) which grades the level of impairment sustained. It is the internationally recognised system of SCI classification and neurological scoring (ASIA/ISCOS, 2011; Alexander *et al.*, 2009; Furlan *et al.*, 2008). A copy of the ISNCSCI assessment is included in Appendix A.

The level of spinal cord injury is categorised according to the last fully functioning spinal nerve (ASIA/ISCOS, 2011; Grundy and Swain, 2002), generally, the higher up the spinal cord that damage occurs the greater the functional impairment can potentially be. An SCI at C2 can affect function from neck down and an L1 SCI can affect function from the hips down. The degree to which function is impaired is classified by the ASIA Impairment Scale (ASIA/ISCOS, 2011) which uses the letters A-E to distinguish between degrees of completeness of a spinal cord injury and so the grade of impairment. A is a complete injury, B a motor (functional) complete injury with retained sensation, C and D grade SCI are progressively more functionally (motor) incomplete injuries and E means that, although there was an initial SCI, there is no longer any neurological impairment. In example of how AIS grades translate in to functional outcomes following SCI (on completion of rehabilitation): an individual with a C2 AIS A SCI will be dependent on a ventilator to breathe, will require a wheelchair for all mobility, will transfer with a hoist and will require constant (24 hours a day) attendance with a carer awake overnight; whereas, an individual with a C2 AIS D SCI will usually be able

to breathe independently, be independent in all elements of their care and, potentially, be able to walk.

### **1.3 Potential for Neurological or Functional Improvement**

In the weeks following an SCI the initial neurological situation may improve. Research and clinical texts state that the earlier that significant improvement is seen, the greater the chance of substantial recovery (Wing, 2008; Scivoletto *et al.*, 2006) and any functional recovery will also be assisted by rehabilitation. A review of international research by Wolfe *et al.* (Wolfe, Hsieh and Mehta, 2012) indicates that in addition to the speed of recovery the potential for neurological improvement is also affected by the AIS grade of the SCI. They identified that over all of the research reviewed, approximately half of those admitted with an incomplete AIS B or C grade SCI showed an improvement in neurology of at least one grade, but only small percentages of those with AIS A or D grade SCI showed this level of neurological improvement. Clinical texts and research indicate that the most significant recovery is suggested to occur within the first six to twelve months although functional improvement may not translate in to a change in either neurological level or AIS grading (Steeves *et al.*, 2011; Kirshblum and Campagnolo, 2011; Wirth *et al.*, 2008), therefore, after this time significant neurological recovery is unlikely to occur and there is unlikely to be any unanticipated functional improvement.

The potential lack of certainty regarding the final functional and neurological outcome for those with an AIS C or D (that is, motor incomplete) SCI may present difficulties for both the treating professional and the SCI individual (Steeves *et al.*, 2011; Wirth *et al.*, 2008; Grundy and Swain, 2002). Psychologically, those with an incomplete SCI are not only coming to terms with a disability with wide ranging impact but also an uncertain prognosis and future which may cause the individual difficulties in adjusting to their disability (Dorsett, 2010; Suyama *et al.*, 1999). Rehabilitation texts and research emphasise the need for the professional to set realistic rehabilitation goals whilst not confronting denial and fostering hope as this will assist the SCI individual to strive in rehabilitation and not confront denial (Dorsett, 2010; Somers, 2010; Hammell, 2006; Grundy and Swain, 2002). Further discussion of the potential impact that an uncertain neurological prognosis may have on the psychological adjustment of the individual following SCI will be discussed in more detail in Chapter 3.

Although there is currently no cure for SCI and any enduring loss of function is likely to be permanent further deterioration as a result of the initial SCI as may be seen in other

neurological conditions such as multiple sclerosis (De Souza and Action and Research for Multiple Sclerosis., 1990) is not generally expected to occur.

#### **1.4 Causes of SCI**

The causes of spinal cord injury (SCI) are either traumatic or non traumatic. Traumatic SCI (TSCI) will generally be due to a sudden event causing immediate damage such as a road traffic accident (RTA), assault, fall, or sporting injury (Furlan *et al.*, 2012; Somers, 2010; Grundy and Swain, 2002).

Non-traumatic SCI (NTSCI) can be caused by many things including spinal tumours (benign and malignant), spinal abscess or inflammatory conditions (McKinley, Seel and Hardman, 1999). Although NTSCI can also be caused by other progressing conditions (for example multiple sclerosis) this thesis will only consider SCI that is due to a one off event that is either internal or external to the individual. NTSCI can present with sudden onset, as in the case of a spinal stroke, or as a gradual loss of neurological function over a significant period of time (Cosar *et al.*, 2010; McKinley, 2008; Grundy and Swain, 2002; McKinley, Seel and Hardman, 1999). Therefore the 'pathway' of these SCI individuals from the point of first presentation of symptoms to diagnosis and admission may have been either significantly longer than those with TSCI or as short (McKinley, 2008). Some SCI individuals may also be coming to terms with a diagnosis of a disease that could have been life threatening (cancer) in addition to adjusting to their disability (McKinley, 2008). Non-traumatic SCI (NTSCI) are often termed spinal cord lesions but for the purposes of this thesis the term SCI will be considered to cover all forms of injury to the spinal cord, traumatic or non-traumatic, unless specified otherwise.

#### **1.5 Sequelae of spinal cord injury**

In addition to the loss of motor, autonomic and sensory function following SCI a range of sequelae are noted to occur (Grundy and Swain, 2002; Hammell, 1995). These sequelae occur due to the dysfunction in the motor, sensory and autonomic systems and although generally manageable on a day to day basis may significantly impact on the individuals functioning or well being, increase their requirement for assistance, or result in severe symptoms and complications (Somers, 2010; Grundy and Swain, 2002). Full details of the sequelae of SCI can be found in one of the many SCI textbooks (Kirshblum and Campagnolo, 2011; Lin, 2010) but due to the potential impact of these issues it is appropriate to briefly discuss these sequelae.

### Autonomic Function Sequelae

Sequelae of the autonomic system are: autonomic dysreflexia (a potentially life threatening elevation of blood pressure), poikilothermia (an inability to fully regulate body temperature), postural hypotension (marked reduction of blood pressure when seated or standing) and continence issues.

### Sensory Function Sequelae

Although the individual with SCI will have lost some or the majority of sensations below the level of their SCI although they can still experience significant levels of musculoskeletal and neuropathic pain (Teasell *et al.*, 2012). An additional consequence of loss of sensation is that the individual with SCI is at significant risk of developing pressure sores as they may be unable to move or adjust position to relieve pressure on the skin and do not have the sensory feedback of pain when skin damage is occurring (Regan *et al.*, 2012).

### Motor Function Sequelae

As a result of sequelae of the motor systems individuals are at risk of developing contractures (a joint remaining in a 'fixed' position due to an abnormal shortening of muscle tissue) or osteoporosis. Many individuals may also experience severe spasms/spasticity which can be difficult to manage successfully and may impact upon functional abilities (Adams and Hicks, 2005) and may impact upon functional abilities.

SCI is a lifetime condition and therefore, barring a full neurological recovery, the requirements and costs due to the injury will be ongoing. It would be useful at this point to discuss the potential numbers of individuals with SCI in the UK and sustaining new injuries every year.

## **1.6 SCI Incidence and prevalence in the UK**

Historically there has been little formal information on the incidence or prevalence of SCI in the UK. There is no centralised database or register recording incidence of SCI. Due to this, estimates of incidence have frequently relied upon data based upon admissions to spinal cord injuries centres (SCIC), resulting in varying estimates of the numbers of new SCI occurring each year. For instance Smith (Smith and Spinal Injuries Association., 1999) quotes the UK NHS executive as giving an estimated incidence figure of 473 new SCI in 1995-1996 and the Chair of British Association of Spinal Cord Injury Specialists as estimating between 500 and 700 new injuries per year. A higher figure has been suggested by Grundy and Swain (Grundy and Swain, 2002) of 10 to 15

new SCI per million UK populations per year. Assuming a UK population of 62.3 million (Great Britain. Office for National Statistics, 2010), this would give an incidence of between 623 to 935 new injuries per year, significantly more than the previous figures. More recently, results from nine of the ten UK SCIC stated that there were 744 new SCI patients discharged from participating SCIC in 2007/8 (Barr and Spinal Injuries Association, 2009). As this information lacks data from one SCIC then it is likely that the actual numbers of newly injured SCI individuals passing through the UK SCIC over a year is toward the higher end of the estimates from Grundy and Swain (Grundy and Swain, 2002).

Information that is available for SCI incidence in the UK is either incomplete (Barr and Spinal Injuries Association, 2009), is in excess of 10 years old (Grundy and Swain, 2002; Smith and Spinal Injuries Association., 1999) or focuses mainly on information gained from SCIC admissions. This data may be incomplete for a variety of reasons. Firstly, an unknown number of SCI individuals die prior to admission to an SCIC (National Spinal Cord Injury Strategy Board, 2012; Wing, 2008). Although life expectancy in the initial days post SCI has improved from the 80% mortality rate reported during the First World War (Tribe, 1963) the first 48 to 72 hours following SCI remains a crucial period in terms of the treatment and medical management of the SCI individual (Wing, 2008; Grundy and Swain, 2002; Harrison, 2000; DeVivo *et al.*, 1990). Definitive figures for early mortality are unknown either in the UK or internationally as death certificates may record many causes of death, some of which may not be identified as related to the SCI. It is important to note that although individuals who die in the first days or weeks following SCI may only be in the healthcare system for a short period of time, they are likely to have required a significant amount of high cost healthcare and therefore need to be accounted for in service and budget planning. As these individuals have not survived long enough to be admitted to an SCIC their data will not be included in incidence estimates based on SCIC data alone.

A second issue is that SCI individuals may not be admitted to an SCIC due to not meeting the admission criteria or waiting lists being so long as to preclude admission (National Spinal Cord Injury Strategy Board, 2012). SCIC teams may not routinely retain information regarding individuals who are referred to but not admitted to the SCIC (Barr and Spinal Injuries Association, 2009) and there are no sources of information in the UK on the numbers of SCI individuals who are not referred to SCIC or why they were not referred. This suggests that there may be a significant number of individuals sustaining an SCI each year who are not accounted for in incidence estimates. This potential

underestimate of incidence is not just an issue in the UK, in the Netherlands it has been estimated that between 19 and 30% of those surviving TSCI were not admitted to SCI rehabilitation institutions (van Asbeck, Post and Pangalila, 2000).

Further deficiencies in data may occur due to the tendency in the UK for researchers, support organisations (Barr and Spinal Injuries Association, 2009), service providers and service planners (South of England Spinal Cord Injury Board, 2010) to focus mainly on service provision and research on those individuals with TSCI. Without the availability of an endless number of specialist SCIC beds with unlimited funding, then service providers will always need to set priorities for admission to their service and in many countries the admission of only TSCI individuals is seen as a priority (New, Cripps and Bonne Lee, 2013; Cripps *et al.*, 2011; Wyndaele and Wyndaele, 2006; Ackery, Tator and Krassioukov, 2004). Therefore only information on TSCI individuals is collected in research utilising data from SCIC alone and little information being available regarding NTSCI incidence. However the indication from an international data is that there is the inclusion of individuals with NTSCI in incidence estimates would increase levels by between 40% (New, Simmonds and Stevermuer, 2011) and 100%+ (Osterthun, Post and van Asbeck, 2009). In other words there may be a significant amount of additional individuals with SCI who are neither counted nor accounted for in the majority of research, register and database reporting or in service planning. In addition to the potential deficiencies in data discussed earlier this suggests that much of the data that is available regarding the incidence of SCI is likely to be incomplete and therefore merely an estimate of incidence levels with potentially widely varying levels of accuracy.

Information on the numbers of newly injured SCI individuals admitted to UK general hospitals could be provided by national hospital admission statistics (Great Britain. NHS Connecting for Health, 2012). Reasons for hospital admissions and treatment are classified according to International Classification of Diseases (ICD-10) codes and this information is used to generate national UK information on hospital admissions and incidence of a range of conditions (World Health Organisation, 2010). However issues have been noted with some cases of significant SCI not being coded as such when ICD-10 classifications are used (Dahlberg *et al.*, 2005). Equally, the application of ICD codes can vary between clinical coders due to variations in the issues they identify as pertinent and the resulting codes they apply to the admission potentially affecting the quality of information obtained (Great Britain. NHS Connecting for Health, 2012). These issues suggest that not only are there potential inaccuracies in the data available but also

issues when making comparisons between data collected using the different ICD classification systems.

Clearly there are benefits and pitfalls to all sources and points of data collection if they are taken in isolation. Information from SCIC services may specifically cover SCI individuals with enduring neurological loss but is unlikely to include those who, for varying reasons, were not admitted to the SCIC system and therefore additional sources of information is required. This results in difficulties estimating the incidence of SCI in the UK with any level of accuracy. Information is available for incidence of SCI in other countries, however several international reviews of incidence literature (Cripps *et al.*, 2011; Nordgren, 2008; Wyndaele and Wyndaele, 2006; Ackery, Tator and Krassioukov, 2004) have identified that there is a need for greater rigour and consistency in data collection and reporting procedures as well as in the diagnostic methods and definitions of SCI in use. Additionally due to the issues discussed earlier it is likely that any incidence rates given in research literature are likely to be estimates rather than definite population figures. However in the absence of accurate information for incidence or demographics for the SCI population in the UK it is necessary to supplement what information is available with information from international review papers.

It has been suggested in reviews of international incidence levels that countries of similar economic status are likely to have similar SCI incidence levels and demographics (Cripps *et al.*, 2011; Ackery, Tator and Krassioukov, 2004). If we accept this suggestion and the suggestion that estimates of incidence approximate the actual levels of incidence, it could be estimated that the incidence of TSCI in the UK (as a Western European country) is approximately 15 per million (Cripps *et al.*, 2011). Assuming a UK population of 62.3 million (Great Britain. Office for National Statistics, 2010) this would give an estimated figure of 935 newly injured TSCI people per year. Although this number may appear quite low compared to the estimated 2,500 to 3,000 new cases of multiple sclerosis in the UK each year (Multiple Sclerosis Trust, 2012) it needs to be remembered that there are also an additional unknown number of new NTSCI cases that could potentially equal this figure or exceed it (DeVivo, 2012; Osterthun, Post and van Asbeck, 2009). Additionally, an increasing rate of SCI has been noted in international review papers (van den Berg *et al.*, 2010; Wyndaele and Wyndaele, 2006; Ackery, Tator and Krassioukov, 2004). If this trend is correct the lack of reliable information regarding the incidence of SCI in the UK is a significant issue.

As a potential estimate of the incidence of SCI in the UK has been identified it would be useful to identify the demographics of this potential population.

### **1.7 Potential Demographics of the SCI Population**

A UK based case review survey of SCIC patients discharged from nine SCIC in one year identified that 71% of the SCI individuals identified in the survey were male, the average age was 44 years, 44% were reported to have co-morbidities at the time of SCI and 71% had a TSCI (Barr and Spinal Injuries Association, 2009) although the authors acknowledge that the data is incomplete and that at least 11% of those identified were patients who had been readmitted to the SCIC. In this study 50% of new injuries were tetraplegic. Lack of other UK based studies result in difficulties in confirming the findings from this study. Data from international reviews will be utilised where possible to give further depth to this information (Table 1.1).

Changes in the demographics of the SCI population have been noted in recent years. Table 1.1 illustrates currently reported SCI population demographics from international reviews and the most recent UK study. The proportion of SCI individuals sustaining tetraplegia has increased and is reported in an international review to be one third of newly injured SCI individuals in developed countries (Wyndaele and Wyndaele, 2006). Additionally although the majority of newly injured individuals are still males, the numbers of females sustaining SCI has increased (Wyndaele and Wyndaele, 2006).

A UK based survey identified that mean age at injury was 44 years (Barr and Spinal Injuries Association, 2009), confirming an international trend for increasing age at incidence of SCI resulting in the majority of newly injured individuals being reported to be in their early thirties with a second spike in the 60's (van den Berg *et al.*, 2010). This increasing age at the time of injury is likely to have implications for the treatment requirements of SCI individuals.

The latest UK based survey suggests that road traffic accidents (RTA) are the cause of 27% of SCI (Barr and Spinal Injuries Association, 2009) with 26% due to falls echoing earlier findings (Grundy and Swain, 2002; Smith and Spinal Injuries Association., 1999). The latest review of international data (excluding the UK) reports higher levels of TSCI in Western Europe due to transport (mean 46%) with an increased proportion of TSCI (mean 37%) occurring due to falls (Cripps *et al.*, 2011). This reported increase in the proportion of fall related SCI (van den Berg *et al.*, 2010; Wyndaele and Wyndaele, 2006) is of note as these individuals are generally reported to be older (Cripps *et al.*, 2011).

Where information regarding the incidence and demographics of NTSCI are available they are noted to be older with a greater proportion of females, incomplete lesions and paraplegics (New, Cripps and Bonne Lee, 2013; McKinley, 2008). However there are variations in demographics according to the cause of the NTSCI; resulting in a population that is just as heterogeneous as the TSCI population (New *et al.*, 2013b; New, Cripps and Bonne Lee, 2013; Wolfe, Hsieh and Mehta, 2012; Cosar *et al.*, 2010; McKinley, 2008; McKinley *et al.*, 2001; McKinley, Seel and Hardman, 1999). Just as the demographics of those sustaining TSCI as a result of a suicide attempt may vary significantly from those sustaining TSCI as a result of an RTA, the demographics of those sustaining NTSCI as a result of spinal stenosis may vary from those who sustained an NTSCI as a result of a sarcoma. In essence there may be no archetypal individual who sustains an NTSCI, just as there is no archetypal individual who sustains a TSCI. Despite this much research persists in drawing comparisons between these two groups and therefore, where appropriate, these distinctions will be referred to in this thesis.

	TSCI	NTSCI (New, Cripps and Bonne Lee, 2013) for Western Europe
Incidence (estimated)	16/million (Cripps <i>et al.</i> , 2011)	6/million
Mode of Injury	RTA – 27% (Barr and Spinal Injuries Association, 2009) - 46% (Cripps <i>et al.</i> , 2011) Fall – 26% (Barr and Spinal Injuries Association, 2009) - 37% (Cripps <i>et al.</i> , 2011)	Neoplastic conditions 33% Neural tube disorders 31%
Gender	Male – 71% (Barr and Spinal Injuries Association, 2009) - 77% (Wyndaele and Wyndaele, 2006)	Male 54.6-63.3%
Tetraplegic %	50% (Barr and Spinal Injuries Association, 2009) 33% (Wyndaele and Wyndaele, 2006)	Tetraplegic 32%
Complete %	Complete 50% (Cripps <i>et al.</i> , 2011)	Not given
Mean Age	44 (Barr and Spinal Injuries Association, 2009) 15-29 and 65+ (van den Berg <i>et al.</i> , 2010)	Not given

Table 1.1 Demographics of SCI population

At present there is no clear information regarding the incidence of SCI in the UK. Whilst information is available for many other countries, including those that are similarly developed to the UK, there is the potential that this may not accurately reflect the situation in the UK. This may explain some of the variations in demographics noted

between the UK based survey and international reviews (Cripps *et al.*, 2011; van den Berg *et al.*, 2010; Wyndaele and Wyndaele, 2006). Equally as the UK based survey only including information from nine out of ten UK based SCIC, the impact of missing data, both in terms of the information that would have been provided by the tenth SCIC and information regarding those individuals not admitted on the demographic profile can only be estimated. The demographics of the SCI population are noted in international reviews to be changing (Cripps *et al.*, 2011; van den Berg *et al.*, 2010; Wyndaele and Wyndaele, 2006; Ackery, Tator and Krassioukov, 2004). In this situation the value of focusing on differences between the NTSCI and TSCI is limited and may draw attention away from the important issue of the overall changing demographics and requirements of the SCI population.

SCIC services in the UK were originally established to deal with an SCI population who were predominantly male (82%), paraplegic or at most low tetraplegic, with a median age of 25 (Hammell, 1995). Changes and variations in demographics may significantly impact not only on the requirements of SCIC service planning and provision (DeVivo, 2012) but also general medical and community based services. Information that is currently available, due to the focus on TSCI could be presenting inaccurate information on the requirements and size of the SCI target client group (New, Cripps and Bonne Lee, 2013; Cripps *et al.*, 2011; van den Berg *et al.*, 2010; Wyndaele and Wyndaele, 2006). The lack of reasonably accurate UK specific information regarding the incidence of SCI and the demographics of the SCI population is likely to present difficulties in ensuring that the size and format of SCIC services in the UK reflect the needs of the UK based SCI population. Due to this lack of information it may be useful to examine information that we do have regarding life expectancy following SCI and current service provision. Following this information regarding requirements, potential outcomes and potential facilitators or barriers of these outcomes will be examined.

### **1.8 Life Expectancy Following Initial Stages of SCI**

Advances in SCI management are suggested to be continuing to improve outcomes and life expectancy once initial treatment is completed (Middleton *et al.*, 2012; Cripps *et al.*, 2011; Strauss *et al.*, 2006). Unfortunately no UK based information on life expectancy, mortality rates or main causes of death in the SCI population was identified. In the USA longitudinal information regarding a cohort of SCI individuals who are under care of a select number of SCIC is available from the National Spinal Cord Injury Statistical Center (NSCISC) (National Spinal Cord Injury Statistical Centre, 2012). Although trends from this information suggests that post-SCI life expectancy in the USA has improved

over the past 50 years (DeVivo, 2012) stable prevalence figures in Europe and America despite increasing incidence is suggested to indicate that life expectancy, although improving, is still poor (DeVivo, 2012; Wyndaele and Wyndaele, 2006). Evidence from the NSCISC database also suggests that improvements in life expectancy in the general population are not being matched by improvements in the SCI population (DeVivo, 2012). NSCISC data identified an increase in USA mortality rates for those with an injury of 2-5 years between 1993 and 1998 (DeVivo, Krause and Lammertse, 1999). The authors suggest but could not confirm that this was due to changes in funding policies for initial and ongoing treatment. In the USA the main causes of death in the SCI population are reported to be respiratory issues (such as pneumonia, respiratory failure), infections (such as septicaemia) and pulmonary embolus (DeVivo, 2012), which the author asserts are all issues which may be impacted upon by changes in funding and provision of healthcare. If correct, this suggests that life expectancy following SCI is vulnerable to reductions or deficiencies in funding and service provision.

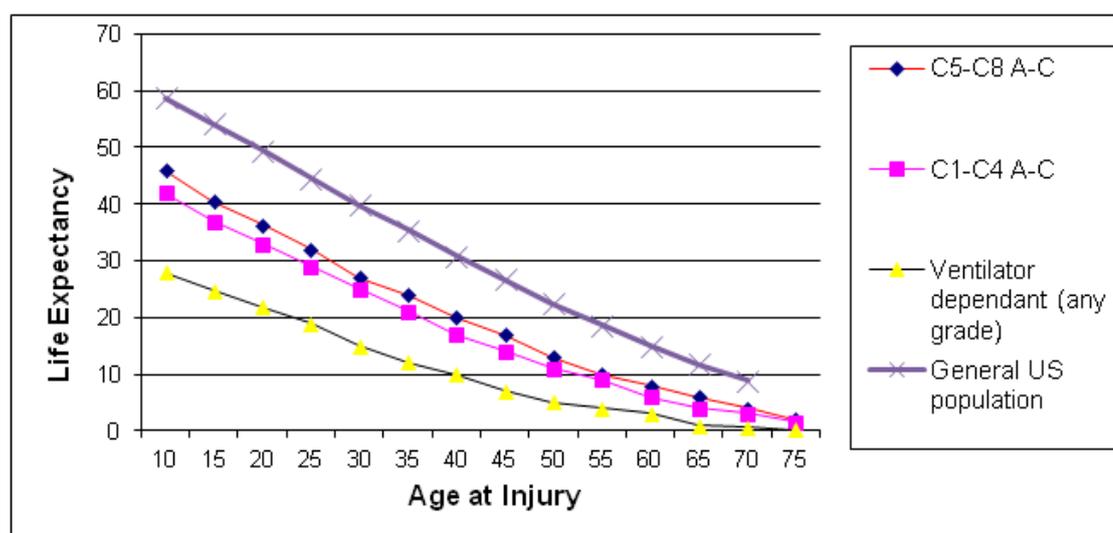


Figure 1.1 Life expectancy for SCI Individuals surviving at least 1 year post injury. (National Spinal Cord Injury Statistical Center, 2012). (Chart Courtesy of Rik Fox (Fox, 2013))

Post-SCI life expectancies have been noted to vary significantly according to level and completeness of injury (DeVivo, 2012; Cripps *et al.*, 2011; O'Connor, 2005; Yeo *et al.*, 1998). Utilising information from a literature review and longitudinal trends from the USA NSCISC, DeVivo (DeVivo, 2012) identified significantly better life expectancies amongst those who had incomplete or lower level SCI and better overall health and independence. This is particularly notable in those with higher level SCI as shown in Figure 1.1.

Research utilising NSCISC data also identified that the risk of mortality increased with each year of additional age at the time of injury (DeVivo, Krause and Lammertse, 1999) particularly for those who were aged over 40 at the time of injury (O'Connor, 2005). In light of this the trend for increased age at the time of injury is particularly notable (van den Berg *et al.*, 2010) and has implications for life expectancy following SCI (Middleton *et al.*, 2012; DeVivo, 2012). In addition to the potential shorter life expectancy, there is an increased rate of co-morbidities in an aged or aging SCI population which is likely to have a significant impact on lifetime costs (Hitzig *et al.*, 2011; Coll, 2007) and overall costs to the state. These co-morbidities and associated increased costs will be relevant both for those injured later in life (van den Berg *et al.*, 2010; Wyndaele and Wyndaele, 2006; Ackery, Tator and Krassioukov, 2004) as well as for those surviving for long periods of time (aging) post injury. DeVivo suggests (DeVivo, 2012) that as the numbers of individuals who sustain SCI at a greater age increases then there will be an increase in the rate of potentially life threatening SCI related complications such as pneumonia. This will be in addition to an increase in pre-existing medical conditions, psychological issues and death due to non-SCI related risk factors such as cancer and cardiac issues. These issues are likely to present challenges not only during rehabilitation but also during and following reintegration.

In summary, life expectancy following SCI is reported to have improved over recent decades but is still not at the levels of the general population. In addition there are potential variations due to level and completeness of injury and age at injury. Decreasing prevalence of SCI noted in the USA suggests that fewer individuals are sustaining SCI each year than are dying. In view of the noted trend for increasing numbers of high level injuries and increasing age at the point of injury (including an increase in co-morbidities) these issues suggest there is likely to be an increased demand on SCIC and general health and social care services. This may require an increase in funding for services or at least an adjustment to the way that services are provided. Therefore the scarcity of information regarding the numbers or requirements of SCI individuals in the UK may become a more prominent issue in the years to come. The unconfirmed link between inadequately funded healthcare provision and higher mortality rates in the USA is of particular concern in this situation.

The potential numbers demographics and life expectancy of SCI individuals in the UK have been identified and gaps in our knowledge discussed. The following sections will discuss the services that are available in the UK for the treatment and management of

the SCI individual and potential issues that may arise if provision of these services is delayed or inadequate.

### **1.9 UK Spinal Cord Injury Acute Care**

SCI has been defined by the UK Department of Health as a high cost low incidence condition and SCI management and rehabilitation is defined as a 'Specialised Service' (National Specialised Commissioning Group, 2010) which can only be provided in one of the 11 specially designated centres within the UK. These centres are 'tertiary' care services; which means they cannot be accessed directly by an SCI individual, unlike primary or secondary care services. Referral to SCIC services can occur by a variety of routes. An individual may be referred by an Accident and Emergency (A&E) Consultant whilst they are still in the Ambulance on the way to the A&E, alternatively they may not be referred until several months later by another Consultant or, in some cases, their GP following discharge home from a 'non-specialist' facility. In the author's experience this can lead to a wide variety in lengths of time from the point of injury to the point of referral.

In an ideal clinical pathway the SCI individual will receive emergency treatment and then specialist acute management as close to the point of injury as is feasible (National Specialised Commissioning Group, 2010; Webster *et al.*, 2004). The aim of this acute management is to surgically and/or medically stabilise the SCI individual, implement the necessary ongoing management regimes that will reduce the risk of complications and health issues and to prepare the SCI individual for the rehabilitation process that will ultimately facilitate their reintegration in to their community. This initial management of SCI is highly complex and it is recommended that where possible this should be undertaken either in an SCIC or with guidance from SCIC teams (National Specialised Commissioning Group, 2010). There are differences in UK SCIC services which will affect the ability of some SCIC to admit those who are acutely unwell or have experienced complex polytrauma. Whilst some UK SCIC are attached to a trauma facility or may have an acute SCI management and surgical facilities attached others are purely rehabilitation facilities which may or may not be able to admit SCI individuals who are ventilated. Where possible, early transfer to an SCIC is advocated, in order to improve outcomes, reduce mortality, and increase the potential for neurological recovery as well as to reduce the potential for complications, prolonged lengths of stay and increased costs (Grundy and Swain, 2002). However the differences in services at SCIC will affect how quickly an individual can be admitted to a particular SCIC as will bed availability issues (Wolfe, Hsieh and Mehta, 2012).

There is an expectation that if an SCI individual is unable to be admitted to an SCIC for acute management that any treatment given at an alternative facility will be performed in collaboration with the input and specialist knowledge of SCIC teams (National Spinal Cord Injury Strategy Board, 2012). The complexity of the initial management of an SCI individual means that there is a high risk of sustaining complications and mortality (National Spinal Cord Injury Strategy Board, 2011; Wing, 2008). Clinical texts highlight that complications such as pressure sores and contractures can be sustained at this time if the individual with SCI is not managed appropriately (Wing, 2008; Grundy and Swain, 2002; Harrison, 2000; Hammell, 1995); these may take a substantial amount of time and clinical input to resolve. The Department of Health advocates that clinicians attending to the newly injured SCI individual should liaise with the SCIC team at the earliest opportunity to promote seamless care and the avoidance of unnecessary complications. The Department of Health restates that: 'early liaison and agreed protocols with SCI centres will ensure seamless care and the avoidance of unnecessary complications.' (National Specialised Commissioning Group, 2010, p.3). Unfortunately UK based evidence of delays in referrals (Barr and Spinal Injuries Association, 2009; Gardner, 2007; Amin *et al.*, 2005) suggests that this liaison is not occurring. Delays in referral may occur for a variety of reasons including delay in diagnosis (Couris *et al.*, 2010), a lack of knowledge on the part of treating teams regarding SCIC services or lack of guidelines and protocols for onward referrals of SCI individuals (Gardner, 2007). These delays are of concern to those involved in SCI management as delays in referral indicate delays in liaison with SCIC teams and delays in accessing specialist advice on the management of the SCI individual (National Specialised Commissioning Group, 2010; Grundy and Swain, 2002; Harrison, 2000).

Ludwig Guttmann maintained that the acute period of treatment post-SCI should not be viewed separately to rehabilitation and that essentially rehabilitation should commence as early as practically possible for the individual (Guttmann, 1977). A systematic review of literature by the SCIRE network (Wolfe, Hsieh and Mehta, 2012) identified that those who were admitted to a Specialist Acute SCIC facility were found to have fewer complications when transferred to SCIC rehabilitation and to make greater progress during their rehabilitation stay. UK based research (Barr and Spinal Injuries Association, 2009; Amin *et al.*, 2005) indicates that SCI individuals are often delayed in admission to an SCIC either due to delays in referral or due to lack of an available bed in the SCIC and therefore will experience a delay in this process. Of 744 SCI individuals admitted to 9 UK SCIC 41% were not admitted within one month of injury with a mean time to admission of 46 days (Barr and Spinal Injuries Association, 2009). The main reasons for

delays in admission were delays in referral, health issues preventing transfer and lack of available SCIC beds.

In the UK the implicit message in clinical texts and guidance is that the best outcomes occur when an SCI individual is admitted to an SCIC for acute management and particularly when they are admitted early (NHS England, 2013a; Spinal Injuries Association, 2012; National Spinal Cord Injury Strategy Board, 2012). One UK-based survey identified a significant relationship between delays in admission and the presence of complications on admission (Barr and Spinal Injuries Association, 2009) but little other UK-based empirical evidence to confirm this assertion is available (Bagnall *et al.*, 2003).

A review of available international literature regarding the relationship between lengths of time to admission to specialist rehabilitation and outcomes (Parent *et al.*, 2011) found that those who were admitted to an SCIC service earlier had reduced acute and rehabilitation lengths of stay (LOS). There is no firm UK evidence to support this conclusion but a UK survey identified a highly significant relationship between increased lengths of stay and the presence of complications on admission which were in turn significantly related to delays in admission (Barr and Spinal Injuries Association, 2009). A survey of medical notes of 150 Italian SCI individuals also reported significantly improved progress in rehabilitation and neurological recovery in those who were admitted in less than 30 days following SCI (Scivoletto, Morganti and Molinari, 2005) however it is debatable if within 30 days could be considered to be an early transfer of care.

Internationally there is also little information regarding what timescale for admission to an SCIC is viewed as 'early' (Wolfe, Hsieh and Mehta, 2012; Wing, 2008). In part the lack of research on the optimal clinical pathway for an SCI individual is due to the relatively low incidence of SCI which results in small sample groups, but also the difficulties with establishing robust controls for comparisons due to ethical issues surrounding withholding of potentially effective treatment. Attempts have been made in the UK to address the first of these issues through several measures: the introduction of a Common Admission and Waiting List Management Policy for all SCIC in England (National Spinal Cord Injury Strategy Board, 2012), the piloting of a proposed National Care Pathway for the Care of People with Spinal Cord Injury (National Spinal Cord Injury Strategy Board, 2011), and guidance from the NHS Clinical Advisory Group Report on Management of People with Spinal Cord Injury (NHS Clinical Advisory Group,

2011). However it will be some time before the benefit of these developments can be measured.

In summary, the acute management of the newly injured SCI individual is a complex process which if not done appropriately can lead to a range of issues and complications. This management should ideally take place in either a specialist facility or with close liaison and collaboration between the treating team and the specialist SCIC team. Evidence suggests that transfer to a specialist acute SCIC facility results in reduced complications, shorter lengths of stay and better rehabilitation outcomes. Researchers and clinicians also suggest that these outcomes are mainly achieved with early transfer to an SCIC but there is little evidence to suggest what constitutes an early transfer.

The emphasis in this thesis until now has been on the initial injury and the treatment pathway, the focus of the remainder of this chapter will be on the rehabilitation process which provides the skills necessary for the SCI individual to be able to reintegrate in to their society. This will permit development of a framework for the evaluation of outcomes for the SCI individual during rehabilitation and reintegration.

### **1.10 UK SCIC Rehabilitation History, Structure and Approaches**

Once acute management is completed in the SCIC rehabilitation will commence to enable the SCI individual increase their functional abilities where possible, as well as to learn how to manage their condition and function in society following their SCI. In order to understand how this rehabilitation process will occur as well as the philosophy and drivers behind the process this is an appropriate point to view the history of rehabilitation and SCI services in the UK.

#### **1.10.1 Evolution of Rehabilitation and SCI Rehabilitation Services in the UK**

Publically funded rehabilitation services in the UK evolved during the first and second World Wars, initially driven by a need to return soldiers to active service. Whereas previously the focus of treatment had been the medical management of the SCI and life expectancy was short (Tribe, 1963) in peacetime it became necessary to assist the SCI individual to recover from or adjust to their disabilities and return to productive civilian life (Grahame, 2002). Although a review of UK rehabilitation services in the 1950's (Piercy, 1956) emphasised the need for a restorative approach to rehabilitation the lack of distinction between the social, medical or vocational elements of rehabilitation resulted in several government departments being involved in rehabilitation services but without collaboration leading to confusion and ineffectual services (Tunbridge, 1972;

Mair, 1972). During this time rehabilitation began to move from a medical 'physical treatment' model however it was still lacking grounding in models of health and disability that promote reintegration. This was the political and healthcare environment in which Sir Ludwig Guttmann developed the first UK SCIC at Stoke Mandeville.

In contrast to the existing services Guttmann created a system of SCI rehabilitation in which the aim was for the individual to reintegrate in to their society at the end of their rehabilitation. The SCI individual was to be an active participant in this society, to work, have relationships and, potentially, have children (Schultke, 2001; Guttmann, 1977), however the community services necessary to facilitate this were still evolving or absent. Therefore Guttmann advocated that services be developed to permit SCI individuals in the UK to be housed in adapted properties in the Community rather than institutions, to be trained and encouraged to return to work where possible (Schultke, 2001) and to be an autonomous individual with a meaningful role in society. These aims were echoed in later reviews of, and further proposals for, general rehabilitation services (Mair, 1972; Tunbridge, 1972) and influenced how physical and vocational rehabilitation services would be structured in the future. The formal development of a medical sub-specialism for rehabilitation stressed that rehabilitation had import in its own right, and was not just an adjunct to surgical management or other forms of medical treatment. Following this the concepts of cross-professional collaboration and teamwork that would be cornerstones of future rehabilitation services were developed (Ward *et al.*, 2009; Grahame, 2002).

### **1.10.2 Specialist SCI Rehabilitation Services**

Just as the acute treatment of SCI individual is deemed to be a specialist service (NHS England, 2013a) the rehabilitation of the SCI individual is also viewed as a specialist service (NHS England, 2013a; Royal College of Physicians, 2010). Specialist rehabilitation is defined by the Royal College of Physicians as 'the total active care of patients with a disabling condition, and their families, by a multi-professional team who have undergone recognised specialist training in rehabilitation, led or supported by a consultant trained and accredited in rehabilitation medicine' (Royal College of Physicians, 2010, p. 9, pp. 2.17.). Improved long term outcomes, including greater reintegration and fewer complications, are reported for those admitted to an SCIC for specialist SCI treatment and rehabilitation compared to those admitted to other rehabilitation facilities, both in the UK and internationally (Wolfe, Hsieh and Mehta, 2012; Smith and Spinal Injuries Association., 1999). It is therefore an appropriate point to evaluate what constitutes an SCIC rehabilitation programme.

SCI rehabilitation in the UK generally uses a combination of interdisciplinary and discipline specific models and frameworks of rehabilitation (Ivey and Mew, 2010; Ward *et al.*, 2009). Where restoration of function (restorative/medical model) is not possible the adaptive (also known as the compensatory or functional) model of rehabilitation aims to compensate for loss of functional ability by enabling the individual to perform the task in new ways. For example, teaching the SCI individual to perform a transfer as a means of getting out of bed, or providing equipment such as a wheelchair or prosthetics to compensate for enduring physiological impairment. The rehabilitation team will draw on elements of these models as appropriate as the individual progresses through their rehabilitation. Rehabilitation, in short consists of using a combination of approaches to restore what can be restored and assist the individual to learn new skills to compensate for what cannot be restored (Ward *et al.*, 2009; Hammell, 2006). The individual then has the ability to choose how they apply those skills as they reintegrate in to their society.

A specialist SCI rehabilitation programme will be provided by a rehabilitation team comprising of a variety of medical, nursing and therapy staff, working with the SCI individual both on a one to one and group basis. UK based SCIC rehabilitation teams work either on an interdisciplinary basis where team members collaboratively work towards patient goals that are not discipline specific or a multidisciplinary basis where team members work as individuals with a discipline specific perspective (Korner, 2010). The rehabilitation team in an SCIC only treat individuals with SCI, this means that their knowledge and expertise in the treatment and rehabilitation of an individual with SCI is highly specialised.

As a means of clarifying the requirements of specialist SCIC rehabilitation programme the three SCIC services in the South of England, in collaboration with other organisations, have established standards for the provision of SCI rehabilitation (South of England Spinal Cord Injury Board, 2010). These standards make recommendations for the availability of the rehabilitation team members and equipment within the SCIC, as well as access to additional services and specialities (internal and external). Indications are also given of how the rehabilitation programme will be structured, the assessments that will be performed, target lengths of stay and rehabilitation outcomes that should be achieved. However these agreements are loose and lack the fine detail necessary to be 'who, what and when' guidance or to enable comparisons across facilities, resulting in these three services still having significantly different rehabilitation programmes and differing service provision.

This variation in rehabilitation provision is not a situation that is unique to the UK. In a survey of nine SCIC in nine countries, New et al (New *et al.*, 2013b) highlighted the differences between how SCIC rehabilitation services were provided. These differences included the availability, or access to, other medical or therapeutic teams, as well as differences in staff roles, staffing levels, and therapy intensity, amongst others. They identified that each SCIC facility had a unique structure to their service and rehabilitation programme to the extent that a 'like for like' comparison was not possible. Even where similar processes were in place there were fundamental differences in how these were implemented.

These differences in rehabilitation services provided in all SCIC present difficulties in establishing a clear definition of specialist SCI rehabilitation (New *et al.*, 2013b; Whiteneck *et al.*, 2011), in addition to difficulties in the comparison of rehabilitation processes and outcomes across SCIC. Although it is suggested that improved outcomes occur for SCI individuals who receive specialist SCI rehabilitation (Wolfe, Hsieh and Mehta, 2012; Parent *et al.*, 2011) it is not possible to categorically state why this is the case. Comparisons of SCI rehabilitation services have tended to examine the whole 'package', the sum of the parts rather than the individual elements (Whiteneck *et al.*, 2009). Therefore comparisons between SCI rehabilitation programmes tend to focus on outcomes such as functional improvement, discharge destination or lengths of stay (Wolfe, Hsieh and Mehta, 2012).

### **1.10.3 SCIC Rehabilitation Approaches**

The rehabilitation of an SCI individual is not only a physical process but also an educational and psychological one. In addition to learning how to perform functional activities in a new way and how they may reintegrate into society and their previous role, the SCI individual will also learn how to manage all the sequelae of their SCI including how to 'troubleshoot' if problems occur. Most importantly the knowledge and skills acquired during rehabilitation need to be dynamic in order to facilitate the SCI individual adjusting to their changing environment and future situations (Somers, 2010; Ward *et al.*, 2009; Hammell, 1995; Trieschmann, 1988). This final point highlights why the rehabilitation process can be viewed as merely the beginning of a continuing process of adjustment that the SCI individual will go through (Hammell, 2006; Trieschmann, 1988). An important aim of rehabilitation will be to restore the autonomy of the SCI individual through empowering them to direct their care and control their lives. This is consistent with the Expert Patient programmes advocated in Quality Requirement One of the UK

National Service Framework (NSF) for Long Term Conditions (Great Britain. Department of Health Long Term Conditions NSF Team., 2005).

In the UK SCI rehabilitation a client-centred and collaborative approach advocated in which the SCI individual is not only the focus of the SCIC rehabilitation programme but also an active member of the rehabilitation team (Papadimitriou and Carpenter, 2013). This endeavours to ensure that rehabilitation meets the needs and requirements of the SCI individual (Papadimitriou and Carpenter, 2013; Ward *et al.*, 2009). Although the SCIC rehabilitation team will have a rough template for the SCI individual's rehabilitation, based upon the level and severity of the SCI, this template will need to be adjusted under the guidance of the SCI individual to suit their requirements and situation (Somers, 2010; Ward *et al.*, 2009; Wade and de Jong, 2000; Hammell, 1995). One example of how this is done is through the use of a system of goal planning.

Goal planning is widely utilised in rehabilitation services as a method of guiding the rehabilitation process, as well as for setting achievable and measurable targets for rehabilitation involving both the individual and their treating team (Wade, 1998). It is suggested to promote both successful completion of rehabilitation (Duff, Evans and Kennedy, 2004; Kennedy, Walker and White, 1991), and SCI individual satisfaction with rehabilitation (Byrnes *et al.*, 2012). It is formally noted as a requirement in the SCI rehabilitation programmes in the UK (National Spinal Cord Injury Strategy Board, 2011; South of England Spinal Cord Injury Board, 2010) and echoes the requirements of the UK NSF for Long Term Conditions (Great Britain. Department of Health Long Term Conditions NSF Team., 2005). However, although goal setting was proposed by Locke to be a process which individuals naturally engage in within their lives (Locke *et al.*, 1981), in the author's experience, goal planning in rehabilitation can be a process which many newly injured (and newly admitted to an unfamiliar, hospital, environment) SCI individuals find a significant challenge to participate in, even with the guidance of rehabilitation professionals.

Although the client-centred model of SCI rehabilitation is promoted both internationally (Papadimitriou and Carpenter, 2013) and in the UK (South of England Spinal Cord Injury Board, 2010) this approach may not actually transfer in to practice, either due to the SCI individual feeling disenfranchised or due to a lack of training, experience or time on the part of the rehabilitation professional (Papadimitriou and Carpenter, 2013; Hammell, 2006). Further deviation from the client-centred model may occur due to the current emphasis in both research and rehabilitation practice on objective measurement of

rehabilitation outcomes and comparisons (Ward *et al.*, 2009). However, in the UK at least, client satisfaction focussed outcome measures are increasingly becoming a requirement for healthcare providers (NHS England, 2013b).

During rehabilitation the SCI individual is going through a significant period of physical and psychological adjustment (Kennedy *et al.*, 2000). In this time a range of emotions and behaviours may occur, including engagement, or conversely denial and/or avoidance (Byrnes *et al.*, 2012; Dorsett, 2010; Pollard and Kennedy, 2007; Kennedy *et al.*, 2000). These latter behaviours will be discussed in more detail in Chapter 3, but are likely to present challenges for the treating team. Additionally, the willingness of the individual to engage in rehabilitation, or rather the rehabilitation that is available to them due to their physical abilities may be variable (Dorsett, 2010). Although clinical texts recommend that the SCI individual is engaged in a rehabilitation programme which reflects their requirements as well as their *wishes* (Byrnes *et al.*, 2012; Somers, 2010) there is often only passing consideration given to whether the aims of the SCI individual are the same as the aims of the rehabilitation professionals (Papadimitriou and Carpenter, 2013; Playford *et al.*, 2009; Hammell, 2006). A failure to engage the SCI individual in their rehabilitation planning may lead to them disengaging from their rehabilitation or potentially being in conflict with SCIC team members (Somers, 2010; Wing, 2008; Grundy and Swain, 2002).

In summary, the treatment of rehabilitation is defined as a specialised service in which there is a concentration of *experience and expertise* in the field of SCI management and functional rehabilitation (National Specialised Commissioning Group, 2010). This is accompanied by an ethos of interdisciplinary (or at least multidisciplinary) working, functional restoration, education, and an aspiration for client-centred practice, empowerment and enablement (Papadimitriou and Carpenter, 2013). This is primarily what appears to differentiate SCIC rehabilitation from other non-specialist rehabilitation programmes, rather than the detail of how the rehabilitation is provided.

### **1.11 Summary**

There is currently no confirmed curative treatment for SCI. If significant neurological recovery does not commence in the initial period, it is unlikely to occur in the longer term. SCI occurs as a result of traumatic (TSCI) and non-traumatic (NTSCI) causes. Researchers and service providers largely focus upon those with TSCI however the NTSCI population is significant and may be as large as the TSCI population. Both the NTSCI and TSCI groups are heterogeneous and this should be considered in treatment

as outcomes may not vary if varying requirements are attended to. In addition to the loss of motor and sensory function SCI can also result in sequelae which may be difficult to manage successfully and can result in further impairment.

The incidence of SCI internationally is suggested to be increasing, however there are gaps in the information available regarding the incidence of SCI internationally but particularly in the UK. Figures available for the incidence of SCI will generally be incomplete estimates due to the omission of data for those with NTSCI or who are not admitted to SCIC, as well as issues with data validation. The lack of clear information regarding the incidence of SCI in the UK has significant implications for health, rehabilitation and community service planning. Utilising information from reviews of international literature and UK population estimates it has been possible to estimate that there may be 935 new SCI's sustained annually in the UK with the possibility that this figure could increase by 40% to over 100% with the inclusion of figures for NTSCI.

The potential for morbidity in the early stages following SCI remains high due to the complex and specialist requirements of the newly injured individual. Issues may arise if the recommended clinical management following SCI is not implemented. SCI management is a specialist service which incorporates expertise from a range of team members. Optimal outcomes are suggested to occur if SCI individuals received specialist SCI rehabilitation in an SCIC. The structure of SCIC rehabilitation services vary throughout the UK; what is common to all is the experience, specialist knowledge and philosophy of IDT/MDT working in which the SCI individual is an active part of the team.

Due to these variations in SCIC service provision it is not possible to give a clear definition of when transfer to an SCIC should occur, although research and guidance consistently stresses the need for this to be at the earliest opportunity although there is no clear definition of what constitutes an 'early' transfer. An ideal clinical pathway of early admission to an SCIC for the SCI individual has been identified as this can result lower incidence of complications, shorter overall lengths of stay and better rehabilitation and functional outcomes. Despite this delayed admissions to SCIC services occur regularly due to a variety of issues including delayed contact with and referral to SCIC services or lack of available beds, however there is little UK based evidence regarding the frequency of delays to admission.

International literature reviews have identified that the demographics of the SCI population in developed countries are changing with an increase in the proportion of tetraplegics and females as well as a trend for increasing age at the time of injury. This has implications for initial and ongoing management as well as SCI services as the newly injured SCI population is older and has higher level injuries than those the SCIC services were originally developed to cater for. These issues have significant implications for service provision and structure due to the differing requirements of individuals with high level SCI or of a greater age, as well as the increased potential for co-morbidities in an older cohort.

Life expectancy post acute treatment, although still below that of the general population and likely to vary with a range of demographics, has improved, resulting in SCI individuals living for a significant period of time. SCI is recognised to be a low incidence but high cost condition. SCI individuals will have significant healthcare and support requirements that will need to be met for a substantial period of time. These requirements will vary dependent on the SCI, the age of the SCI individual and in the presence of co-morbidities which will impact on the cost of services. These potential service requirements and costs can also increase significantly if the individual is inappropriately managed prior to their admission to an SCIC. The incidence of complications as a result of inappropriate management has been linked to delays in admission to SCIC as well as delays in liaison with specialist SCIC professionals; however consistent evidence confirming this is lacking in the UK.

This chapter has described the presentation, impact and potential causes of SCI. SCI and the accompanying sequelae can have a variety of physiological and psychological impacts on the SCI individual. The incidence of SCI in the UK is unclear but international evidence suggests that both incidence and life expectancy are increasing. Research suggests optimal outcomes occur if the SCI individual received specialist SCI rehabilitation but that some outcomes may be impacted upon by issues occurring early in the pathway such as delayed admission. There is little evidence in the UK regarding the pathway and outcomes of SCI individuals in view of the potential increase in the SCI population and demographics which may impact upon both pathway and outcomes this is of concern. In the following chapter popular models of disability and the outcomes following completion of rehabilitation will be discussed.

## **CHAPTER 2: SCI Rehabilitation and Reintegration**

### **Outcomes**

#### **Overview**

In this chapter the impact of SCI on the individual will be discussed in the context of popular models of health and disability. The remainder of the chapter will focus on the outcomes that the SCI individual may achieve at the end of their rehabilitation and on reintegration to the community. In addition, potential process and health care outcome measures will be identified and their potential impact upon the SCI individual discussed.

*“Never give up*

*No matter what is going on around you*

*Never give up”*

— Dalai Lama XIV

## **2.1 Introduction**

In the preceding chapter it was discussed that SCI is a lifelong condition with associated high costs not only in terms of initial management but also the care and equipment requirements in the longer term (National Specialised Commissioning Group, 2010). There are an estimated 935 new TSCI sustained every year in the United Kingdom (UK) with the potential that an equal number of NTSCI occur. Delays in appropriate initial and ongoing management can result in issues or complications which can be life threatening if not managed appropriately or have long term impacts. Suggestions have been made regarding the optimal pathway for the SCI individuals but little evidence is available in the UK regarding the short term and long term implications of deviations from this pathway. However, it has been identified that optimal outcomes are associated with the provision of specialist SCI rehabilitation. One aim of the SCI rehabilitation programme is, to assist the individual to be able to close the gap between the physical impact of the SCI and their goals and aspirations, where necessary with some (varying) level of physical and environmental support. Changing demographics in the newly injured population have been noted which, along with increasing life expectancy, are likely to result in changing demands on SCIC and community services over the coming years.

This thesis will aim to identify the outcomes that can be attained by SCI individuals on completion of this rehabilitation and reintegration in to the community as well as factors which may facilitate or limit these outcomes. Whilst the previous chapter focussed on the injury, treatment and rehabilitation pathway, the focus of this chapter will be on these potential outcomes. Some outcomes will also be identified which are primarily process and healthcare system outcome measures but may also impact upon the ability of the SCI individual to progress through the rehabilitation and reintegration processes. In Chapter 3, factors which may impact upon the ability of the SCI individual to achieve the proposed outcomes will be identified and discussed. This will permit development of the framework for the evaluation of outcomes for the SCI individual which is the purpose of this study.

## **2.2 Theoretical Background and Models of Disability**

Prior to discussions regarding potential outcomes it may be beneficial to view SCI and SCI rehabilitation in the context of the various models of health and disability. Although the strengths and weaknesses of these popular models will not be evaluated in depth the inpatient and community services for SCI individuals which will be examined in this thesis have evolved during the time that they been utilised. Therefore, it is beneficial to

understand a general outline of them and their potential impact upon how SCI people are viewed and engaged in the services established to meet their needs.

### **2.2.1 Models of Disability**

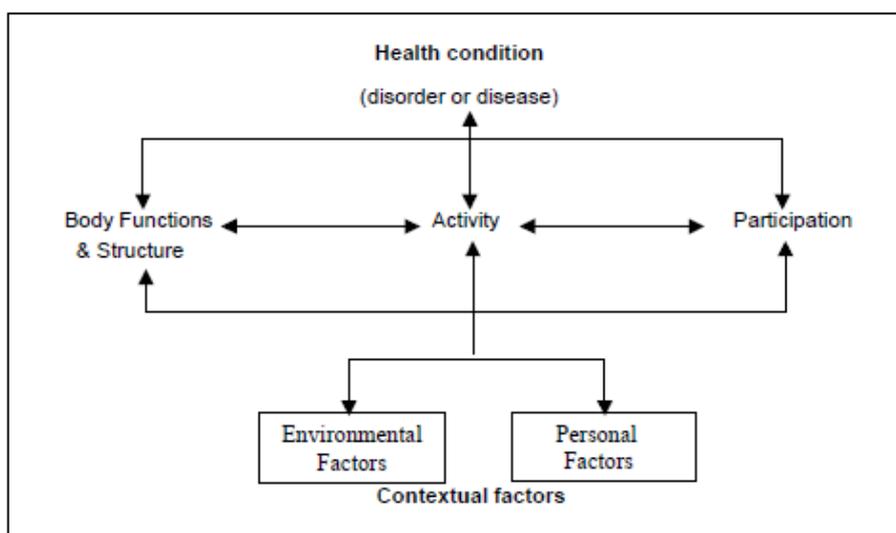
Disability can be distinguished from illness as a permanent state that cannot be cured. A variety of theoretical models have evolved and been applied to the perception disability and disabled people and this section will discuss those most widely acknowledged. Although theorists and researchers with disabilities have also proposed models of disability in addition to disability researchers they are, in the main, not acknowledged in the research journals and professional manuals widely utilised in disability and SCI rehabilitation practice and research (Hammell, 2006, Ch.10). Although these models may have merit they present conceptual frameworks which are different to the ones utilised in the services, research and guidance evaluated in this thesis and therefore will not be considered further in this thesis.

The two most widely known models of disability are the medical (Hammell, 2006) and social models (Oliver, 1990) of disability. These models represent bipolar perspectives in which either disability is viewed as a range of symptoms and impairments, deviations from 'normality', which are to be treated or adjusted, or disability is viewed in relation to the impact that the environment and society has upon the individual, in essence it suggests that society creates the disability. Neither of these models is comprehensive enough to include the components necessary to reflect how the SCI individual functions in society. The concept of normality and an optimal physical and mental state, promoted in the medical model is a simplistic perspective which does not reflect the reality that human beings are a heterogeneous group with greatly varying levels of health, physical abilities and intellectual capabilities. In other words there is no real 'normal'. It also ignores the impact of society and the environment upon the individual. Equally, the social model does not acknowledge the impact which individual differences may have influences the difficulties experienced by the disabled person in integrating in to society.

The Biopsychosocial model (Engel, 1977) is suggested to represent a more holistic view of disability and views disability as a result of the interaction between the individual, their illness, disability or condition and society. This model also highlights how two individuals with the same level of disability may perform differently in the same situation through the introduction of a personal (psychological) element which may impact upon the level of disability experienced by the individual as much as societal or physical barriers. This model was central to the development of further notable models of health and disability

including the International Classification of Impairments, Disease and Handicaps (ICIDH) (World Health Organisation, 1993), which later evolved into the International Classification of Functioning model of disability (World Health Organisation, 2001).

The ICIDH (World Health Organisation, 1993) and the subsequent ICF model (World Health Organisation, 2001) were proposed by the World Health Organisation as a means to conceptualise the impact that illness or injury, in this case SCI, can have on the life of an individual. The ICIDH used the classifications of impairment, disability and handicap as a means of conceptualising of the impact of disability (Figure 2.1). The ICF revised and expanded upon this, proposing a model in which disability and function are viewed as products of a dynamic, multi-dimensional interaction between the individual's health/body function, their activities/participation (including any restrictions on these) and the society in which they attempt to perform these activities (World Health Organisation, 2002, p.10). See Figure 2.1 for further details and a diagrammatic representation of this model. Ill-health and disability are viewed as issues that can happen to many people and, unlike the previously used medical and social models of disability, the ICF takes account of the impact of environmental factors on the ability of an individual with a disability to participate.



**Figure 2.1: ICF Model of Disability and Function and interactions between components.** World Health Organisation (2002) *Towards a Common Language for Functioning, Disability and Health*. ICF Training Beginners Guide. World Health Organization, Geneva

Participation, or lack of, is viewed as an important element of disability. Additionally, two forms of contextual factors, personal and environmental factors (Figure 2.1), are identified which may influence how the individual perceives their disability and is able to participate. Personal factors in addition to psychological factors include gender, sex,

age, and educational level. As with the Biopsychosocial model, personal factors are also noted to potentially influence how two individuals with the same disability, level of function, and the same environment may respond very differently in similar situations. Environmental factors may be either facilitators or barriers, as they can hinder or assist the individual to participate in society and are factors over which the individual has no control and are suggested to refer to provision and disadvantage as much as physical environmental barriers (World Health Organisation, 2013). Some of these contextual factors may be easily modifiable, for example provision of ramping to enable access or training to facilitate the development of personal skills, whilst others such as extreme weather or old age are not.

Using the ICF model the impact of the SCI on the individual can be seen as not just a collection of functional impairments but a collection of interrelating physical, psychological, social and environmental factors that are unique to the individual and may impact upon or facilitate the SCI individual's ability to participate and be active in society. Although the ICF is popular with rehabilitation professionals and researchers critics argue that it is a system for classifications of disease and impairments, not a model for assessing requirements and as such it merely focuses on identifying and categorising variations from normality (Hammell, 2006).

In summary, it appears that there is no ideal model of disability conceptually. As discussed earlier, the medical model views disability as a deviation from normality and it could be suggested that the rehabilitation process (in which the aim is to increase the functional abilities of the individual and return them to a state of 'normality') embodies this view (Somers, 2010; Ward *et al.*, 2009; Hammell, 2006; Wade and de Jong, 2000). However, use of the ICF model as a framework for rehabilitation and this research may permit the exploration of compensatory and adaptive processes that facilitate participation. As the ICF model is often utilised in SCI and rehabilitation research (Post *et al.*, 2010; World Health Organisation, 2002) this is the model of disability that will be utilised in this thesis where one is required.

### **2.3 Outcomes Following SCIC Rehabilitation**

It is suggested that successful rehabilitation benefits the individual through functional gains and the reduction of unnecessary complications but also benefits the state through better more cost-effective use of resources and enabling the individual to reintegrate in to society (Ward *et al.*, 2009). There are healthcare systems based outcomes, as well as activity based outcomes which rehabilitation professionals and researchers commonly

refer to and view to be important (Wolfe, Hsieh and Mehta, 2012; Hammell, 2006, Ch.8.). The healthcare systems based outcomes identified on completion of rehabilitation which will be examined in this thesis are Lengths of Stay and Discharge Delays. These outcomes may impact upon the ICF based components of health, activity and participation through delays in the process or be impacted upon by the health of the SCI individual. A further outcome on completion of rehabilitation is Functional Improvement; this outcome relates to the ICF components of activity and potentially participation, as well as the component of body function (World Health Organisation, 2002).

### **2.3.1 Functional Improvement**

Following completion of SCI rehabilitation certain functional outcomes are expected (Table 2.1.). These outcomes reflect the potential functional achievements that an individual with a complete (ASIA Impairment Scale (AIS) A) spinal cord injury and no significant co-morbidities could attain. These expected outcomes are based on a combination of the author's professional experience and the Target Rehabilitation Outcomes established in the 'Standards for Patients Requiring Spinal Cord Injury Care Service Standards' (South of England Spinal Cord Injury Board, 2010). Similar estimates of potential functional improvement are available in a variety of resources (Somers, 2010; Grundy and Swain, 2002).

The level of functional impairment that remains on completion of rehabilitation can be viewed on a continuum of low to high level of disability (Table 2.1). Further variations in functional impairment from these stated abilities may occur due to a combination of AIS grade and a range of personal factors including co-morbidities (World Health Organisation, 2001). The level of functional impairment that is experienced by the SCI individual is classified in SCIC rehabilitation using two well established measures of functional ability/impairment. These measures are the Functional Independence Measure (FIM) (Keith *et al.*, 1987) and the Spinal Cord Independence Measure (SCIM) (Catz *et al.*, 1997).

<b>Key:</b> V = Mechanical Ventilation required, A = Full Assistance Required, E = Independent with equipment (e.g. Splints, Sliding Board), S = Independent with set up by another, I = Independent								
<b>Functional Activity</b>	<b>Level of Complete Spinal Cord Injury</b>							
	C1-C3	C4	C5	C6	C7-C8	T1-12	L1	L2-L5
Breathing (awake)	V	I	I	I	I	I	I	I
Breathing (sleeping)	V	V/I	I	I	I	I	I	I
Eating and Drinking	A	A	E	E/S	I	I	I	I
Grooming	A	A	E	E/S	I	I	I	I
Upper Body Washing	A	A	S	S	I	I	I	I
Upper Body Dressing	A	A	A	S	I	I	I	I
Lower Body Washing	A	A	A	A	I	I	I	I
Lower Body Dressing	A	A	A	A	I	I	I	I
Light Domestic Activities	A	A	A	A	I	I	I	I
General Domestic Tasks	A	A	A	A	A	A/I	I	I
Transfers	Hoist	Hoist	Hoist	Hoist/E	I/E	I	I	I
Mobility	Chin /Mouth Control Powered Wheel Chair	Powered Wheel Chair	Powered /Manual Wheel Chair	Light weight Manual Wheel Chair	Light weight Manual Wheel Chair	Manual Wheel Chair	Walk with aids/ Manual Wheel Chair	Walk with/without aids

Table 2.1 Levels of Functional Independence or Assistance Required According to Level of Complete SCI

FIM contains two subscales, motor and socio-cognitive, totalling 18 items with scores from one (total dependence) to seven (total independence) on each subscale. However, issues have been noted with the ability of FIM to detect some of the functional and self-management changes that occur to SCI individuals on completion of rehabilitation (Eng *et al.*, 2010a; Alexander *et al.*, 2009). This prompted the development of the SCI specific measure, SCIM, which has since been extensively validated (Bluvshstein *et al.*, 2011; Alexander *et al.*, 2009; Fromovich-Amit *et al.*, 2009; Catz *et al.*, 1997).

SCIM reflects the functional and self-care activities affected by SCI and is extensively used as an outcome measure in SCI rehabilitation. It consists of 3 subscales (self care, respiration and sphincter management, mobility) totalling 19 items on which individuals are graded at varying levels of dependence or independence, although it has been noted that SCIM is not sensitive to some of the differences in upper limb function present in those with tetraplegia (Eng *et al.*, 2010a; Alexander *et al.*, 2009). As with FIM, individuals can only score the maximum if they are independent without aids or equipment. Due to the relatively recent development of the SCIM scale, FIM is still reported as an outcome measure in many longitudinal studies and historical surveys (Eng *et al.*, 2010a; Alexander *et al.*, 2009), therefore it is necessary to be aware of both measures.

Table 2.1 also identifies areas in which assistance and equipment may be required for each SCI level. Higher functional outcomes may result in greater levels of independence and lower levels of support of equipment being required. Therefore, ensuring that SCI individual attains their maximum potential level of functional independence on completion of rehabilitation is viewed as a desirable outcome of rehabilitation (Wolfe, Hsieh and Mehta, 2012; Hammell, 2006, Ch 8). However, there are factors which are outside of the remit or control of the rehabilitation programme which may influence the outcomes of the rehabilitation programme (Wolfe, Hsieh and Mehta, 2012). Some of these factors are internal to the individual and some are specifically related to the SCI. Internationally research has consistently identified that neither gender or ethnicity impact upon functional rehabilitation outcomes, including discharge AIS grading and FIM scores (Wolfe, Hsieh and Mehta, 2012; McKinley *et al.*, 2001). Although it has been suggested that those of a greater age may still be able to achieve these goals if they are given a longer period of rehabilitation (Cifu *et al.*, 1999) the presence of co-morbidities have been demonstrated to limit the ability of the SCI individual to achieve or sustain their optimal level of functional ability (DeVivo, 2012; Aito *et al.*, 2007; Cifu *et al.*, 1999).

Higher FIM scores on admission have been noted in those with non-traumatic SCI (NTSCI) (Cosar *et al.*, 2010; McKinley *et al.*, 2001), however variable results have been found in FIM scores at discharge (Pouw *et al.*, 2011; Cosar *et al.*, 2010; Ones *et al.*, 2007; McKinley *et al.*, 2001). This highlights that the specific cause of NTSCI may have an effect on rehabilitation outcomes, resulting in greater or lesser goal achievement for some forms of NTSCI (Wolfe, Hsieh and Mehta, 2012; McKinley, 2008). However, it is necessary to acknowledge the role that age may play in this relationship as some forms of NTSCI will be more likely to occur in those of greater age (Wolfe, Hsieh and Mehta, 2012; Cosar *et al.*, 2010; McKinley, 2008). This indicates the need to recognise the heterogeneity of this group when evaluating outcomes.

### **2.3.2 Length of Rehabilitation Stay**

Establishing optimal rehabilitation lengths of stay (LOS) for SCI individuals enables rehabilitation teams to plan the rehabilitation programme effectively and ensure effective use of SCIC resources. This SCIC service planning is also important for ensuring that services have sufficient capacity to meet the needs of newly injured SCI individuals and are structured in a way to meet those needs (BASCIS British Association of Spinal Cord Injury Specialists, 2014; Wolfe, Hsieh and Mehta, 2012; South of England Spinal Cord Injury Board, 2010; Cardenas *et al.*, 2001; Eastwood *et al.*, 1999; Smith and Spinal Injuries Association., 1999). As SCIC services in the UK are specialist they will not have an unlimited number of beds in to which a patient can be admitted. They will be housed in specific facilities with finite resources. Lack of available SCIC beds has been noted to be a barrier to the admission of newly injured individuals in the UK (Barr and Spinal Injuries Association, 2009). Ensuring that SCI individuals have an optimal LOS not only ensures that the individual is able to reap the maximum benefit from their period of rehabilitation but also ensures that SCIC resources are utilised effectively, an issue that may become particularly important with an increasing incidence of SCI (van den Berg *et al.*, 2010; Wyndaele and Wyndaele, 2006; Ackery, Tator and Krassioukov, 2004).

Although two reviews of international research suggests that shorter rehabilitation LOS occurred if SCI individuals were transferred to an acute SCIC more quickly (Wolfe, Hsieh and Mehta, 2012; Parent *et al.*, 2011), this conclusion hides a variety of complex issues as comparisons of rehabilitation LOS across SCICs present as many difficulties as comparisons of the SCI rehabilitation programmes. Precise descriptions of the commencement of rehabilitation are rarely given in research studies and where they are given there are either significant variations in when rehabilitation is considered to commence or no identification of when rehabilitation commenced (Wolfe, Hsieh and Mehta, 2012). Frequently rehabilitation LOS is simply defined as the point of admission

to the rehabilitation facility (Wolfe, Hsieh and Mehta, 2012). Although this may be an easy distinction to apply it may hide differences between the admitted SCI individuals' physical state, ability to mobilise and length of time since injury. Those who are transferred to an SCIC for rehabilitation soon after their injury may not, physically, be as 'rehabilitation ready' as those who are transferred later; equally those who are admitted later may have sustained complications that delay the commencement of rehabilitation (Wolfe, Hsieh and Mehta, 2012). Additionally, SCIC with internal Acute facilities may have a less defined point at which an SCI individual is no longer counted as requiring acute care and has commenced rehabilitation (Wolfe, Hsieh and Mehta, 2012; Parent *et al.*, 2011), resulting in a blurred distinction between these phases of treatment.

Although some researchers do identify when the individual's rehabilitation commenced there are still variations as some researchers consider rehabilitation as having commenced at the point of first mobilisation whilst others will consider it to be when the individual is able to sit out for four hours (New *et al.*, 2013b; Wolfe, Hsieh and Mehta, 2012; National Spinal Cord Injury Strategy Board, 2011). Both of these definitions will exclude those who are on bed rest, and one will exclude those who are unable to sit out for significant periods due to health issues, pain or poor skin tolerance but still able to attend therapy sessions and so participate in a rehabilitation programme. The inclusion of periods of bed-rest, readmissions to acute care or discharge delays within the rehabilitation LOS figures can also artificially inflate LOS figures and create difficulties comparing rehabilitation LOS both within and between samples (Wolfe, Hsieh and Mehta, 2012). Significantly longer LOS have been noted in SCI individuals who were admitted with avoidable complications in the UK (Barr and Spinal Injuries Association, 2009) highlighting the importance of appropriate management of SCI individuals prior to admission to an SCIC and the potential impact of avoidable complications. These issues highlight the need to distinguish between overall LOS and the actual length of rehabilitation.

Although an international review of literature suggests LOS is not affected by either ethnicity or gender (Wolfe, Hsieh and Mehta, 2012), evidence suggests that rehabilitation LOS varies according to the level and completeness of injury. In this a (proportional) rank order LOS applies of complete tetraplegic (longest LOS), complete paraplegic, incomplete tetraplegic and finally incomplete paraplegic (Wolfe, Hsieh and Mehta, 2012). These variations between these injury groups must be acknowledged in comparisons of 'overall' mean LOS for subjects as variations in injury group representations in samples may result in variations in overall mean LOS. Additionally, these variations in LOS between injury groups may be particularly important as the

changing demographics of the newly injured SCI population with increases in the number of higher level lesions and incomplete lesions (Wolfe, Hsieh and Mehta, 2012; Cripps *et al.*, 2011; van den Berg *et al.*, 2010; Wyndaele and Wyndaele, 2006; Ackery, Tator and Krassioukov, 2004) will impact on LOS overall. This may then impact on the number of SCI individuals who can be rehabilitated in the number of rehabilitation beds available.

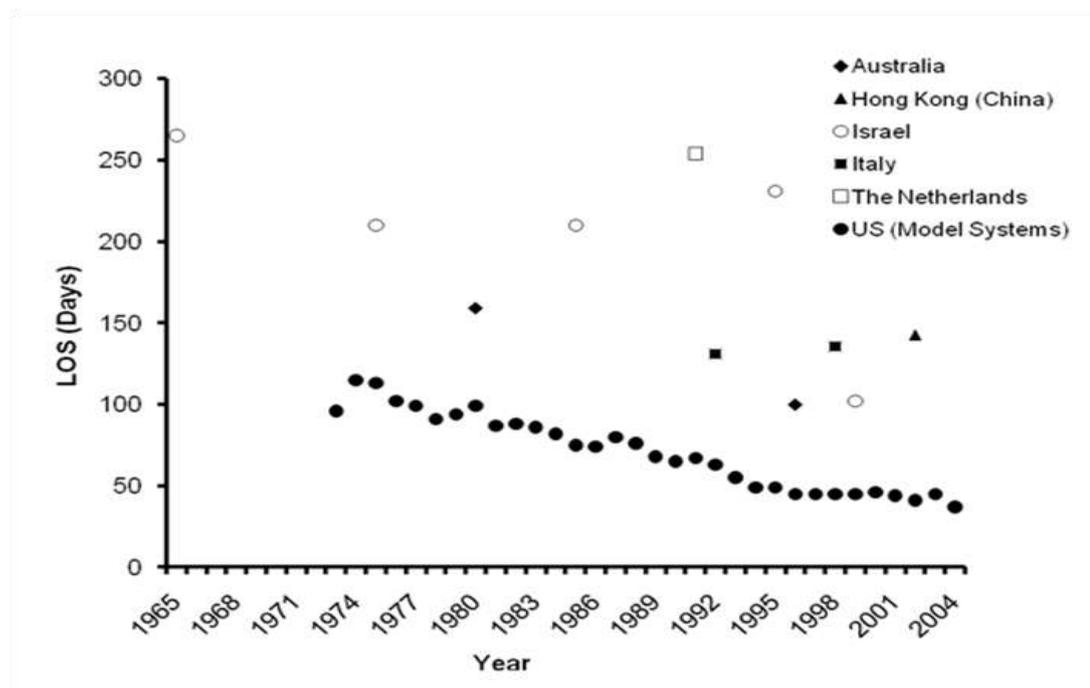


Figure 2.1 Mean Rehabilitation Length of Stay Reported From Different Countries Wolfe, D.L., Hsieh, J. and Mehta, S. (2012) 'Rehabilitation Practices and Associated Outcomes Following Spinal Cord Injury.', in Eng, J., Teasell, R., Miller, W., Wolfe, D., Townson, A., Hsieh, J., Connolly, S., Mehta, S., Sakakibara, B. and Boily, K. (eds.) Spinal Cord Injury Rehabilitation Evidence. Available on-line at <http://www.scireproject.com/rehabilitation-evidence>. Accessed: 11/12/2012. 4th edn. Vancouver: SCIRE Project / Monkey Hill Health Communications

As illustrated in Figure 2.1, a trend has been noted over the past two to three decades for reducing LOS in many countries (Wolfe, Hsieh and Mehta, 2012; Ragnarsson, 1998), particularly in the USA (DeVivo, 2012; DeVivo, 2007). Although it is suggested that functional outcomes at discharge have not changed increased rates of avoidable readmissions and pressure sores post discharge have been reported in the USA (Eastwood *et al.*, 1999; Ragnarsson, 1998). This may suggest that reductions in LOS may impact upon rehabilitation training on self-management techniques. A shorter LOS may also impact upon the ability for suitable accommodation to be identified and made available, potentially leading to the individual being discharged to unsuitable accommodation or a nursing home (Wolfe, Hsieh and Mehta, 2012; DeVivo, 2012; Eastwood *et al.*, 1999). These issues will be discussed further in section 2.3.3.

International review of case notes on discharge have identified individuals with NTSCI have both shorter LOS (Osterthun, Post and van Asbeck, 2009; McKinley *et al.*, 2001) and comparable LOS to those with TSCI (Ones *et al.*, 2007). The former finding may reflect the potential for those with TSCI to have sustained additional injuries at the time of injury which will require further treatment. The finding that LOS was comparable between the two groups (Ones *et al.*, 2007) may be a reflection of the interpretation of results as although the NTSCI group did have a shorter mean LOS the difference was not statistically significant. Variations in group proportions and time to admission may have also accounted for differences in these findings.

Although LOS have been discussed extensively in research there is little consistency or clarity in definitions of when rehabilitation commences and ends. This presents difficulties in comparisons both across facilities and countries. However, LOS has been shown to vary proportionally with the presence of complications, varying levels, AIS grades and mode of injury. Identification of an optimal rehabilitation LOS for an SCI individual is essential to ensure that optimal rehabilitation outcomes can be achieved as well as for effective SCIC service and resource planning. LOS variations may impact not only on healthcare systems and process but could also impact on the ability of individuals to achieve the optimal rehabilitative and reintegration outcomes. With potentially increasing incidence and changing demographics of the newly injured SCI population the lack of knowledge of the requirements and limitations of SCIC resources in the UK may become an increasingly important issue.

### **2.3.3 Discharge Delays**

A further factor which may influence both systems and individual outcomes is whether an SCI individual is actually able to be discharged at the anticipated time. Although ideally discharge to the community will occur at the point of completion of rehabilitation 16% of discharges from SCIC were reported to be delayed in the UK between 2007 and 2008 (Barr and Spinal Injuries Association, 2009) and similar issues have been reported internationally (Wolfe, Hsieh and Mehta, 2012).

The UK Department of Health formally defines a delayed discharge as: 'A delayed transfer of care from acute or non-acute..... care occurs when a patient is ready to depart from such care and is still occupying a bed. A patient is ready for transfer when:

- A clinical decision has been made that a patient is ready for transfer AND
- A multi-disciplinary team decision has been made that a patient is ready for transfer AND

- The patient is safe to discharge/transfer.’ (Great Britain. Department of Health, 2011, p.6.)

Essential objectives for safe discharge have been identified by the South of England Spinal Cord Injury Board (South of England Spinal Cord Injury Board, 2010) but some of these factors such as the provision of accessible accommodation or assistance are outside either the immediate or long term control of the either SCIC team or the SCI individual and can lead to a delay in discharge.

Issues with securing accommodation have been reported to be a significant cause of delays to discharge in the UK historically (Oliver *et al.*, 1988) and are still one of the most significant issues reported more recently (Barr and Spinal Injuries Association, 2009). Similar issues have been reported in other countries (Anzai *et al.*, 2006; Post *et al.*, 1997; Forrest and Gombas, 1995). Delays in establishing responsibility for funding of care or nursing home placements by the NHS or SSD have been noted to be the other most frequent cause of discharge delays for SCI individuals (Barr and Spinal Injuries Association, 2009). Although UK government guidance states that this should not occur (Great Britain. Department of Health, 2007), press and official circulars report that delays due to funding issues are reaching crisis point (Lungu-Mulenga *et al.*, 2013; Samuel, 2009; London Councils, 2007; Brangwyn, 2007). UK SCIC are permitted to levy a delayed discharge charge to the SCI individual's Social Services Department (SSD) or Clinical Commissioning Group (CCG) as a means of encouraging them to assist in facilitating discharge (Great Britain. Department of Health, 2011). However, this charge can be at a level lower than the costs that will be incurred once the individual is discharged therefore the impetus to assist in facilitating discharge may be lost.

During any delay to discharge the SCI individual will remain in a specialist SCI rehabilitation bed that they no longer require, effectively blocking that bed to the admission of another SCI individual. Although it has been suggested that there is an ‘optimal’ time for patients to be discharged following completion of their rehabilitation if they are to fully utilise the skills that they have acquired during their rehabilitation and avoid sustaining other issues associated with prolonged hospital stays (New *et al.*, 2013a), there is no UK-based evidence to confirm this. However, it is likely that remaining in an SCIC that is potentially several miles from the SCI individual's community will impact on their ability to reintegrate and participate in their community (World Health Organisation, 2002).

In addition to the impact that a discharge delay may have on the SCI individual awaiting discharge, there is likely to be an impact to the SCI individual who remains in an Acute Care facility waiting to be transferred to an SCIC. This may put them at risk of developing avoidable complications and then requiring a prolonged LOS in the SCIC (Gardner, 2010; Barr and Spinal Injuries Association, 2009). There will also be a further impact on the individual who is waiting to be admitted to the Acute Care bed for treatment/surgery but may have their admission cancelled. Therefore the delay to discharge does not impact on one individual but, potentially, several individuals, as well as several clinical facilities. Despite this, there is little evidence regarding the impact that delayed discharges may have on the ability to admit new patients to the SCIC either in the UK or internationally.

In summary, delays to discharge from SCIC can be viewed as both a healthcare systems outcome measure and a factor which may influence reintegration outcomes for the individual. These delays may occur due to a variety of issues but accommodation and funding issues have been noted to be the most frequent causes of delays. The impact of these delays is not only experienced by the SCI individual awaiting discharge but also on those awaiting admission to the SCIC. Additionally, the impact of this blockage in throughput of patients will be experienced in several clinical facilities not just the SCIC. Despite the potential impact on the SCI individual and healthcare systems there is little research in to this issue.

#### **2.4 Outcome Measures Following Discharge to the Community**

In clinical texts the rehabilitation of an SCI individual has been viewed as a lifelong process (Somers, 2010; Kirshblum *et al.*, 2007; Hammell, 2006; Trieschmann, 1988) in which the time spent in the SCIC is only a small, albeit important, part at the beginning (Smith and Spinal Injuries Association., 1999). On completion of rehabilitation it is anticipated that the SCI individual will be able to begin the process of reintegrating in to society and participating in their community (Somers, 2010; McKinley and Meade, 2004; Grundy and Swain, 2002).

Once inpatient rehabilitation goals have been achieved and all necessary provisions are made the individual will be able to be discharged from the SCIC. The outcomes discussed so far have, other than functional achievement, been system and process focussed, reflecting the process to completion of rehabilitation and discharge; the remaining outcome measures to be discussed reflect outcomes which affect the individual in the community and comprise of community reintegration and participation, quality of life, residing in the community and vocational activity.

### 2.4.1 Community Reintegration and Participation

On discharge the individual will begin applying the skills that they have acquired during their rehabilitation in order to resume their role in their society and in their community; to reintegrate and participate in their community. In order to investigate if individuals successfully achieve this outcome a form of measurement needs to be applied. The International Classification of Functioning, Disability and Health defines participation as an 'involvement in a life situation.' (World Health Organisation, 2001, p.10.). This, all encompassing, definition of participation does not permit meaningful measurement of participation through identification of the constituent elements of participation following SCI (Eng *et al.*, 2010b; Noonan, Miller and Noreau, 2009). A review of a wide range of measures of participation identified many used differing approaches to measurement and vague or varying definitions of participation (Noonan, Miller and Noreau, 2009). These variations suggest that there is no clearly defined construct of participation and that individuals will vary not only in what they consider participation to be but also in how important elements of participation are. To counter this some researchers have utilised concrete measures of activity as a means of identifying participation as well as measures that include the individual's perception of participation (Ripat and Woodgate, 2012). As with many areas of SCI research discussed in this thesis there are few studies from the UK. A search of international studies also identified that of the few studies available many are over 10 years old, however, in absence of more recent relevant studies, they still have merit.

At the end of rehabilitation the SCI individual should have had the opportunity to acquire the skills to be able to overcome, as much as is possible, the obstacles which their SCI and the environment impose upon them (Wolfe, Hsieh and Mehta, 2012; McKinley and Meade, 2004; Forchheimer and Tate, 2004; World Health Organisation, 2001). It is suggested that, due to this, the SCI individual should be able to access community resources and activities, including vocational and recreational activities and active participation in their family and social network, re-establishing their role in their family and their community (Forchheimer and Tate, 2004). The ICF model of disability (World Health Organisation, 2001) highlights that functional ability/disability as well as environmental and personal factors may impact upon the ability of the SCI to participate in the community and society (Figure 1.2). Evidence confirming factors which may influence participation is scarce. Although survey results from over 3,000 SCI individuals in the USA identified that nursing home residents were less likely to participate in community activities on a regular basis than those residing in their own homes (Eastwood *et al.*, 1999). Although it could be argued that these findings are a reflection

of the high levels of support typically required by those discharged to a Nursing Home to go into the community rather than their place of residence another USA-based survey identified that environmental barriers and transportation were amongst the top five barriers to community participation (Whiteneck *et al.*, 2004) suggesting that residential situation may have an impact on level of participation, however help at home (a further environmental factor) was also identified as a significant and frequent barrier to participation. That these surveys identified similar results is not surprising as they both utilised the same measurement tool and the same data pool (the NSCISC database). Levels of participation have also been reported to be affected by issues with the sequelae of SCI particularly pressure sores (Regan *et al.*, 2012; Somers, 2010), pain (Jensen *et al.*, 2011; Raichle *et al.*, 2007), spasms (Adams and Hicks, 2005) and continence issues (Akkoç *et al.*, 2013; Schurch *et al.*, 2007). Combined these findings suggest that it is not just the physical environment which may limit community participation levels but also physical health and the availability of assistance to overcome barriers in the physical environment.

UK-based research identified that participation and higher levels of social and community activity are a significant predictor of higher ratings of quality of life (QOL) in SCI individuals (Kennedy *et al.*, 2010b). However, the Life Opportunities survey (Great Britain. Office for Disability Issues, 2011) identified that disabled adults in the UK struggle to participate in normal activities including work or enjoying leisure pursuits and report limited engagement with the modern world. This suggests that despite the recommendations of the World Health Organisation (World Health Organisation, 2002) and UK legislation (Great Britain. Government Equalities Office, 2010; Great Britain. Minister for Disabled People, 2005) individuals with disabilities in the UK are still experiencing difficulties in participating in society and the community and potential reductions in QOL as a consequence of this.

Although, the research reviewed potentially echoes the ICF model of disability (World Health Organisation, 2001) in suggesting that participation in the community may be influenced by both environmental factors as well as body functions, UK-based evidence is scarce. In part this may be due to difficulties in the measurement of participation. It may also be due to researchers focusing on specific, more easily definable, definitions of participation such as engaging in employment. It is also worth noting that the UK based study identified the over 12% of the variation in levels of participation were explained by the SCI individual's negative appraisals (Kennedy *et al.*, 2010b). Whatever the reason, the potential for the SCI individual to participate in society and their community is one that is considered of primary importance both in the ICF model of

disability (World Health Organisation, 2001) and in SCI rehabilitation (Wolfe, Hsieh and Mehta, 2012; Eng *et al.*, 2010b; Marmot, 2010; Hammell, 2006; Kennedy, Lude and Taylor, 2006) and therefore requires further attention.

#### **2.4.2 Readmissions**

Following completion of rehabilitation the individual is discharged to the community, however, for some readmission to an SCIC or other hospital may be required. A UK-based survey (Barr and Spinal Injuries Association, 2009) identified that 11% of admissions were emergency readmission but information was not available on time since discharge for these individuals. Another UK-based study estimated that each SCI individual will require 4.9 hospital bed days per year on an ongoing basis (Savic *et al.*, 2000) with increasing rate of readmission in those with SCI of a longer duration. Frequency and length of readmission to hospital for SCI individuals are important both from a health care systems approach (the need for readmission beds will need to be factored in to potential service models) but also for the SCI individual as additional time in hospital may impact upon reintegration, particularly if the admission is lengthy.

As with many areas of SCI research the scarcity of UK-based studies makes it necessary to consider research from other countries, potentially with varying health services. Additionally, in the UK an SCI individual may be readmitted to a general hospital due to lack of SCIC bed availability, resulting in an underestimate of any UK figures due to lack of central recording of this data. A systematic review of international literature by Wolfe *et al* (Wolfe, Hsieh and Mehta, 2012) identified that readmission to hospital rates tend to be higher during the first year following discharge than at any other period, with between 27.5% and 55% of SCI individuals being readmitted for a variety of planned or unplanned reasons. Many of the studies reviewed had variations in classification of readmissions, means of data analysis and lengths of time since discharge which may account for the notable variation identified in year one readmission rates.

In an attempt to simplify the issue Wolfe *et al* (Wolfe, Hsieh and Mehta, 2012) identified that there are potentially three different types of readmission: 1) planned, 2) unplanned and avoidable or 3) unplanned and unavoidable, but research often fails to distinguish between these three. Each of these forms of readmission can be interpreted in differing ways as outcome measures and will present different issues for the SCI individual as well as requiring varying lengths of stay and interventions. Unplanned and unavoidable admissions tend to be due to emergency clinical issues such as neurological deterioration due to a syring (Wolfe, Hsieh and Mehta, 2012) and both LOS and

treatment paths will vary, dependent on the reason for admission but they should not be viewed as a failure in the rehabilitation or reintegration process. Unplanned and avoidable readmissions are frequently due to chronic complications such as pressure sores which, in addition to potentially requiring long periods of costly inpatient treatment, will impact on the reintegration process of the individual (Young *et al.*, 2006). Dependent on the reason for readmission it could be viewed as a failure of the rehabilitation process if the SCI individual has not learnt to manage their condition effectively (Ragnarsson, 1998), or it may be due to a failure on the part of community services to support the individual to manage their condition effectively. Planned readmissions in the UK have been reported to be for further treatment or rehabilitation, for example following removal of a brace or orthosis (Barr and Spinal Injuries Association, 2009). These forms of admission will generally be for a defined period of time and result in a positive outcome for the SCI individual.

Just as there may be difficulties with comparisons of readmission figures when reasons for readmission are not defined there are also difficulties with comparisons of figures obtained in differing healthcare systems. For example, readmissions to hospital within one year of discharge, particularly due to pressure sores, are suggested to be related to shorter rehabilitation LOS in the US (Eastwood *et al.*, 1999; Ragnarsson, 1998). This may result in higher readmission rates than would be seen in the UK and emphasises that although it may be useful to compare information on potential causes and trends readmission figures should only be compared with data from the same country.

In summary, readmission rates may be higher in the first year post discharge than in subsequent years. If readmissions to hospital within the first year of discharge are to be considered to be an outcome measure of rehabilitation and reintegration then further research is required clearly identifying the reason for readmission as well as length of stay and number of admission. This research may be particularly important if trends for LOS in SCIC rehabilitation facilities to decrease are achieved at the price of an increase in readmission rates (Eastwood *et al.*, 1999; Ragnarsson, 1998).

### **2.4.3. Vocational Status**

If return to previous life roles and participation in society is a desired outcome for SCI individuals (World Health Organisation, 2002) and vocational activity (not just employment) is viewed as a measure of participation, then vocational activity could be viewed as a measure of the successful rehabilitation and community reintegration of the SCI individual (Eng *et al.*, 2010b). A UK publication estimates that reductions in employment are responsible for approximately 80% of disability costs (Ward *et al.*,

2009) therefore employment following SCI is at least an outcome measure for the state. Whether vocational status is viewed as a valid outcome measure by those with an SCI, or an example of rehabilitation professionals telling disabled people what constitutes successful reintegration and empowerment (Hammell, 2006, Ch. 8)), is a debate that will not be pursued in this thesis. The term vocational activity will be used in this thesis to describe the purposeful activity which the SCI individual engages in, including paid employment, voluntary work, education and care-giving roles. However, much of the available research investigates paid employment at the expense of considering other forms of vocational activity (Tasiemski *et al.*, 2000); therefore where a distinction is made in research toward paid employment this will be acknowledged.

The importance ascribed to ensuring that those with SCI have the opportunity to engage in employment in the UK is apparent in drives to support disabled people to gain employment (Great Britain. Department for Work and Pensions, 2012b). Despite this there is little UK based research in to levels of either employment or vocational activity post-SCI that is less than 10 years old; therefore research from other countries will need to be considered where appropriate. Additionally, as with many areas of SCI research, some of the articles available for discussion are from the last decade or older, in the absence of later research covering the same topic these studies will be reported and discussed. The Spinal Cord Injury Rehabilitation Evidence (SCIRE) project in Canada has thoroughly and systematically reviewed the international research in to the myriad options for outcome measurement and potential influencing factors for employment (Noreau *et al.*, 2010). This review will be referred to when other later or more relevant references are not available. Papers included within this review will not generally be discussed separately unless specific points referring to individual references are made.

As discussed in Chapter 1, the SCI population is a heterogeneous one; it includes people of a variety of ages, marital, socioeconomic and educational status, differing levels of disability and differing pre-SCI work history and status. At the time of injury some SCI individuals will have been preparing to enter the workforce, some will have already retired, whilst others may never have been employed either due to ill-health, long term unemployment or being engaged in care giving or voluntary activities prior to injury. A review of internationally published research by Noreau *et al.* for the SCIRE project identified that being in employment prior to SCI not only predicts employment post-SCI but also resulted in shorter transitions in to work (Noreau *et al.*, 2010). The findings from this review also highlight the need to consider pre-SCI employment history when investigating interventions which may improve vocational outcomes as results may be influenced by this. A cross-sectional survey of 495 Swiss SCI individuals identified

that being in employment at two years' post injury was associated with later employment (Marti *et al.*, 2012). Although caution should be exercised in drawing conclusions about causality from a cross-sectional study, this suggests that there may be an optimal time during which participation in employment needs to be promoted post-SCI.

Some SCI individuals may be able to return to their previous employment easily but with revised duties or at an alternative, accessible location, and Noreau *et al.* (Noreau *et al.*, 2010) identified that changes in working hours and role, as well as adjustments to the workplace facilitated SCI individuals returning to or securing employment. They also identified that unwillingness of employers to make physical or role adjustments were considerable barriers to the SCI individual returning to employment (Noreau *et al.*, 2010). Legislation in the UK, such as the Disability Discrimination Act 2005 (Great Britain. Minister for Disabled People, 2005) and the Equality Act 2010 (Great Britain. Government Equalities Office, 2010) places an obligation on many employers to make adjustments for disabled people in the workplace and so should prevent this occurring here; however, there is no evidence to confirm that this is the case.

The UK Department of Work and Pensions can offer a range of assistance to aid disabled people to return to, or gain employment including advice and assistance to access work support services and assessments through a Disability Employment Advisor (Great Britain. Department for Work and Pensions, 2012a). If the SCI individual already has a job, financial assistance may be available through the Access to Work Scheme (Great Britain. Department for Work and Pensions, 2012a) to meet the cost of equipment including a wheelchair or specialist computer equipment. Assistance may also be provided to overcome environmental barriers through assistance with transport costs, a support worker or some adaptations to the workplace. This may assist in countering the trend noted for issues with environmental access, both in the home and workplace to limit the ability to gain or retain employment (Noreau *et al.*, 2010).

If the SCI individual does not have a job then support is available in the UK to explore options for retraining or to make an application for employment (Great Britain. Department for Work and Pensions, 2012b). Despite the availability of this practical and financial assistance, a survey of 350 SCI individuals across four European countries identified that those in the UK had the lowest rate of either paid or unpaid employment activities at approximately 38% (Kennedy, Lude and Taylor, 2006). Additionally, 45% reported they were dissatisfied with their employment or occupation (that is vocational) situation and felt that this was one of the least addressed areas of their lives. However, issues with the sample need to be noted as a disproportionate 58% of the UK subjects

were tetraplegic and although subjects were up to 76 years old results for subjects above retirement age were not separated. Inclusion of those who are retired in simplistic groups of employed or unemployed may artificially deflate the figures for employment. Although another UK based study identified 32% employment following SCI, subjects up to 81 years old were included in the analyses (Kennedy *et al.*, 2010a). These rates of UK employment post-SCI are at the lower end of the 30% to 63.8% reported internationally (Marti *et al.*, 2012; Noreau *et al.*, 2010) and suggest that, at least in the UK, this vocational support is not yielding improved employment outcomes.

In other countries vocational rehabilitation or further training have been suggested to increase chances of paid employment post-SCI (Marti *et al.*, 2012; Noreau *et al.*, 2010), however conclusive evidence of the benefit of any specific intervention is lacking due to variations in methodologies and definitions between studies and a frequent lack of distinction between those who were or were not employed pre-SCI. Noreau *et al.* (Noreau *et al.*, 2010) did note that the ability to access transport and skills such as being able to drive independently or to work with computers, facilitated return to work or new employment. Additionally, they noted that in the research reviewed employment roles post-SCI tended to be sales, office based or professional roles, all roles in which the above skills would be useful, suggesting that there is a desired skill set that the SCI individual should either have or acquire to improve their chances of employment.

Low levels of employment may result in issues for UK based SCI individuals. A trend towards ill-health and mortality is recognised to be associated with poor socioeconomic status and unemployment in the UK general population (Rask, O'Malley and Druss, 2009). A review of data for 7955 SCI individuals registered on the NSCISC database in the USA identified that this trend is more prominent following SCI (Krause, Saunders and Acuna, 2012). This results in those who are unemployed following SCI being significantly more at risk of ill-health and death than their employed counterparts. Research from a range of countries has also identified that the benefits of paid employment post-SCI included high levels of job satisfaction (Noreau *et al.*, 2010), financial benefits (Marti *et al.*, 2012; Krause, Saunders and Acuna, 2012), higher levels of social integration, improved psychological functioning and better perceived quality of life (Noreau *et al.*, 2010). Therefore research seems to suggest that there are potential benefits for the SCI individual if they are in paid employment or vocationally active and potential physical and psychological consequences if they are not. It would be useful to identify if there are facilitating factors or barriers which may assist or prevent those with SCI in gaining or retaining employment.

Noreau et al (Noreau *et al.*, 2010) identified that research has consistently identified that certain, non-modifiable, personal factors such as being male, Caucasian or having a higher level of education prior to SCI increase the likelihood of an individual working post-SCI as well as being married, and having support from family, friends and employers. Additionally they identified that those with a lower level of disability and greater functional independence were more likely to be in employment post-SCI (Noreau *et al.*, 2010). In contrast Marti et al (Marti *et al.*, 2012) identified no differences in levels of employment between individuals with a range of levels of SCI. However, this research was conducted in Switzerland, a country which has a unique and very comprehensive support system in place to assist individuals with SCI to gain or retain employment resulting in high levels (63.8%) of employment post-SCI. These research findings may not be able to be generalised to the wider SCI population but it is worth noting that this study identified that, even in such a supportive system, there was a trend for those with tetraplegia to work less hours than those with paraplegia (Marti *et al.*, 2012).

In their literature review, Noreau et al (Noreau *et al.*, 2010) identified that research indicates that those injured at a younger age, currently under mid 40's and injured for longer periods of time were more likely to be in employment. A survey of 760 SCI individuals in the USA also identified that 29.9% of those aged 45-54 and 71.7% of those aged 55-64 and not in employment considered themselves to be retired (Krause, 2001). Although it may be that some older SCI individuals are not considering employment due to having to retrain and/or commence a new career, when viewed in combination with the findings by Noreau et al these results suggest that there may be another influencing factor rather than just age *per se*. It may be that the impact of aging with a spinal cord injury is influencing decisions regarding employment. A greater number of health issues and an accelerated aging process, along with the potential for long term issues due to complications have been reported following SCI (Hitzig *et al.*, 2011; Coll, 2007) and research has consistently identified that physical limitations or ill health due to SCI are barriers to gaining and retaining employment (Marti *et al.*, 2012; Noreau *et al.*, 2010; Krause, 2001). There are also likely to be additional costs as a result of these issues and so, for these individuals, the potential loss of healthcare benefits including free prescriptions (Noreau *et al.*, 2010; Fiedler *et al.*, 2002; Krause, 2001). Combined these issues may impact significantly on the decision to maintain or seek employment even with a comprehensive welfare benefit system such as that in the UK. Therefore it appears that the impact of age on employment following SCI is multifaceted and further investigation is required with potential confounding factors, such as ill-health or variations in age at injury, acknowledged and accounted for.

As with many areas of SCI research, there is a notable lack of UK-based studies in to vocational and employment outcomes. Differences in methodology, measurements and definitions have been noted make comparisons between studies difficult (Noreau *et al.*, 2010) and some of the variations in findings may be due to differences in application of categories as much as to variations in the setting of the research or the manipulation of variables. Therefore, although a range of studies have been undertaken, research has rarely been replicated and so many findings cannot be confirmed or disputed. The social and welfare environment in which the individual with SCI is looking for work needs to be considered in research, particularly in between country comparisons, as varying levels of support and societal emphasis on employment post-SCI are likely to influence outcomes (Marti *et al.*, 2012; Kennedy *et al.*, 2010a; Noreau *et al.*, 2010; Schonherr *et al.*, 2004; Siosteen *et al.*, 1990). In addition to the inclusion of those over retirement age in the calculations of those who are employed or unemployed, there is often a lack of consideration for pre-SCI work history or other vocational activities (Noreau *et al.*, 2010; Schonherr *et al.*, 2004). The reason why an individual does not work may also be an important factor for consideration.

In summary, the research reviewed suggests that a complex range of both personal and environmental contextual factors (World Health Organisation, 2001) potentially facilitate or limit engagement in employment post-SCI (Table 2.2). Some of these factors such as environmental barriers or financial disincentives are modifiable and may improve the rates of employment if manipulated, however, evidence is generally inconclusive and further research is required to confirm this (Noreau *et al.*, 2010). Other contextual factors such as age and age at the time of injury are not modifiable and are potentially linked to issues with poor health which may also influence the decision to work or not (Noreau *et al.*, 2010; Krause, 2001).

The research identified mainly investigates paid employment post-SCI rather than vocational activity as a whole (Noreau *et al.*, 2010). Although paid employment is suggested to yield significant health and psychological benefits for the SCI individual (Krause, Saunders and Acuna, 2012; Noreau *et al.*, 2010); it could be argued that this is in part due the benefit of the activity, social interaction and structure that engaging in employment will bring in addition to the potential financial benefits of employment (Krause, Saunders and Acuna, 2012; Noreau *et al.*, 2010). In addition to addressing the methodological issues identified it may be beneficial for future research to consider all forms of vocational activity including retraining/education, voluntary work and full-time care giving.

	Facilitators	Barriers	Inconclusive evidence
Employment	<ul style="list-style-type: none"> <li>• Male</li> <li>• Caucasian</li> <li>• ↑Level of education</li> <li>• ↓level of Disability</li> <li>• ↑Functional independence</li> <li>• Family support</li> <li>• Friends support</li> <li>• Pre-SCI work</li> <li>• Adjustment to work role</li> <li>• Adjustment to work hours/pattern</li> <li>• Independent driving</li> <li>• ↓Age</li> <li>• ↑time since injury</li> <li>• Computer skills</li> </ul>	<ul style="list-style-type: none"> <li>• ↓Access issues in the home</li> <li>• ↓Access issues in the workplace</li> <li>• ↓Finances (including removal of financial and healthcare benefits)</li> <li>• Poor health status</li> <li>• No adjustment to work role</li> <li>• No adjustment to work hours/pattern</li> <li>• ↑Pain</li> <li>• ↑Age</li> </ul>	<ul style="list-style-type: none"> <li>• Training/vocational rehabilitation &amp; other interventions</li> <li>• Marital status</li> <li>• Individual perceptions</li> </ul>

Table 2.2 Facilitators and Barriers to Employment following SCI

#### 2.4.4 Quality Of Life

The sense that life that has good qualities and that an individual has a good quality of life (QOL) is suggested to be an important indicator of better psychological and health outcomes in the population as a whole (McKevitt *et al.*, 2003; The WHOQOL Group, 1998). In the SCI population good QOL is also suggested by researchers to be a measure of successful adjustment (Post and van Leeuwen, 2012; Dunn and Brody, 2008; Manns and Chad, 2001). Although QOL is not an outcome of rehabilitation, it is hoped that following completion of rehabilitation and discharge back in to the community the SCI individual will have the ability to be able to experience a sense of a good quality of life (Kennedy *et al.*, 2010b; Dunn and Brody, 2008).

In research the term QOL is applied quite broadly and interpreted to mean several things, including life satisfaction, well-being or perceived health status (Bergland and Narum, 2007; McKevitt *et al.*, 2003). The lack of clarity of definition of quality is further muddied by QOL being viewed as both an objective and subjective concept. In objective assessments it is often viewed as Health Related QOL (Hill *et al.*, 2010; Leduc and

Lepage, 2002) which, as the name indicates, is suggested to be strongly influenced by general health and physical status. Therefore, quality of life in this sense relates to how the illness or condition the individual lives with impacts upon their life, not necessarily their sense of their QOL in relation to other domains.

An alternative interpretation to objective of QOL is subjective QOL. Subjective QOL has been defined as ‘the fit between a person’s expectations and his or her achievements, as experienced by the person...’ (Duggan and Dijkers, 2001, p.5.). It is the gap between the individual’s expectation and achievement that is measured in subjective QOL. It has been suggested that, just as what is viewed to be important in life will vary from individual to individual, the perception of what improves or enhances people’s lives (and therefore what constitutes QOL) will also vary (Bergland and Narum, 2007; Duggan and Dijkers, 2001). Also, the perception of what QOL means is suggested to have the ability to change over time (Sakakibara *et al.*, 2012; Duggan and Dijkers, 2001). As this research project aims to identify a range of health and social outcomes following SCI, the focus in this thesis will be on subjective QOL.

The difficulties with establishing a common definition of QOL have been noted to transfer into difficulties both in measuring subjective QOL and in identifying factors that may impact upon it (Sakakibara *et al.*, 2012; Eng *et al.*, 2010a; Hill *et al.*, 2010; Bergland and Narum, 2007). In example, Duggan and Dijkers (Duggan and Dijkers, 2001) identified that, in addition to perceiving QOL as containing both objective and subjective elements, subjects also perceived that some factors may influence QOL in opposite ways depending on the levels of the factor present (Duggan and Dijkers, 2001). This suggests that not only is QOL subject to individual interpretation and evaluation, but also potentially multi-factorial in nature. This may cause significant difficulties in accurate measurement of subjective QOL.

As with many areas of SCI research, scientific rigour has improved over recent years, however, the concept of quality of life is a wide ranging one and this has resulted in researchers taking differing approaches to measuring facilitators of, or the impact of, the QOL. In qualitative research both structured or semi-structured interviews and surveys have been utilised. Although subject numbers are often small and studies difficult to replicate, the data obtained can be both wide ranging and informative (Hammell, 2004). Reviews of available literature have identified that a variety of standardised and non-standardised measures have been utilised in quantitative examination and measurement of subjective QOL (Sakakibara *et al.*, 2012; Post and van Leeuwen, 2012; Eng *et al.*, 2010c; Bergland and Narum, 2007). An alternative, pragmatic method of

simply asking the individual what they perceive their quality of life to be has also been proposed, as this utilises the individual's perception of what QOL actually is, as well as how they rate their QOL (McKevitt *et al.*, 2003). The studies reviewed present a mixture of these methods of investigation. Whilst the use of differing methodologies and forms of measurement across studies can make comparisons between research findings problematic, it may also present an opportunity to gain more information about potential interactions.

As little UK-based research is available, research from a range of Western countries will need to be considered in this thesis. Research papers over 10 years old have been included when the study has not been replicated and the original paper brings meaningful discussion. Where recent reviews of literature were available, they have been included (Post and van Leeuwen, 2012; Sakakibara *et al.*, 2012; Post and Noreau, 2005) and papers referred to in these reviews will not be discussed individually unless they have specific and pertinent findings of interest.

The SCI individual's level of neurological impairment will impact on their functional abilities and their reliance on others for assistance. This could impact upon their perceived QOL. In order to investigate this Kennedy *et al.* (Kennedy *et al.*, 2010b) performed a quantitative survey of 81 SCI individuals in the UK and identified that lower functional ability (measured by the FIM scale) did not negatively impact upon QOL. However, there are methodological issues with this study which include the use of the FIM scale to detect functional differences in a group of SCI individuals which included tetraplegics (Eng *et al.*, 2010a; Alexander *et al.*, 2009) and a version of the scale intended for use in professional, objective assessment being utilised for self-report by subjects. These issues suggest that findings from this study must be viewed with caution. In an earlier review of both quantitative and qualitative literature, Hammell concluded that tetraplegics reported an average or better than average QOL (Hammell, 2004). Conversely, a qualitative study from Canada identified that potential dependence and loss of functional ability had a greater negative impact on the QOL of tetraplegics (potentially more dependent) compared to paraplegics (Manns and Chad, 2001), however, very small subject numbers (N=15) in this study suggests that further evidence is needed to confirm these findings. In summary, as concluded in a review by Post and van Leeuwen (Post and van Leeuwen, 2012) it appears that there is no conclusive evidence that impairment (World Health Organisation, 2001) in the form of level of SCI influences perceived QOL.

The impact of health issues and secondary conditions on QOL has received much attention resulting in a wide range of studies (Sakakibara *et al.*, 2012; Post and Noreau, 2005). Although there has been little replication due to the range of issues investigated and the range of methodologies utilised, three literature reviews identified a consistent theme of issues with poor health and sequelae post-SCI being notable predictors of lower ratings of QOL, both in the short and long term, particularly pain, spasm, continence issues and dissatisfaction with sexual function (Sakakibara *et al.*, 2012; Post and van Leeuwen, 2012; Post and Noreau, 2005). Combined the findings in relation to the impact of level of SCI and health issues on QOL suggest that, although the evidence for the impact of the level of SCI on QOL is inconclusive, secondary health issues both generally and individually have been found to significantly impact upon QOL. However, as suggested by Post and Noreau (Post and Noreau, 2005), this impact on QOL may be a result of the impact of secondary health issues on participation rather than a direct relationship.

Reviews of research indicate that following SCI QOL ratings increase initially following injury and discharge and then remain generally stable over time (Sakakibara *et al.*, 2012; Post and van Leeuwen, 2012). This highlights the need to ensure that studies investigating the impact of time since injury ensure that not only have subjects been injured for the same amount of time but also that longitudinal studies are applied when potential changes over time are being investigated. A review of international literature also concluded that, regardless of age at the time of injury, all SCI individuals have the potential to improve their QOL (Sakakibara *et al.*, 2012) with a notable trend for improvement and then stability over the first five years post-SCI. When considered together these results suggest that length of time since injury and having a greater age at the time of injury may not negatively impact on QOL in the first five years post-SCI.

Better QOL has been suggested to evolve in the presence of social interaction (Dunn and Brody, 2008). A Canadian survey utilising standardised repeated measures on 93 SCI individuals at 3-15 months post discharge identified that the influence of family support on QOL increased over time compared to the support of friends (Mortenson, Noreau and Miller, 2010). In this study one fifth of the subjects had an AIS E grade SCI indicating complete neurological recovery; this could have skewed results to some degree (Mortenson, Noreau and Miller, 2010). However, a review of available literature did identify a consistent theme of good QOL in the presence of good social relationships and support confirming the importance of this factor in facilitating QOL (Post and van Leeuwen, 2012).

Quantitative research from the UK and Canada highlights the importance of participation in community and leisure activities in promoting good QOL (Kennedy *et al.*, 2010b; Mortenson, Noreau and Miller, 2010) and that environmental barriers to participation, both in the home and community, have a significant detrimental impact on perceived QOL (Kennedy *et al.*, 2010b; Mortenson, Noreau and Miller, 2010). This is suggested to become more apparent as individuals have been in the community and living with these issues for a longer period of time (Mortenson, Noreau and Miller, 2010). That the deleterious influence of environmental issues was detected in a study in which two fifth of the subjects had AIS D or E grade injuries, therefore potentially ambulant and less likely to have felt the impact of environmental issues severely, is noteworthy (Mortenson, Noreau and Miller, 2010).

Vocational activity has been found in both qualitative studies and reviews of available literature to predict higher ratings of QOL (Sakakibara *et al.*, 2012; Noreau *et al.*, 2010). This may be related to the positive effect of better finances but could equally be due to a perception of having a meaningful role in their society and being an important part of their social network. Therefore, the association between QOL and vocational activity may be a reflection of the importance of having a meaningful role in society for the SCI individual (Sakakibara *et al.*, 2012) or a reflection of the improved financial status of those individuals (Noreau *et al.*, 2010), both of these factors may be modifiable. When considered with the findings discussed earlier that health status and mortality rates are improved in those in employment (Krause, Saunders and Acuna, 2012) this clearly identifies that further research is needed in this area.

A review of available literature identified that SCI individuals report significantly lower QOL than the general population (Post and van Leeuwen, 2012) and that the psychological disposition of the SCI individual may impact upon perceived QOL. The SCI related research reviewed has identified that personality factors (Mortenson, Noreau and Miller, 2010; Manns and Chad, 2001), including negative appraisal styles (Kennedy *et al.*, 2010b), low levels of perceived control and self efficacy, that is *negative appraisals* of control and efficacy, (Post and van Leeuwen, 2012) are related to lower ratings of QOL, whilst adaptive coping strategies are related to higher QOL ratings (Post and van Leeuwen, 2012). International reviews of research also suggest that a potential shift in expectations following SCI will lead to some individuals re-evaluating, and so re-appraising, their QOL influences and expectations (Sakakibara *et al.*, 2012; Post and van Leeuwen, 2012). The 'Life Span Evaluation' theory (Sprangers and Schwartz, 1999), proposes that as an individual's age or experience changes in health or physical function they may re-evaluate their lives and expectations. Sakakibara *et al.* (Sakakibara

*et al.*, 2012) propose that this is what some individuals may do following SCI resulting in an increased or at least non-deteriorating perception of QOL in certain domains. Further research is needed to investigate if perceptions of QOL can be influenced through the adjustment of this re-appraisal process.

	Facilitators	Detractors	Inconclusive evidence
Quality of Life	<ul style="list-style-type: none"> <li>• ↑Time since injury</li> <li>• ↑Adaptive coping strategies</li> <li>• ↑Social support and relationships</li> <li>• ↑Community Activity</li> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• Internal locus of control</li> <li>• ↓Self efficacy</li> <li>• Maladaptive coping strategies</li> <li>• ↑Health issues</li> <li>• ↑Pain</li> <li>• ↑Spasm</li> <li>• ↑Contenance issues</li> <li>• ↓Satisfaction with sexual function</li> <li>• ↓Environmental access (home and community)</li> </ul>	<ul style="list-style-type: none"> <li>• Functional ability</li> <li>• Functional dependence</li> <li>• Age</li> <li>• Meaningful role in society/social network</li> </ul>

Table 2.3 Facilitators and Detractors of Perceived QOL

In summary, a good perceived QOL is deemed to be important in both the general and SCI populations and is a recognised outcome measure of successful adjustment and reintegration following SCI. QOL in some domains of life may be affected significantly following SCI whilst others are relatively unaffected (Post and Noreau, 2005). The research reviewed suggests that subjective QOL (a personal contextual factor) can be affected by a variety of other contextual factors that are both environmental and personal as detailed in Table 2.3. Some of these factors, such as coping strategies, levels of community activity and appraisals may be modifiable and further research may be of benefit to identify if manipulation of modifiable factors may lead to better QOL ratings. Additionally, it appears that no one factor predicts or enhances QOL, rather QOL may be affected by a range of factors as shown in Table 2.3. However, difficulties with differing methodologies, different forms of measurement, lack of consistency in definitions of QOL, as well as a range of variable interactions with QOL being investigated, results in a frequently researched area that has few replicated findings.

#### **2.4.5. Discharge Destination: Accommodation/Residential Situation**

In the Hierarchy of Needs (HON) Theory (Maslow, 1968) the attainment of shelter, or accommodation is suggested to be a basic, primary, physiological need (Figure 2.2) that must be fulfilled before individuals are able to pursue the fulfilment of other needs including, attaining QOL or social participation. This is no different for individuals who

have sustained SCI and due to the potential limiting factor of the environment (World Health Organisation, 2002), arguably more important. In the author's experience, it is an issue that the newly injured SCI individual will highlight as a concern early in their treatment and rehabilitation pathway.

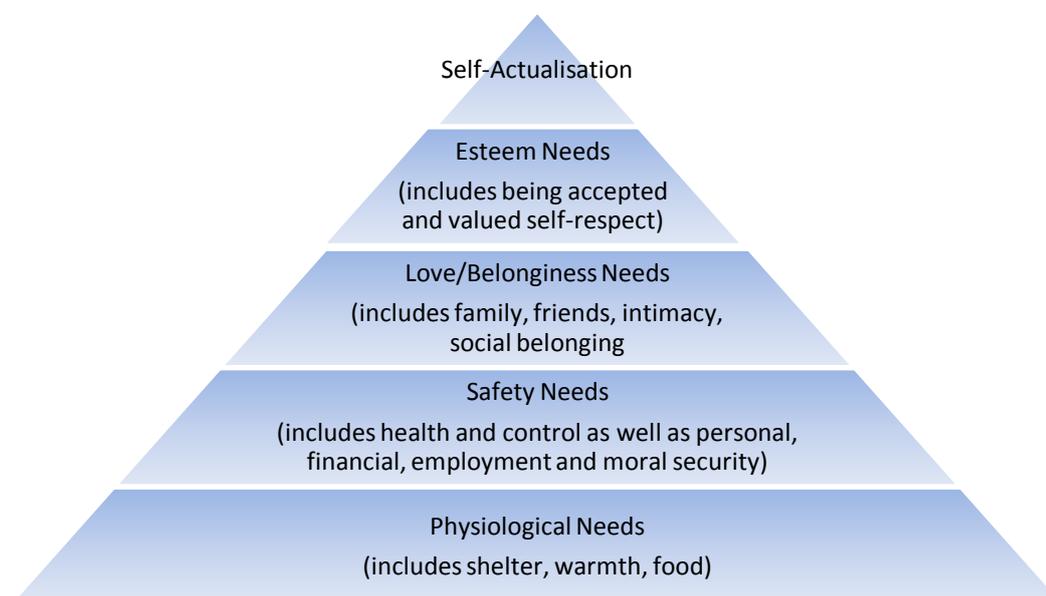


Figure 2.2 Diagrammatical Representation of Maslow's Hierarchy of Needs. (Maslow, A.H. (1968) *Toward a Psychology of Being*. 2nd edn. New York: Van Nostrand Reinhold)

Securing accommodation to permit the SCI individual to be discharged in addition to being a widely accepted outcome measure (Wolfe, Hsieh and Mehta, 2012; Boucher, Ballantyne and Boschen, 2012) is also the means by which an SCI individual can begin to reintegrate in to their society and therefore a variable which may also affect outcomes.

As with other subject areas discussed in this thesis, few papers were identified investigating housing provision for SCI individuals either in the UK or in other countries. A recent SCIRE review (Boucher, Ballantyne and Boschen, 2012) of available housing related literature also identified that, internationally, there have been comparatively few studies exploring the issues faced by SCI individuals in terms of their accommodation and much of this is in excess of a decade old. Where necessary international research, will be discussed to supplement or support findings from the UK. Research which discusses forms of accommodation that are not widely utilised in the UK (such as shared, supported living accommodation) will not be discussed.

The South of England 'Standards for Patients Requiring Spinal Cord Injury Care' requires 'safe and accessible accommodation' to be provided in order for discharge of the SCI individual to occur (South of England Spinal Cord Injury Board, 2010, Std 9.2.1, p.55.). This emphasis on the importance of securing suitable accommodation is echoed in both the UK Department of Health guidance on discharges (Great Britain. Department of Health, 2004) and Quality Requirement 7 of the National Service Framework for Long Term Neurological Conditions (Great Britain. Department of Health Long Term Conditions NSF Team., 2005). Whilst these documents give details of the requirements for access and physical structure of suitable accommodation they do not state where the accommodation should be sited or the form that the accommodation should take.

Although there is consensus that accommodation is required for discharge, in the UK obtaining suitable accommodation for the individual (and potentially their family) in time for discharge can be difficult for a variety of reasons. The accommodation should, in addition to being in the geographical area that facilitates the SCI individual participating in their community and returning to their vocational activities, also meet the needs of any non-disabled person who lives with the SCI individual. Additionally, as 80% of SCI individuals are dependent on a wheelchair for a significant proportion, if not all, of their mobility (de Groot *et al.*, 2011) they will require a property that is either wheelchair accessible or capable of being adapted to be. Accommodation requirements may be quite specific as the SCI individual may also require accommodation large enough for the use of a hoist, that has a room for one or possibly two carers and can be adequately and easily heated and ventilated (South of England Spinal Cord Injury Board, 2010, Appendix 9,1).

In the 1980's most UK public and private sector housing stock was noted to be unsuitable for wheelchair users (Oliver *et al.*, 1988, p.132.). In 2005 there was estimated to be a shortfall of 300,000 wheelchair accessible homes (John Grooms/Livability, 2005). UK government policy has encouraged the building of properties suitable for disabled individuals (Building Regulations (Part M) Amendment Access to and Use of Buildings, 2010; Great Britain. Minister for Disabled People, 2005) but not all of these properties will be wheelchair accessible. Although some wheelchair accessible accommodation has been built in the UK public and private sectors (Aspire, 2009) there is still likely to be a shortage. If provision of public sector housing is required this may be problematic in many areas, particularly the South East of England, due to a high population density, the reduction in housing stock due to the sale of many council properties under the 'Right to Buy' scheme (British Broadcasting Corporation, 1979) and the resulting substantial over-subscription of public sector properties (Great Britain.

Communities and Local Government, 2012). A UK-based survey identified that although 74% of SCI individuals were discharged to their pre-injury home, these individuals accounted for 53% of the delayed discharges (Barr and Spinal Injuries Association, 2009; Aspire, 2009). In the absence of suitable accommodation for discharge other options will need to be investigated in order to facilitate discharge and allow another SCI individual to be admitted to the SCIC to commence their treatment and rehabilitation.

Temporary accommodation may be able to be secured through UK charitable organisations such as Aspire (Aspire, 2012) and Transhouse (Transhouse, 2011), however, there are few of these properties and demand for them is high. The accommodation that is available through these providers may not be suitable for all as it may be a group living situation, not be in the required geographical or not large enough for a family. Any other small pockets of temporary accommodation across the UK are generally uncoordinated, and so, unknown.

Research from several countries has consistently identified that the majority of SCI individuals would prefer to live in the community rather than an institution and that most SCI individuals feel that living in their own home is the housing option that would permit the most privacy and freedom (Smith and Caddick, 2012; Boucher, Ballantyne and Boschen, 2012; Bergmark, Winograd and Koopman, 2008; Boschen, 1988). Despite this, case reviews of the discharge destination of individuals in the USA (DeVivo, 1999) indicate that 12% of SCI individuals were discharged to a nursing home. This has been noted to be particularly likely to be the case for high level tetraplegics (Anzai *et al.*, 2006; DeVivo, 1999). In a UK survey 10% of individuals were discharged to a nursing home or similar facility (Barr and Spinal Injuries Association, 2009).

Research regarding the impact of discharge to a nursing home has produced variable results. A quantitative, UK based, survey of 20 SCI individuals (Smith and Caddick, 2012) identified that they perceived their time in a nursing home to be 'lost' with gains made in rehabilitation undone due to a disabling environment. Further issues ranging from lack of choice and autonomy, loss of identity, reduction in QOL and psychological distress were also reported. Additionally, survey respondents raised concerns regarding lack of nursing home staff knowledge of SCI, inappropriate care resulting in complications including pressure sores, mismanagement of autonomic dysreflexia episodes and feelings of lack of safety and confidence in the support received. Similar results have been reported in qualitative studies of tetraplegics in the USA (Duggan *et al.*, 2002). Although this study only had 6 subjects it reinforces the findings of Smith and Caddick (Smith and Caddick, 2012) that although residing in a nursing home may meet

the primary physiological need for accommodation it falls short of attaining the next HON level of safety needs which may result in significant stress and distress for the SCI individual (Maslow, 1968).

Lack of information on alternatives and lack of support to pursue these options has been cited as a potential barrier to moving in to the community by SCI individuals in the UK (Smith and Caddick, 2012). For those who are dissatisfied with this situation and feel that their safety, choice and control needs are not met this is likely to result in a prolonged period of stress and anxiety (Maslow, 1943) and potential restriction in their ability to participate in their community (Smith and Caddick, 2012; Eastwood *et al.*, 1999). Conversely, in a survey of 22 SCI individuals living in a combination of group homes, parental homes and their own homes in the USA, Bergmark *et al.* (Bergmark, Winograd and Koopman, 2008) identified that some individuals viewed nursing homes as promoting a greater sense of independence than the parental home. Duggan *et al.* (Duggan *et al.*, 2002) also identified that nursing homes in which sufficient choices were perceived to be available (Duggan *et al.*, 2002; Boschen, 1996) were viewed more positively by SCI individuals, and in some cases as a stepping stone, with the potential for positive outcomes and further rehabilitation (Duggan *et al.*, 2002). The importance of the perception of choice in facilitating residential satisfaction was further highlighted in two papers by Boschen evaluating data from a quantitative survey of 82 Canadian SCI individuals (Boschen, 1996; Boschen, 1988).

Lack of choice does not only appear to be an issue for SCI individuals living in nursing homes as those residing in the parental home have also been reported to perceive an impaired QOL and the perception that this was a restrictive environment (Bergmark, Winograd and Koopman, 2008). However, small subject numbers in this study and the focus on tetraplegia mean that further investigation of this issue is required with a larger, wider group. The results do reaffirm that it is important that the environment in which the individual resides is perceived as providing choice, enabling and facilitative, psychologically as well as physically (Duggan *et al.*, 2002; Boschen, 1996; Boschen, 1988). It also stresses that although the HON physiological needs (Maslow, 1968) are met in this environment the HON belongingness (higher level) needs that would normally be expected from the close social context of the family home cannot be met due to the lack of the control that is required to fulfil the HON safety needs. In support of these assertions, Boschen (Boschen, 1996) identified that the feeling that one has sufficient choice was strongly correlated with overall residential satisfaction and this is then suggested to be a predictor of life satisfaction. In essence, the perception that

choice is available and that the place of residence is the chosen place of residence is important and promotes a greater perceived QOL.

Combined these research findings suggest that there may be a complex interplay of factors affecting the SCI individual's satisfaction with their residential situation: that the environment in which a person lives is not just a physical one and, although the physical environment is a significant influencing factor, it is not the sole determinant of satisfaction with where they live. It also must be acknowledged that for SCI individuals satisfaction with their environment (the HON physiological need) is likely to be influenced to some extent by their satisfaction with the care and support (the HON safety need) they receive, and vice versa, therefore these two factors will be difficult to analyse separately.

An alternative option to the SCI individual being reliant on securing public sector housing or being discharged to a nursing home is for them, and potentially their family, to privately rent or purchase a property however there is no UK based research investigating the numbers of SCI individuals who are discharged to a new property. In addition to cost implications, the identification of suitable housing may still take a significant period of time and so accommodation may not be available by the proposed discharge date. The scarcity of recent research on this issue makes it difficult to establish the size of this issue in the UK, but the low availability of wheelchair accessible housing in the private and public sector (Aspire, 2012; John Grooms/Livability, 2005) suggests that it is likely to be notable.

Wherever in the community the SCI individual is discharged to, it is likely that some adaptations will be required to the accommodation to facilitate access either into or around the home, including access to washing and toileting facilities. This may require major building work, the costs of which can be prohibitive. In England, the Disabled Facilities Grant (Great Britain. Communities and Local Government, 2007) is a grant of up to £30,000 that is paid by local councils to assist with the costs of performing the adaptations to a property necessary to facilitate a disabled person living there. The grant has a lengthy application process of up to 18 months and a strict means test with income thresholds set at the level of basic state benefits before a contribution will be required from the applicant. This results in many individuals not qualifying for the grant and even when they do a delay to adaptations being performed.

In the UK other sources of funding for adaptations or accommodation may be available for those who are making a personal injury compensation claim. Recommendations are

made in the Rehabilitation Code 2007(IUA/ABI, 2007) that there should be early involvement by insurers to facilitate the release of funds to assist the individual to restore their lives to the point that they would have been had the injury not occurred (as much as monetary payments are able to) through the provision of treatment, equipment, adaptations, or accommodation. However, the Code is voluntary and so may not be adhered to by one or all parties and when it is variations in definitions of 'early' involvement may result in the SCI individual being discharged before the benefit of this collaborative working is felt. If private funding of adaptations is possible then the adaptations process may be expedited. However, due to the need to establish the works required, find workmen and possibly apply for planning permission, it may still not be possible for works to be fully completed prior to the date that the SCI individual will need to leave the SCIC. Therefore, delays to discharge or the need for alternative accommodation, including nursing home placements, may not be completely eradicated. This issue is of particular importance as lengths of stay at SCIC in the UK, as well as internationally, are noted to be becoming shorter (Wolfe, Hsieh and Mehta, 2012) and is an area that requires research.

With the potential for delays in provision of adaptations it is unsurprising that the most recent UK investigations suggest that only between 59% and 74% of SCI individuals were able to be discharged to the Community (Aspire, 2009; Barr and Spinal Injuries Association, 2009), with up to 64% still awaiting significant adaptations when they were discharged (Aspire, 2009). One possible outcome of any lengthy delay in provision of adaptations or accommodation is that the SCI individual will be discharged to a property in which they can only use one room and are unable to access washing, toileting or cooking facilities (Aspire, 2009). The importance of the perception of access within the home has been highlighted as important in facilitating residential satisfaction and therefore this may result in dissatisfaction for the SCI individual (Boschen, 1996; Boschen, 1988). Despite this, in the author's experience, many SCI individuals choose the option of a restricted home environment rather than discharge to a nursing home. A UK postal survey of 81 SCI individuals, reported that 49% experienced a delay in the provision of adaptations and 29% felt that the lack of adaptations made transition in to the Community difficult (Kennedy *et al.*, 2010a), therefore limiting their participation levels (World Health Organisation, 2001). This survey had a low (31.8%) response rate and was a cross-sectional survey of individuals who were between 3-18 months post-discharge which could have skewed results due to the potentially high proportion of individuals still being in the process of obtaining adaptations. However, these findings are supported by a survey of 262 individuals with a range of disabilities that had been through the process of obtaining UK state funded adaptations (Heywood, 2004).

Heywood identified that un-adapted properties were associated with increased support requirements, health issues for the disabled individual, including risk of accidents, as well as psychological distress. Issues reported around lack of control, loss of privacy and dignity as well as depression reflect those reported by individuals in nursing homes (Smith and Caddick, 2012; Duggan and Dijkers, 2001).

Perceptions of safety are also noted to be important factors in residential satisfaction and a USA based quantitative survey of 69 SCI individuals identified that although 88.4% felt safe from crime in their home only 64.7% felt prepared for a fire (Cesar *et al.*, 2002) underlining the need for the SCI individual to feel that the home environment facilitates their safety and well-being as much as their functional activities. Potentially, not only is there a limitation of participation due to the environmental factors (World Health Organisation, 2001) but also although HON physiological needs are being met, HON safety needs (Maslow, 1943) are not, potentially resulting in increased levels of stress, anxiety and psychological issues. This echoes results for those residing in nursing homes. Delays in adaptations were also reported to impact on the health and well-being of family members and care givers (Heywood, 2004). Therefore, although residing in the community in one's own home may be the preferred residential situation of individuals with SCI this situation may not be without issues if there are access problems within the home. It is noteworthy that there is little research in to the impact of poor access within the home in the UK, particularly regarding potential impacts on community participation, or if there are additional costs incurred due to increased care needs or potential reliance on benefits due to the inability to return work or on the psychological and health impacts on the individual or their family. These are areas that would warrant attention in research.

Heywood (Heywood, 2004) also identified that, despite lengthy waits, once adaptations were performed this may not be the end solution that was hoped for. Some subjects reported further distress and frustration due to issues with inadequate or incorrectly performed adaptations. This echoes findings reported from a very small quantitative study in Canada that SCI individuals become frustrated with able bodied people labelling environments as accessible when they are not easily accessible by a wheelchair user (Manns and Chad, 2001). These findings suggest that even when discharge to the Community occurs, significant and deleterious issues may be experienced not only whilst awaiting the provision of adaptations but also following completion of adaptations if they are performed inadequately. Further UK-based research investigating the occurrence of these issues following SCI is required.

In summary, the provision of accommodation for discharge is not only an outcome measure but also a factor which may significantly affect other outcomes including community participation. Internationally there is little research available regarding the provision of accommodation following SCI or of outcomes associated with the optimal or lesser provision of accommodation. Considering that provision of suitable accommodation for discharge is classed as a significant rehabilitation outcome measure (Wolfe, Hsieh and Mehta, 2012), is cited as a requirement for discharge (South of England Spinal Cord Injury Board, 2010, Std 9.2.1, p.55.; Great Britain. Department of Health, 2004), is viewed as essential for promoting participation in society (World Health Organisation, 2001) and important for the most basic levels of the HON (Maslow, 1968) the lack of UK-based and international research in to this issue is surprising. The majority of studies identified are in excess of 10 years old and many also had subject numbers which could only be classed as small, even for a client group with a small population. More up to date research is required that complies with current standards of scientific rigour. Until this occurs the available research needs to be acknowledged and considered, but with caution.

The research reviewed identified that delays in provision of accommodation frequently result in delays to discharge in the UK (Barr and Spinal Injuries Association, 2009) although there is still little research regarding this and the implications of it. Additionally a trend for those with tetraplegia to be discharged to a nursing home was identified but UK-based data is required to confirm this. Issues were also noted due to delays in provision of adaptations restricting the potential for participation and increasing the requirement for support. It is an area for concern that issues were also identified in the UK due to inadequate or badly planned adaptations. This suggests that even following a substantial delay in provision individuals may still experience significant limitations and hardship due to their environment. This is an issue which requires further research. It may be useful to compare discharge delays, as well as satisfaction with access, between those who received expedited provision of adaptations or were discharged to a facilitative environment and those were discharged to a property which did not meet access requirements. This may establish if there are significant differences in outcomes with different provisions.

Variations in experiences and levels of satisfaction have been identified with a range of accommodation including nursing homes, parental homes and poorly adapted accommodation. Issues reported in research include dissatisfaction with their environment, lack of control, safety fears, reduced QOL and impaired ability to reintegrate in society. With such notable issues being reported for SCI individuals in a

variety of residential situations this highlights the importance of choice, control and perceived ease of access within the home environment in promoting better outcomes for SCI individuals. However, it is worth noting that in all of these environments there is potential for satisfaction with care provision to affect satisfaction with accommodation and this must be acknowledged in future research. The provision of accommodation and/or adaptations for discharge in the UK is an important, under investigated, issue that has the potential to impact on the individual's ability to reintegrate into society not just initially but also in the longer term (Kennedy *et al.*, 2010a; Aspire, 2009; Bergmark, Winograd and Koopman, 2008; Oliver *et al.*, 1988) and may significantly affect other outcomes following discharge (Kennedy *et al.*, 2010a).

## **2.5 Summary**

The ICF model of disability proposes that disability and function are products of a dynamic, multi-dimensional interaction between the individual's health/body function, their activities/participation (including any restrictions on these) and the society/community in which they attempt perform these activities. Although this thesis is concerned with the evaluation or recommendation of a particular model of disability this will be utilised as framework for discussions regarding outcomes and potential influencing factors where necessary.

This Chapter has discussed the outcome measures of rehabilitation and successful reintegration which will be utilised in this thesis. It has identified that for many of these outcome measures there is little up to date research investigating the impact of variations in these outcomes or of factors which may hinder or facilitate attaining these outcomes, particularly in the UK. Some of the outcome measures which will be examined in this thesis, such as length of stay and readmission rates can be primarily considered to be health care system outcome measures, however, they are still of significant importance to the SCI individual as they may impact upon their ability to achieve optimal functional outcomes or to reintegrate in to their society.

The research reviewed identified that there is little clarity or consistency in the measurements of rehabilitation LOS or delayed discharges. This results in difficulties in comparing data from different studies as well as drawing meaningful conclusions regarding the impact of variables on LOS. A trend for shorter admission periods has been reported internationally. LOS are suggested to be affected by some factors that are internal to the individual such as age, level and grade of SCI or co-morbidities but also by the presence of complications on admission. Delays to discharge are suggested to occur in a significant proportion of cases, and frequently due to housing or funding but

detailed information on the reasons for discharge delays in the UK is lacking. Further, although delays to discharge are suggested to have a deleterious impact on the ability of the SCI individual to reintegrate in to society there is little evidence to confirm this. There is a need for clarity and consistency in measurement of length of stay in UK-based research, commencing with a clear definition of when rehabilitation commences and when it ends.

Functional improvement following completion of rehabilitation is suggested to be influenced by some SCI related demographics as well as age at the time of injury. They are also suggested to potentially be influenced by the length of rehabilitation stay. Although in the USA it is suggested that reduced rehabilitation LOS are resulting in increased levels of readmissions, there has been little UK-based investigation in to the frequency or reasons for the occurrence of readmissions and the research that is available often does not clarify the reason for readmission. Research from other countries suggests that readmissions to hospital may occur for a variety of reasons which may either indicate potential gains that will be made following a period of further rehabilitation or deficits due to health issues that impact upon the ability of the individual to successfully reintegrate and participate in the community. Further research is required to investigate the incidence and reasons for readmissions in the UK.

Other outcome measures which will be examined in this thesis such as community participation and QOL are primarily of importance to the SCI individual, or in the case of accommodation in the community the means by which other outcomes will also be achieved. However, research also suggests that deficits in these outcomes can impact upon the physical and psychological well being of the SCI which then may impact upon the ability of the SCI individual to reintegrate in to, and resume their role in, their society. Participation has been noted to be influenced by environmental and physical health issues however there is a lack of consistency in the forms of measurement utilised which results in difficulties in making comparisons between studies. The available research suggests improved QOL are reported in those who have greater levels of participation, however further research in to this issue is required, particularly in the UK, to identify the factors which may influence levels of participation as well as to clarify the impact of increased levels of participation.

There is some, non-UK based evidence suggesting improved health, morbidity and well-being outcomes for those who are in employment post-SCI, regardless of level of injury, however evidence is inconsistent regarding facilitators and barriers to employment, and particularly lacking in the UK. Inconsistencies in methodologies and classifications result

in difficulties in making comparisons. Further, UK-based evidence is also required to identify if improved outcomes are related to only paid employment or to the engagement in vocational activities in general.

Research reviewed indicates that subjective QOL can be affected by the presence or absence of a variety of factors. The SCI individual's appraisal of their SCI, their current situation and their ability to function and be satisfied within that are also proposed to be important determinants of perceived QOL. This suggests that the SCI individual's perceived QOL may be modifiable by the adjustment of other variables. As with many areas of SCI research issues with small numbers of research studies, differing methodologies as well as the use of varying definitions and forms of measurement results in difficulties in drawing robust conclusions across studies, little replication of findings and little UK-based research.

The provision of accommodation is a pre-requisite for discharge and an essential requirement for an individual to be able to live in society and commence reintegration; however UK-based evidence suggests that SCI individuals experience difficulties in securing suitable accommodation or adaptations to allow access to existing accommodation. There is little UK-based research into the implications of these difficulties. The perception of availability of choice in respect of where the SCI individual lives and how they live in that environment has been highlighted as important however this and other housing related issues have received little attention in research, particularly in the UK. What research is available suggests that many SCI individuals will be discharged to accommodation that does not meet their needs or to a nursing home and that both of these scenarios may result impact upon the psychological or physical well-being of the SCI individual, however further evidence is required to confirm these findings.

When it is considered that SCI is recognised in the UK as a potentially lifelong condition with associated high costs it is surprising that there is such a small amount of research investigating what the achievable optimal outcomes are following SCI. Additionally, there is little UK-based research into the factors which may influence the ability of the SCI individual to achieve these outcomes and the implications of the SCI individual not achieving these outcomes. Variations between funding and welfare systems in the UK and other countries results in difficulties in making comparisons between data from different countries or applying some of the findings of research from another country to the UK. Internationally what research is available in to these issues is dated or suffers due to lack of consistency in measurement, methodology and definitions making

comparisons of findings problematic, even in subject areas that have received much attention. Further systematic research with clear definitions and consistency in measurement is required in order to identify optimal outcomes for the SCI individual and society, as well as the means by which these outcomes may be facilitated.

In summary, the research reviewed in this chapter suggests that the ability of the SCI individual to participate in society and their community may be influenced by a variety of factors including their impairment as a result of their SCI and a range of environmental and personal factors some of which may be modifiable. The research reviewed in this chapter and the professional experience of the author suggests possible areas for investigation as well as some specific questions related to these investigations.

In relation to the healthcare systems outcomes of rehabilitation LOS, functional outcomes, discharge delays and readmissions, potential areas for further investigation include:

- Clarification of acute and rehabilitation LOS and examination of factors which may result in variations in rehabilitation LOS.
- The impact of delays in admission in relation to the presence of complications on admission, LOS, rehabilitation outcomes.
- The impact of avoidable complications present on admission.
- Readmission rates in the first year post-discharge and causes of readmissions.
- The frequency and lengths of discharge delays, the main causes of these and whether discharge delays impact upon reintegration outcomes.

In relation to the reintegration outcome measures identified the following further areas of investigation are proposed

- Community participation
  - Levels of community participation at one year post-discharge and the factors that SCI individuals feel influence the ability to participate in community activities.
- Vocational status
  - The vocational status of SCI individuals on discharge and at one year post-discharge and how this compares to their vocational status on injury.
  - Whether particular modifiable or non-modifiable factors are related to paid employment or further education/training.
  - If vocationally activity is related to a better QOL and a lower incidence of health issues.
- Accommodation
  - The discharge destination of SCI individuals, residence at one year post-discharge and how this compares to their accommodation at the point of injury.

- If individuals with high level SCI are more likely to be discharged to a Nursing Home and whether they will still be living there one year post-discharge
- How many SCI individuals are discharged to accommodation that has been adapted to meet their needs or already meets their needs. How many are still awaiting provision of adaptations or suitable accommodation at one year post-discharge. The sources of funding of adaptations and whether this is related to the speed of provision of adaptations. If delays in provision of adaptations lead to increased care provision, reduced vocational activity and reduced community activity
- Quality of Life (QOL)
  - SCI individuals' ratings of QOL and whether this changes with length of time since injury.
  - Identification of factors which impact upon perceived QOL and if any of these are modifiable.

This chapter has evaluated the evidence available in relation to potential rehabilitation and reintegration outcome measures. Areas for investigation have been proposed in relation to gaps in the research either internationally or in the UK. The proposed areas of investigation will be discussed further in relation to the methodology that will be established for this research in Chapter 4. In the next chapter research investigating additional factors which may influence these outcomes will be examined.

## **CHAPTER 3: Issues and Contextual Factors Which May Affect Rehabilitation and Reintegration Outcomes in the UK**

### **Overview**

In preparation for the investigation of outcomes in a cohort of SCI individuals that will be presented in this thesis this chapter will examine factors which may impact upon the rehabilitation and reintegration outcomes of the SCI individual. Research regarding the potential impact of internal factors will be examined and evaluated. Some factors are modifiable whilst others are not. Other factors may be resources such as care equipment of accommodation which may be delayed in their provision, not provided at all or provided in a lesser form than recommended by the SCIC team. Information regarding requirements for provision of resources and the potential impact of variation in provision will be examined where there is research available. Finally the gaps in research identified in this, and the two preceding, chapters will be discussed and the areas for investigation in this research project will be presented.

### 3.1 Introduction

The preceding chapter identified the potential rehabilitation and reintegration outcomes following SCI which will be evaluated in this thesis. It was highlighted that for many of these outcomes there is little UK-based evidence identifying the occurrence of either optimal or lesser outcomes. The purpose of the research presented in this thesis is to investigate these outcomes in a cohort of SCI individuals both on discharge and at one year post-discharge as well as factors which may have facilitated or hindered the achievement of these outcomes for some subjects. This chapter will focus on identifying the personal contextual factors and the environmental contextual factors which may impact upon outcomes both during rehabilitation and on returning to the community. In Chapter 4 the methodology for the investigation of these outcomes and potential influencing factors will be developed.

The impact of factors which may influence outcomes can either be positive, in facilitating better outcomes following discharge, or negative. Some personal factors are non-modifiable demographics such as age or gender; others are psychological issues such as coping strategies. Regardless of achievements in rehabilitation some external factors such as the provision of care, accommodation or equipment resources or the availability of social support may also limit outcomes following discharge to the community. Utilising the ICF model this thesis proposes that contextual environmental factors (World Health Organisation, 2013) in the form of provision of these resources can impact upon rehabilitation and reintegration outcomes for the SCI individual. The provision of resources to SCI individuals in the UK can be delayed. A consequence of this may be that the individual is unable to reintegrate fully and participate in their community, either because they are unable to be discharged or because the things that are necessary for them to be able to leave their homes and participate in their community are not in place.

Personal contextual factors in the form of psychological variables and social support may impact upon the evaluated outcomes. Psychological factors may also affect an individual's ability to resolve or come to terms with adverse situations, but equally an adverse situation may have a detrimental psychological impact on the individual either singly or in combination with other factors. This potential interplay of influencing and compounding factors and their impact on outcomes is a further area of interest in this study. In this chapter the evidence regarding the impact of these issues and factors will be discussed and evaluated.

## **3.2 Personal Contextual Factors Which May Influence Outcomes**

### **3.2.1 Individual Demographics**

Although SCI individuals who were over 65 tended to have a higher level of disability and required a higher level of care support on discharge than their younger counterparts (Wolfe, Hsieh and Mehta, 2012) they continued to make further functional improvements following discharge, as did their younger counterparts (Aito *et al.*, 2007). Conversely a UK-based case note review of outcomes for 304 individuals with fall related TSCI identified that although they were older than those sustaining TSCI by other means, and made the same amount of rehabilitation gains prior to discharge, their outcomes were poorer (Kennedy, Cox and Mariani, 2013; Wyndaele and Wyndaele, 2006). However the authors of this study acknowledge that they did not match the groups for age and therefore variations in outcomes may be a reflection of differing ages in the groups rather than the differing aetiology. These findings suggest that older individuals with TSCI may not be able to make the same amount of rehabilitation gains as younger SCI individuals but they will continue to progress following discharge. However research utilising data from the USA NSCISC database suggests that although SCI individuals of a greater age or additional conditions, for example obesity or shoulder problems, may not be able to achieve or sustain the level of functional ability usually expected for their level of injury, given a longer admission period they may be able to do so (Cifu *et al.*, 1999).

Although few differences in outcomes between males and females at one year post-discharge have been identified; males generally reported greater satisfaction with living circumstances. However, in the longer term, greater satisfaction with interpersonal relationships was reported by women, but so were greater levels of depression and dissatisfaction with health (Krause and Broderick, 2004; Greenwald *et al.*, 2001).

### **3.2.2 Psychological Factors**

Early psychological theories suggested that the SCI individual would progress through 'stages' of adjustment following their injury with gradual reductions in levels of distress (North, 1999). However a review of the available literature regarding adjustment following SCI suggests that this may not be the case (Galvin and Godfrey, 2001) that the psychological distress experienced following SCI does not necessarily reduce over time and a significant proportion of SCI individuals will still experience anxiety and depression over 2 years post injury. A more recent literature review highlights that although some SCI individuals may experience psychological symptoms of distress, for the majority they will be well within the range experienced by the normal population (Post and van Leeuwen, 2012). Two studies in the USA of monozygotic twin pairs identified that the

psychological profile of the SCI individual was the same as their non-SCI sibling (Hollick *et al.*, 2001; Tirch, Radnitz and Bauman, 1999). These findings suggest that in many cases it may not be the SCI by itself that produces psychological symptoms of distress rather that the reaction to SCI can be determined by the pre-existing personality and psychological make-up of the individual.

Following sustaining an SCI the individual will progress through a significant period of psychological adjustment as they begin to understand the implications of their SCI and then commence rehabilitation. Additionally the individual with a motor incomplete SCI will not only be adjusting to their disability but also to an uncertain prognosis and future due to the potential for neurological recovery but no certainty that this will occur (Dorsett, 2010; Suyama *et al.*, 1999). The process of adjustment will need to continue as the SCI individual plans for discharge and then commences reintegration in to the community. As the date of discharge approaches the SCI individual will have to transition from being in a supportive environment with access to twenty four hour specialist support to living autonomously in the community. This is also likely to require some psychological adjustment.

In an early qualitative survey of reintegration outcomes in 110 SCI individuals in the UK Richards (Richards, 1975) observed that even in cases where adequate provision for housing and support was made there was no guarantee of successful community reintegration. Her results identified two distinct groups; one who may succeed in reintegration following SCI even when difficulties occurred and another group who despite extensive support did not thrive psychologically, physically or socially following SCI. Although the methodology is less rigorous than would be accepted today and conclusions are drawn in respect of loose definitions of reintegration the findings echo assertions in the ICF model of disability (World Health Organisation, 2002) that contextual personal factors in the form of psychological profiles may influence outcomes. This thesis will examine if the psychological profile of an individual in the form of appraisals and coping styles, may influence the outcomes which will be examined in this thesis. In other words, if the psychological profile of an SCI individual can act as a confounding variable and influence rehabilitation and reintegration outcomes. This will be an attempt to identify if and why two individuals with the same level of injury, similar social situations and the same provision of resources may have different outcomes. The following sections will examine the potential for these psychological factors to influence the outcomes achieved by the SCI individual.

The issues previously reported in relation to scarcity of research as well as the age of available research also occur in the areas of coping strategies and locus of control in SCI. The small numbers of papers available is also compounded by the range of measurement instruments utilised in these studies. Where possible the most recent papers will be discussed unless older studies have not been replicated and bring some meaningful point to the discussion. Also where particular theories or standardised measures are discussed the original text supporting this will be utilised. If recent systematic literature reviews are available these will also be utilised and individual papers evaluated in these reviews will not be discussed individually unless they contribute notably to the discussion.

### **3.2.2.1 The Use of Coping Strategies Following Spinal Cord Injury**

Stress has been defined as 'a relationship between the person and the environment that is appraised by the person as relevant to his or her well-being and in which the person's resources are taxed or exceeded' (Lazarus and Folkman, 1984, p.152.). Sustaining an SCI is a stressful event that has significant and wide ranging physical, psychological, financial and social impact. This includes the potential for loss of employment, inability to return to the previous home, prolonged separation from family and loved ones and financial hardship. These issues are likely to require substantial changes to the lives of the SCI individual, their family and close network (Post and van Leeuwen, 2012). They are all significant life-events in their own right but combined they are likely to require significant psychological adjustment by the individual in both the short and long term (Galvin and Godfrey, 2001).

In psychological theory the use of coping strategies is suggested to be the means by which the individual adapts to stressful situations either by resolving the situation or changing their response to the situation, minimising the stress or distress experienced and so facilitating their psychological adjustment (Galvin and Godfrey, 2001; Roger, Jarvis and Najarian, 1993; Lazarus and Folkman, 1984). Although many different forms of coping strategies have been proposed, they are often classed as either adaptive (facilitating adjustment) or maladaptive (Carver, Scheier and Weintraub, 1989).

Other common definitions of coping strategies used are problem focussed, emotion focussed and avoidant coping strategies. Problem focussed coping is an active attempt to change the situation for the better and is generally viewed as an adaptive strategy (Roger, Jarvis and Najarian, 1993; Folkman and Lazarus, 1985), however if used in the longer term it may be maladaptive (Galvin and Godfrey, 2001) as the individual may be striving against a situation that cannot be changed. Emotion focussed coping is

suggested to be a means of regulating or releasing distressing emotions provoked by the situation and so can be both adaptive for example, theorists suggest that it may be useful in the early stages post injury (Ptacek and Pierce, 2003; Folkman and Lazarus, 1985) or maladaptive if used over a prolonged period. Combinations of elements of various coping strategies may be used at the same time. There are a variety of theories regarding avoidance coping, as it has been theorised as a non-destructive form of distraction in some scales and as denial in others (Raichle *et al.*, 2007; Stougaard Nielsen, 2003; de Carvalho *et al.*, 1998; Nieves, Charter and Aspinall, 1991) suggesting that the concept of avoidance coping has not been clearly defined in theory or research.

Two measures of coping trait commonly used in SCI research are: the Coping Orientations to Problems Experienced (COPE) Questionnaire (Carver, Scheier and Weintraub, 1989) and the Spinal Cord Coping Strategies Questionnaire (Elfstrom *et al.*, 2002). Coping as a dynamic, changeable factor is often measured using the Ways of Coping Questionnaire, WOCQ (Lazarus and Folkman, 1984). The WOCQ (Lazarus and Folkman, 1984) is a measure of coping response to stress in the current situation and was designed to be used as a repeated measure. Similar findings have been noted with these questionnaires in relation to coping styles most commonly employed. In a 10 year longitudinal study using the COPE questionnaire, the coping strategies identified as most commonly employed overall by 37 SCI individuals were adaptive coping strategies reflecting what is seen in the general population (Pollard and Kennedy, 2007). A further study utilising the WOCQ also identified that adaptive combination of coping strategies were the ones most frequently used by 28 SCI individuals at five years post-injury (Hanson *et al.*, 1993).

#### *Coping in Relation To Functional Ability*

The use of maladaptive coping strategies has been suggested to be more predictive of psychological distress than the functional impact of SCI (Kennedy *et al.*, 2000), however FIM was used to assess functional abilities which is suggested not to be sensitive to functional differences in some levels of SCI therefore these results must be interpreted with caution. Two longitudinal studies using other standardised measures identified no notable differences in the use of coping strategies across injury groups (Stougaard Nielsen, 2003; Nieves, Charter and Aspinall, 1991). As differing questionnaires were used, the different findings are unsurprising as the questionnaires may potentially have been measuring different concepts and models of coping (Lyne and Roger, 2000). In the main these results suggest that coping strategies do not vary significantly with variations in injury level and severity although further research is required to confirm this.

### *Variations in the Use of Coping over Time*

The coping strategy utilised by an individual is suggested to be related to the presenting stressor, how it is perceived to impact on an individual's goals or access to those goals and how long it does this for (Ptacek and Pierce, 2003). This is an important point when considering long term stressors such as those experienced following SCI, as the use of coping strategies may change as the individual progresses through the evolving situation. When investigating the use of coping strategies over time cross-sectional studies cannot establish causality. In this thesis a longitudinal study will be undertaken. In longitudinal studies the length of time observed is important as, arguably, the coping strategies employed during the initial stages of injury and rehabilitation/reintegration may be different to those required in the longer term. It is important to acknowledge that during the initial period following injury a changing range of stressors will appear as the individual adjusts to their changed functional status, the rehabilitation environment, changes to their expected future and life plans, possible difficulties in obtaining the resources they need and then reintegration in to the community. These changing stressors may require the individual to utilise different coping strategies, or differing levels of a range of coping strategies, as the situation they find themselves in evolves. If this assertion is correct then longitudinal studies may more clearly identify this fluctuation or change in coping strategies.

Using the WOCQ McColl and Skinner (McColl and Skinner, 1995) identified stability in the use of coping strategies over the first year post-discharge; however some non-significant trends indicating changes in utilisation of coping strategies were noted to be evident. Using the same measure Hanson et al (Hanson *et al.*, 1993) identified variation in coping strategies over the first five years post-injury, particularly an increase in the use of adaptive strategies. Hanson et al concluded that the relationship between specific coping strategies and adjustment will change over time with their importance in the adjustment process increasing or decreasing further emphasising the potentially dynamic nature of coping. In the UK a study using the COPE questionnaire identified stability in the use of coping strategies at one and two years post discharge (Kennedy *et al.*, 2000). In a follow-up of the same sample of subjects at 10 years reductions were noted in the use of pro-active stress reduction and support seeking coping strategies (Pollard and Kennedy, 2007). The research suggests that over time there potentially are changes in use of coping strategies following SCI but differences may not be statistically significant in the initial years following injury.

### *Outcomes and Coping*

Studies using a range of questionnaires, have identified a relationship between the use of maladaptive strategies during the early stages of SCI with poorer short and long term outcomes including higher levels of depression (Pollard and Kennedy, 2007; Kennedy *et al.*, 2000). Maladaptive strategies such as avoidance (not denial), emotion focussed coping and catastrophising were identified to be related to poorer outcomes in those with injuries of long duration in studies using differing measures with 40 and 157 subjects respectively (Raichle *et al.*, 2007; Nieves, Charter and Aspinall, 1991). Additionally maladaptive coping strategies are suggested to be more strongly associated with negative pain outcomes than adaptive strategies are with positive pain outcomes (Raichle *et al.*, 2007). However both of these studies measured coping at one point and therefore the direction of causality is difficult to confirm as the situation may be resulting in the maladaptive coping as much as the coping could be resulting in poor outcomes. A study utilising WOCQ identified that the use of adaptive strategies at 5 years post-SCI were indicative of better outcomes generally (Hanson *et al.*, 1993). However using a different measure a longitudinal survey of 37 SCI individuals identified that a decrease in use of rational (adaptive) coping and increase in use of emotion focussed (potentially maladaptive) coping during rehabilitation and the early months of discharge was predictive of lower levels of psychological distress at six months post-discharge (Stougaard Nielsen, 2003). This emphasises that emotion focussed coping can be both adaptive and maladaptive depending on how and when it is used. Similarly a longitudinal qualitative survey of 46 SCI individuals identified the use of denial (in the form of hope for recovery) in the early stages of SCI was linked to lower levels of depression later (Dorsett, 2010). Therefore although some strategies have been linked to better outcomes, there is not necessarily an 'ideal' pattern of coping strategies. SCI individuals may employ a dynamic range of emotional strategies following their injury some of which, although appearing to conflict with the aim of adjustment, may actually aid this process.

A general trend seems to have emerged that adaptive strategies are the ones most frequently employed by SCI individuals and may lead to improved outcomes. Although the use of maladaptive strategies are also suggested to have an impact on outcomes, what is considered to be an adaptive or maladaptive strategy may change over time as the situation that the individual finds themselves in will change (Kennedy *et al.*, 2012; Stougaard Nielsen, 2003; Kennedy *et al.*, 1995; Nieves, Charter and Aspinall, 1991). Due to this, the definitions of adaptive and maladaptive strategies may be too simplistic. SCI is not a 'one-off' stressful event. It contains many individual stressors that will tax the psychological resources of the individual on a changing basis as they go through the

processes of rehabilitation, and reintegration. The value of 'one-off' measures of coping need to be considered carefully when they are being compared with outcomes as causality cannot be confirmed. Longitudinal studies may produce more meaningful results in this situation but it is necessary to carefully consider the timeframe that is being examined in terms of the injury and adjustment process.

Some of the variations in results discussed could be explained by differences in the definition of emotion, problem focussed and avoidant types of coping strategy across different coping measurements (Lyne and Roger, 2000). This indicates that caution needs to be exercised when comparing results of different scales as they do not necessarily mean the same thing. Similarly it appears that the concept of avoidance coping may be loose and considered to contain several factors (Roger, 2013; Raichle *et al.*, 2007; Stougaard Nielsen, 2003; Nieves, Charter and Aspinall, 1991). Additionally questionnaires constructed to measure a relatively stable personality trait may not be sensitive enough to detect changes over time. Dunn and Elliott (Dunn and Elliott, 2008) assert that rehabilitation psychology researchers seem to give little thought to how they are applying the measures they have chosen and are often confused as to whether they are observing a process/coping strategy or a trait/coping style. Additionally emphasis is placed on the detection of differences rather than on the theories that explain the mechanisms and processes behind these changes. If the theories are attended to correctly then measures utilised will be appropriate for the timeframe observed and the hypotheses proposed.

If methods of coping can potentially predict later adaptation as well as physical and psychological well-being then it may be more important to focus on what is happening in terms of perceptions and emotions, the mechanisms that drive coping, rather than just changes, or lack of changes, over time. Negative appraisals of their injury by SCI individuals are suggested to be related to significant levels of anxiety and depression (Chevalier, Kennedy and Sherlock, 2009). The Life Span Evaluation theory (Sprangers and Schwartz, 1999) suggests that over time there will be changes in the appraisal of life and of the situations the individual finds themselves in. This suggests that the coping styles/strategies applied will either change or the amount that they are employed will be adjusted following this reappraisal as the perception of the stressor changes. Until recently few rehabilitation researchers have investigated the subjective appraisal of stress which is a key motivator of coping behaviour. Instead many have focussed on the coping behaviour which is the outcome of this appraisal (Dunn and Elliott, 2008). In more recent years SCI research in the UK has acknowledged this and commenced investigating the role of appraisal in evaluations of coping (Kennedy *et al.*, 2012;

Kennedy *et al.*, 2010b). Literature reviews have also identified that coping should not be viewed in isolation as other factors such as social support (Galvin and Godfrey, 2001) and perception of control (Chevalier, Kennedy and Sherlock, 2009) may have a notable impact on the appraisal and adjustment process. Adjustment to SCI needs to be viewed as the result of a range of inter-related and inter-dependent personality and demographic factors that will influence outcomes.

In summary it appears that adaptive coping strategies, amongst other psychological variables, may be linked with better outcomes, and the early use of 'maladaptive' coping strategies/styles may be linked to psychological distress and poor outcomes later. However, research also suggests that what is an 'adaptive' or a 'maladaptive' strategy may change over time and varying situations. It is counterproductive to focus extensively on changes or lack of changes, in coping strategy use in groups of SCI individuals as a whole but identification of coping strategies used by individuals is important as it may demonstrate issues that need addressing. Ideally the complex interrelation of the SCI individual with their perceptions and emotions should be viewed in the context of their social situation and support network factors as that is how issues that need addressing will be identified and outcomes improved.

### **3.2.2.2 The SCI Individual's Perception of Locus of Control**

Rotter (Rotter, 1966) theorised that individuals perceive that control of their lives is governed by forces that are either internal to them or external and that this perception will affect their behaviour. LOC is an appraisal of the situation that the individual is in and the extent to which they feel they can or cannot influence the outcome of that situation. It is this continuum of internality and externality that is measured by Locus of Control scales. As discussed in relation to QOL and coping, the individual's appraisal of the situation that they are experiencing is potentially important both in the adjustment to SCI and the outcomes that will be achieved (Sakakibara *et al.*, 2012; Kennedy *et al.*, 2012; Post *et al.*, 2010). Unrealistically high expectations of control are suggested to be as psychologically damaging as lack of perceived control (Rotter, 1966). Ideally an individual should perceive control to be at neither end of the continuum, but even at the 'mid-range' of the continuum individuals will tend to favour one or the other perception.

The individual's appraisal of the level of control they have over their lives has been suggested in literature reviews to be related to higher perceived levels of QOL (van Leeuwen *et al.*, 2012), may influence adjustment to SCI (Chevalier, Kennedy and Sherlock, 2009) and potentially the appraisal of control could influence rehabilitation and reintegration outcomes. Despite this there is comparatively little research in to this area

of psychological functioning following SCI and little consistency in forms of measurement. Rotter (Rotter, 1966) originally suggested that LOC could change over time and research has identified that a beneficial belief system that focuses on areas that can be controlled can be promoted in SCI individuals (Krause, Stanwyck and Maides, 1998). If this is correct then it may be possible to manipulate the appraisal of control to promote better outcomes following SCI, therefore it would be useful to identify any associations that have previously been identified in research.

Since the original theory and scale were developed the concept of Locus of Control has been applied to many areas of research including health studies. Much of the research investigating LOC in those with SCI has focussed on the issue of perception of control of health outcomes (Waldron *et al.*, 2010). However the SCI individual is more than just a collection of potential health issues, they interact with others and their environment, therefore measures of perception of control across the whole of an individual's life will be considered in this thesis.

An early qualitative USA-based study of the impact of LOC on psychological variables identified an association between internal LOC and higher levels of perceived well-being as well as high levels of social support (Schulz and Decker, 1985). A qualitative survey of 158 SCI individuals in the USA also identified that higher levels of perceived control were related to greater levels of life satisfaction (Chase, Cornille and English, 2000). A more recent literature review suggests that the SCI individual's perceived control in their life was a consistent determinant of QOL (van Leeuwen *et al.*, 2012). These findings all suggest that a greater perception of control as measured by a more internal LOC is significantly related to better psychological outcomes and well-being, although the direction of causality is not clear in these relationships as the perception of better QOL and higher levels of social support may promote or be promoted by a more internal perception of locus of control.

In a survey of 158 SCI individuals tetraplegics were reported to have lower levels of perceived control but sense of control was promoted in those directing their own personal care services (Chase, Cornille and English, 2000). Although in the USA SCI individuals who live in the parental home are suggested to have an external LOC (Bergmark, Winograd and Koopman, 2008) as all subjects in this study were tetraplegic it is unclear if care issues were also influencing outcomes. Again, the direction of causality is unclear in these studies and further investigation is warranted to identify if care and residential situations are chosen due to the LOC or influence the LOC through the requirement of independence or the reliance on others.

Whilst many measures of LOC focus specifically on a global appraisal of control, an alternative perspective is to view perception of control as being able to vary across three different behavioural dimensions or 'spheres' of an individual's life (Paulhus and Van Selst, 1990; Paulhus, 1983). As these spheres are conceptually independent of each other (Figure 3.1), an individual's perspective of locus of control may vary across each of these spheres.

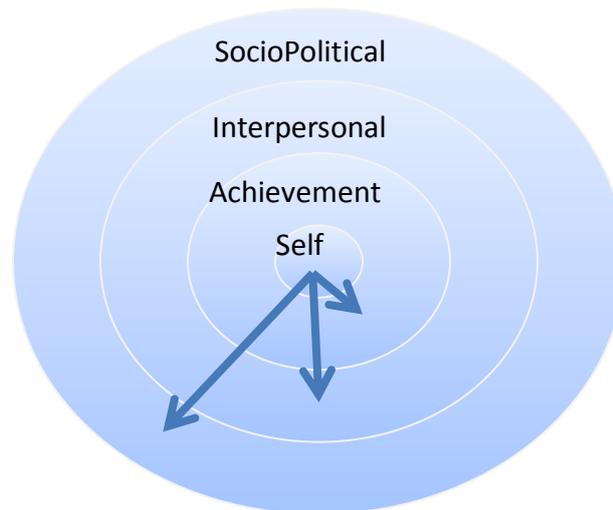


Figure 3.1 Graphical Representation Of The Spheres Of Control.

Paulhus, D.L. and Van Selst, M. (1990) "The spheres of control scale: 10 years of research", *Personality and Individual Differences*, vol. 11, no. 10, pp. 1029-1036

These spheres are: Personal Control, which is defined as the individual's sense of their personal achievement abilities and self-efficacy, their ability to do things and do them successfully. The concept of Self-efficacy has often been linked with LOC and is incorporated in this construct in this domain (Spittal *et al.*, 2002; Paulhus and Van Selst, 1990; Paulhus, 1983). The second sphere represents an area of LOC that is often ignored, interpersonal control, and reflects their perception of their ability to present and defend a position or their requirements, to foster social relationships, or to be an active member of a team. The final sphere represents the individual's sense of SocioPolitical Control, which reflects the extent to which they feel they can influence government and national policy through activities such as protest, voting or lobbying.

The Spheres of Control measure has not been used in the specific field of SCI research but was used a randomised control trial investigating the impact of use of service dogs on 48 individuals with disabilities, including 29 SCI individuals (Allen and Blascovich, 1996). The results indicated a more rapid and greater move toward an internal LOC in the experimental group. Following SCI these domains of control may be affected in differing ways and that the SCI individual's changing perceptions of their situation and

LOC will impact on the different spheres to a varying degree. Potentially this is an area that would bear further investigation.

Although research suggests that psychological well being may be associated with an internal locus of control and poor health with external locus of control, further research is required to confirm the direction of causality. Additionally, if, as originally suggested by Rotter (Rotter, 1966) LOC can change over time and situations, any potential for change would fit with the theorised changes in appraisal of life and life situations proposed in the Life Span Evaluation theory (Sprangers and Schwartz, 1999). If correct, then a change in the SCI individual's appraisal of their situation and control may promote potentially improved psychological functioning and through this improved rehabilitation and reintegration outcomes. However research investigating associations between LOC and these outcomes is lacking.

### **3.2.2.3 The SCI Individual's Perception and Experience of Social Support.**

The Marmot report (Marmot, 2010, p.139) concluded that social isolation can impact upon health and that *"Individuals who are socially isolated are between two and five times more likely than those who have strong social ties to die prematurely. Social networks have a larger impact on the risk of mortality than on the risk of developing disease, that is, it is not so much that social networks stop you from getting ill, but that they help you to recover when you do get ill."* The importance of social support in assisting the SCI individual to attain successful reintegration has been stressed in research from many countries over many years (Noreau *et al.*, 2010; Raichle *et al.*, 2007; Stougaard Nielsen, 2003; McColl and Skinner, 1995). However the lack of consistency in definitions and the multi-faceted nature of social support results in a variety of measures and methodological approaches being used in its measurement (Müller *et al.*, 2012) and results in difficulties with cross-study comparisons as it is rarely possible to perform 'like for like' comparisons.

A recent literature review identified that social support is suggested to contain several elements, these are: instrumental (practical, tangible), emotional and informational support (Müller *et al.*, 2012). However social support has also been suggested to have elements such as collusion, which can have a negative effect on outcomes particularly in pain management (Raichle *et al.*, 2007) and therefore cannot always be presumed to be beneficial to the SCI individual. As discussed in previous sections perceived high levels of social support have been found to be associated with better outcomes post SCI in terms of employment (Noreau *et al.*, 2010), higher perceptions of self efficacy (Stougaard Nielsen, 2003) and higher levels of perceived control and adjustment

(Schulz and Decker, 1985), as well as better psychological functioning and lower levels of pain (Raichle *et al.*, 2007; McColl and Skinner, 1995). Low levels of social support are suggested to be a risk factor for, amongst other things, higher levels of distress (Stougaard Nielsen, 2003). Despite the potential benefits and impact of social support little research has been undertaken specifically looking in to this issue and none was identified in the UK.

Social support could be viewed as a factor that is both internal and external to the SCI individual as although the receipt of social support is dependent on the availability of a social network however the perception of the level and effectiveness of the social support will be determined by the SCI individual's attitudes and appraisals (Mortenson, Noreau and Miller, 2010; McColl and Skinner, 1995). A review of available research also highlighted that the social skills of an individual can influence the provision of social support (Müller *et al.*, 2012). This is potentially an important element to consider as social skills training may be required to assist the SCI individual to be able to reap the maximum benefits from available support. This may also suggest that the locus of interpersonal control may be an important element in determining the perception that the SCI individual has of their ability to access support and, as suggested by the scales author (Paulhus, 1983) measure the social skills of the SCI individual.

Changes in social support over time were noted in a Canadian longitudinal study of 93 SCI individuals. The study identified that although social support generally promoted better QOL and assisted the SCI individual to reintegrate successfully over time, family support became more important in this than support from friends (Mortenson, Noreau and Miller, 2010). However Muller *et al.* (Müller *et al.*, 2012) noted that contact and support from peers has also been linked to better QOL and well-being.

The potential impact of social isolation has been noted in the Marmot report (Marmot, 2010) and the potential protective nature of social connections and support in promoting better health, psychological, social and reintegration outcomes post SCI has been noted internationally in SCI research studies (Müller *et al.*, 2012; Mortenson, Noreau and Miller, 2010; Raichle *et al.*, 2007; Stougaard Nielsen, 2003; McColl and Skinner, 1995; Schulz and Decker, 1985). The ability to influence the levels of social support received or perceived to be received has also been noted to be a potential therapeutic option that could be explored for SCI individuals (Müller *et al.*, 2012). Despite the potential for social support to facilitate or limit outcomes following SCI this is an under researched area, particularly in the UK.

### 3.3 Environmental Contextual Factors Affecting Reintegration Outcomes

There are some environmental factors (World Health Organisation, 2013) that are external to the SCI individual which have the potential to affect outcomes following discharge to the community. The issue of provision of accessible accommodation has already been discussed and two further environmental contextual factors are the provision of necessary resources in the form of equipment and care support. As noted in ICF guidance materials environmental contextual factors may be as much about variation in the provision of resources such as care and equipment as they are about environmental barriers (World Health Organisation, 2013, p.65).

As post-SCI life expectancies increase there will be a longer period of time during which the individual will need to draw on a range of healthcare and support services in order to stay healthy, ideally complication free, and to continue to function as an active member of their social group and society. As noted by the Department of Health SCI is a high cost condition (NHS England, 2013a). SCI organisations in the UK estimate conservative annual costs of SCI at £500 million (The Every Eight Hours Campaign, 2011) however the source of this information is unclear. The majority of information regarding the long and short term costs of SCI comes from the USA where lifetime healthcare costs for an individual aged 25 at the time of injury are estimated to be \$2.1-5.4 million, dependent on level of SCI (Cao, Chen and DeVivo, 2011). Although this information is the product of a health and social care system that is markedly different to that in the UK, and so will demonstrate different actual costs, in the absence of similar information for UK costs this information may be useful for comparisons of proportions of costs and potential influencing factors.

In the UK all healthcare is free at the point of use but provision of associated social care or equipment and supplies is often either means tested or rationed. In the USA it has been estimated that care costs account for approximately 44% of estimated annual costs for SCI (Harvey *et al.*, 1992). Improved survival rates and a changing demographic pattern (DeVivo, 2012; DeVivo *et al.*, 2011) following SCI have significant implications for funding bodies in terms of initial and life-long costs following SCI as a greater level of support and equipment will be required by these SCI individuals (DeVivo *et al.*, 2011). Higher level injuries and lower functional abilities are stated to be associated with higher costs (Cohen *et al.*, 2012; DeVivo *et al.*, 2011) as are poor health, the incidence of complications and greater age (DeVivo, 2012; Hitzig *et al.*, 2011; Coll, 2007). Unless those close to the SCI individual are able to meet care support needs, individuals will require some level of formal care ranging from occasional assistance with some domestic activities to support 24 hours per day. Additionally an array of equipment will

be required and SCI individuals may require financial assistance if they are unable to return to work.

### **3.3.1 Care and Assistance**

Having completed their rehabilitation and secured accommodation, the SCI individual is ready for discharge (South of England Spinal Cord Injury Board, 2010). Dependent on the SCI individual's functional ability, assistance will be required with a range of personal and domestic care activities, as well as potentially being required to engage in social activities and other activities in the community. Details of the levels of functional ability and potential assistance required are detailed in Chapter 2, Table 2.1. Where assistance is required this will need to be provided by a carer or other nominated person in the community and without this assistance the individual will be unable to be discharged (South of England Spinal Cord Injury Board, 2010, Std. 9.2.). As with many areas of research discussed in this thesis no relevant UK-based research was identified. A systematic review of international research studies (Boucher, Ballantyne and Boschen, 2012) summarised research findings for both formal and informal care provision and this will be discussed where other more recent or relevant research is not available, however the focus in this thesis will mainly be on formal care provision.

Many SCI individuals will only require assistance once a day or less however those with a motor complete SCI at C6 or above are likely to require the assistance of one to two people on an ongoing basis through a 24-hour care package (Boucher, Ballantyne and Boschen, 2012). Care requirements may be quite substantial (possibly eliminating the potential for an informal carer to work), extremely intimate in nature and likely to be lifelong (South of England Spinal Cord Injury Board, 2010; Grundy and Swain, 2002). Due to this partners and relatives of SCI individuals are not encouraged by UK SCIC teams to be actively involved in formal care procedures (Joyeux and Spinal Injuries Association, 2002; Grundy and Swain, 2002). However Boucher et al (Boucher, Ballantyne and Boschen, 2012) identified that a many SCI individuals receive a notable amount of support from family members for a significant amount of time but this is often not formally recognised, indicating that even if formal support is provided a significant but unrecognised amount of informal support may be provided by family and friends. They also identified that family care givers experience health, career and social issues as a consequence of their caring role. A USA-based study also identified tetraplegic individuals who rely on family members for care report a loss of autonomy and privacy, as well as deteriorating family relationships (Bergmark, Winograd and Koopman, 2008). Combined these findings suggest that informal care provision has negative outcomes for both the provider and the recipient of care. However the small amount of research

investigating the impact of source of care on outcomes suggests that further research is required to clearly identify the sources and amounts of care provided to SCI individuals and well as the implications of this.

In the UK state funding for care is in the main from Social Services (London Councils, 2007) or the National Health Service (NHS) via Continuing Healthcare funding (Great Britain. Department of Health, 2012). Care funding can also be provided from a variety of other sources such as private funds, the Department of Work and Pensions Access to Work schemes (Great Britain. Department for Work and Pensions, 2012a) or funds from a compensation claim (IUA/ABI, 2007). In the UK issues have been noted with obtaining state funding for care which have occurred for many years but (in the author's experience) have become more prevalent in the current economic situation as council Social Service Departments (SSD) and the NHS seek to curtail expenditure where possible (Lungu-Mulenga *et al.*, 2013; Samuel, 2009; London Councils, 2007; Brangwyn, 2007). These budgetary restrictions often manifest in the form of NHS or SSD teams contesting the level of care support that SCIC discharge teams have recommended, or NHS and SSD teams disputing funding responsibility. Research has indicated that inadequate levels of care or badly provided care and support in the community lead to significant health and integration issues (Boucher, Ballantyne and Boschen, 2012; van Loo *et al.*, 2010) and discharge delays (Barr and Spinal Injuries Association, 2009) but further UK-based research into these issues is required.

A review of literature identified that Independent Living programmes (in which carers are recruited and directed by the individual) are perceived to give the individual more choice and control over their care (Boucher, Ballantyne and Boschen, 2012) however no UK-based research was identified in this survey. In the USA care provided in this way has been found to reduce costs, lead to greater satisfaction levels and better health outcomes in those receiving the care (Mattson-Prince, 1997). Satisfaction with personal assistance services has been identified to be significantly related to life satisfaction and, so, improved QOL (Chase, Cornille and English, 2000), whereas those in receipt of care from family members report impaired choice and control (Bergmark, Winograd and Koopman, 2008). Options are available in the UK for the SCI individual to actively manage and co-ordinate their care through direct payments (Joyeux and Spinal Injuries Association, 2002). However due to the onerous responsibility on the recipient of direct payments to recruit, manage and train carers, ensure sickness and annual leave cover as well as to calculate tax and national insurance many SCI individuals prefer to appoint an agency to provide their carers or rely on their Community Professionals to make these arrangements (Joyeux and Spinal Injuries Association, 2002). Research suggests

that provision of care through programmes in which the SCI individual has control promotes better outcomes and higher levels of satisfaction however there is no UK-based evidence to confirm these findings.

In summary, as with many of the factors discussed in this thesis the perception of control and choice are reported to increase sense of satisfaction with care services (Boucher, Ballantyne and Boschen, 2012; Mattson-Prince, 1997). Research indicates that care provision should promote the autonomy of the individual if they are to succeed in applying the skill that they have learnt during their rehabilitation programmes (Boucher, Ballantyne and Boschen, 2012; Bergmark, Winograd and Koopman, 2008; Mattson-Prince, 1997). If the way in which care is provided is dictated to the SCI individual, rather than by them, this may erode the sense of autonomy and satisfaction that the individual has, as well as potentially restricting the activities they may participate in. Receipt of care to meet functional needs post-SCI is essential, whether those functional needs are assistance with washing and dressing or accessing the community. Although international studies suggest that restriction of care provision will potentially lead to increased costs in the longer term (Boucher, Ballantyne and Boschen, 2012; van Loo *et al.*, 2010; Mattson-Prince, 1997) budgetary constraints often mean that UK NHS and SSD are increasingly focusing on immediate need at the expense of aspirations and long-term well-being (Lungu-Mulenga *et al.*, 2013; Samuel, 2009; London Councils, 2009; Bergmark, Winograd and Koopman, 2008; London Councils, 2007; Brangwyn, 2007). Further UK-based research in to the impact of sources and levels of care on outcomes following SCI is required.

### **3.3.2 Equipment**

A variety of equipment will be required by SCI individuals dependent on the level of injury. Equipment such as wheelchairs, hoists, adapted vehicles, amongst other things, may be required to assist the individual to perform tasks independently or, in the case of pressure relieving equipment or orthoses, to maintain their general health and well-being (Somers, 2010; Kirshblum *et al.*, 2007). Details of estimated requirements can be found in the South of England Standards (South of England Spinal Cord Injury Board, 2010) and a range of clinical texts (Kirshblum and Campagnolo, 2011; Somers, 2010; Grundy and Swain, 2002).

The SCI individual will have learnt during their rehabilitation to maximise their functional abilities and independence where possible and in many cases this will have required the use of some pieces of equipment. Some equipment will be essential at the point of discharge for example hoists, wheelchair, a bed and ventilatory assistive devices and

associated equipment (National Spinal Cord Injury Strategy Board, 2011; Somers, 2010; South of England Spinal Cord Injury Board, 2010). Others equipment (for example environmental control systems) can be provided after discharge however delays in provision or lack of provision of equipment may result in increased requirements for care to assist the SCI individual to perform the tasks they would have performed independently with the equipment (World Health Organisation, 2013). The incidence of complications is suggested to result in greater SCI related costs (DeVivo, 2012) and may be significantly higher than the costs of the required resources (Regan *et al.*, 2012). Despite claims by professionals that failure to provide assistive equipment or inadequate provision results in impaired function, reduced participation and potentially increased risks of health consequences there is little evidence relating to this either in the UK (Joyeux and Spinal Injuries Association, 2002) or other countries (Bushnik, 2002).

A wheelchair is a piece of equipment that is essential for approximately 80% of SCI individuals (Connolly *et al.*, 2012; de Groot *et al.*, 2011) and provision of a suitable, permanent, wheelchair with which the individual can independently mobilise and access the community, although very costly, is essential if the primary aim of rehabilitation, *participation* is to be achieved (World Health Organisation, 2001; Guttmann, 1977). Despite this a significant level of variation in the provision of long term wheelchairs has been noted in the UK (Rose and Ferguson-Pell, 2002). Often interim wheelchairs are given to SCI individuals on discharge with (in the author's experience) a potentially lengthy wait for formal assessment. Interim wheelchairs are often standard issue heavy wheelchairs which potentially limit the mobility of the SCI individual and the ability to access the community, particularly in those with reduced upper limb strength (Rose and Ferguson-Pell, 2002).

The majority of paraplegics and a sizeable minority of tetraplegics will be able to independently propel a manual wheelchair (Chaves *et al.*, 2004) but the provision of a powered chair is required to permit those with a high level SCI or with otherwise impaired upper limb strength and function to mobilise independently (Hastings *et al.*, 2011). If individuals with high level SCI are only provided with a manual chair they will be dependent on the assistance of another person to mobilise. Those with a C3 AIS A or B level SCI or above will also require a more sophisticated powered chair with alternative means of control, such as mouth operated controls to facilitate independent mobility.

Improved outcomes in the form of higher employment rates as well as better physical function and mobility have been identified in motor complete C6 and C7 SCI individuals

who used a manual wheelchair in the USA compared to those using a powered wheelchair (Hastings *et al.*, 2011). However although the use of a manual wheelchair has been suggested to increase options for accessing the community and transportation (Harvey *et al.*, 2012; Connolly *et al.*, 2012; Chaves *et al.*, 2004) and assist in maintaining upper body strength and the cardiovascular activity it may result in a significant risk of shoulder strain and potentially long term shoulder damage (Hastings *et al.*, 2011). This potential damage is likely to be further exacerbated if a heavy or inappropriate manual chair is used for any length of time. Research in the USA and UK has noted that an inadequate wheelchair can be more limiting to the SCI individual's participation than their impairment (Chaves *et al.*, 2004; Rose and Ferguson-Pell, 2002). The appropriate prescription and set up of a wheelchair can, to a similar extent, improve the functional ability of SCI individuals (Connolly *et al.*, 2012).

Inappropriate wheelchair provision will limit the ability of the individual to access their community (Chaves *et al.*, 2004). Unfortunately in the current economic situation UK Wheelchair Services are experiencing the same budgetary restraints as other public services with resulting limitations in service and equipment provision (Spinal Injuries Association, 2012; Brangwyn, 2007; Kennedy, Lude and Taylor, 2006; Rose and Ferguson-Pell, 2002).

It is widely acknowledged (Spinal Injuries Association, 2012; Loughborough University, Public Relations Office, 2012; Aspire, 2009; Kennedy, Lude and Taylor, 2006) that there is often a shortfall in the provision of resources such as equipment, care or housing to SCI individuals. The costs of the consequences due to lack of provision of resources in the UK for example pressure sores may occur due to inappropriate mattress provision (Regan *et al.*, 2012; Kirshblum *et al.*, 2007), or additional care requirements due to lack of appropriate wheelchair provision (Rose and Ferguson-Pell, 2002) will inevitably be met by the UK state. As Local Authority and NHS budgets have been increasingly cut (Lungu-Mulenga *et al.*, 2013; Samuel, 2011; Samuel, 2009; London Councils, 2009; Brangwyn, 2007; Rose and Ferguson-Pell, 2002) there has (in the author's experience) been an increased demand to justify the provision of resources such as care or equipment. Additionally there have been increased requirements for evidence to support requests in the absence of supporting research but no research investigating outcomes associated with this. This has led to some resources such as equipment not being provided or a delay in provision occurring due to lack of evidence to support timely provision. Potentially this lack of provision may also result in the SCI individual not being able to achieve the primary object of rehabilitation, to participate in their society (Somers, 2010; World Health Organisation, 2001). In the UK we are currently unable to

provide information in order to compare these costs. This not only results in difficulties justifying the provision of care and equipment but also an unknown level of need as a consequence of not providing these resources. If it were possible to demonstrate that resources, spent effectively or ineffectively, affected outcomes this information would be extremely useful for SCI individuals, staff at SCIC and service Commissioners.

### **3.4 Summary**

The SCI individual's appraisal of their SCI, their current situation and their ability to function and be satisfied in that are suggested to be important determinants of their psychological well being and ultimate functioning. Until recently much research focussed on potential changes in psychological profiles over time rather than the underlying psychological constructs and appraisal that would elicit responses. Issues with varying definitions of psychological concepts and differing forms of measurement present difficulties in comparisons across studies. The process of appraisal and the ability to re-evaluate appraisals are important underlying mechanisms for psychological processes. The research reviewed suggests locus of control is an attribution of control in a situation; coping styles are how the information gained from this attribution is processed and adapted to. Improved outcomes including better psychological well-being have been identified in those who utilise internal perceptions of control and adaptive coping and appraisal strategies. Poorer outcomes and greater levels of psychological distress have been suggested to occur in those who use maladaptive coping and negative appraisals although the direction of causality in these relationships is unclear. However the definitions of adaptive and maladaptive coping strategies are loose as coping is a dynamic construct which changes as the environment the individual finds themselves in changes.

Social support and the perception of social connectedness is considered to be important for the population as a whole but arguably could be more important in the SCI population due to poor access in the community resulting in isolation, however there is little research confirming the impact of social support or the effect of social support on outcomes. Social skills training has been suggested as a means of promoting social support for SCI individuals and may be a means of increasing the SCI individual's perception of control.

SCI is a lifelong condition and therefore any healthcare and support requirements the SCI individual has may need to be met for a substantial period of time. Despite this there is little UK based evidence regarding either the initial or ongoing costs of SCI. This coupled with the lack of information regarding the incidence or prevalence of SCI in the

UK or potential changes in demographics of those sustaining SCI presents potential difficulties for service planners and budget managers. It could also potentially lead to a significant shortfall in service provision.

The ability to discharge individuals to the community is potentially affected by funding issues. Reduced provision of a variety of resources may significantly impair the ability of the individual to participate in society and maintain health and well-being however there is no UK based evidence to confirm this. The provision of care and equipment are two factors which are central to the ability of an SCI individual to participate in society at basic level but are subject to stringent budgetary and provision constraints in the UK, the impact of which usually means inadequate provision. This is suggested to lead to an increased incidence of avoidable health and psychological issues and increased costs to the state however evidence confirming or disputing this is lacking. Further evidence is also required to confirm if delays in or inappropriate provision of equipment, including wheelchairs limit outcomes following discharge to the community, particularly in terms of participation.

The perception that the individual has choice and control is important in many areas of their lives but the perception of choice and control over care provision has been suggested to be particularly important for the psychological well being of the SCI individual. Research indicates that lack of choice and control is detrimental to psychological well-being and the perception of autonomy. Provision of care through the relatives of SCI individuals may be detrimental to the well-being of the care-giver and the autonomy of the SCI individual. Research regarding the levels of support provided by relatives is patchy and comparisons across studies are difficult due to differing definitions or lack of clarity over sources of care provision. Difficulties have also been noted with identifying if SCI individuals are experiencing issues with care provision or their residential situation.

This chapter has reviewed research investigating a range of environmental and personal contextual factors which may affect rehabilitation and reintegration outcomes. This has identified that there is little research available and often no UK-based evidence investigating the potential impact of these factors on rehabilitation and reintegration outcomes. What little research is available is frequently in excess of 10 years old, issues with differing methodologies and forms of measurement also result in difficulties in comparing results obtained from these studies.

This thesis aims to investigate rehabilitation and reintegration outcomes following SCI and factors which may enhance or limit those outcomes. Following the review of research discussed in this and the previous chapter the following areas of investigation in relation to the outcomes measured in this research project are proposed:

*Healthcare systems outcomes*

- Clarification of acute and rehabilitation LOS and examination of factors which may result in variations in rehabilitation LOS.
- The impact of complications sustained prior to admission on LOS, rehabilitation outcomes and reintegration outcomes.
- Readmission rates in the first year post-discharge and causes of readmissions.
- The frequency and lengths of discharge delays, the main causes of these and whether discharge delays impact upon reintegration outcomes or psychological profiles.

In relation to the reintegration outcome measures identified the following further areas of investigation are proposed

- Community participation
  - Levels of community participation at one year post-discharge and the factors that SCI individuals feel influence the ability to participate in community activities.
  - Do SCI individuals with higher levels of social interaction and community activity and access to a vehicle have a higher perceived QOL and lower levels of psychological distress as measured by emotional coping?
- Vocational status
  - The vocational status of SCI individuals on discharge and at one year post-discharge and how this compares to their vocational status on injury.
  - Whether particular modifiable or non-modifiable factors are related to paid employment or further education/training.
  - If vocationally activity is related to a better QOL and a lower incidence of health issues.
- Accommodation
  - The discharge destination of SCI individuals, residence at one year post-discharge and how this compares to their accommodation at the point of injury.
  - If individuals with high level SCI are be more likely to be discharged to a Nursing Home and whether they will still be living there are one year post-discharge
  - How many SCI individuals are discharged to accommodation that has been adapted to meet their needs or already meets their needs. How many are still awaiting provision of adaptations or suitable accommodation at one year post-

discharge. The sources of funding of adaptations and whether this is related to the speed of provision of adaptations. If delays in provision of adaptations lead to increased care provision, reduced vocational activity and reduced community activity

- If the residential situation and outstanding adaptations influence SCI individual's perceptions of current QOL and psychological profile
- Quality of Life (QOL)
  - SCI individuals' ratings of QOL and whether this changes with length of time since injury.
  - Identification of factors which impact upon perceived QOL and if any of these are modifiable.

Through the experience of the author the following research questions are also proposed:

- Whether levels of care received will be reduced at one year post-discharge and if the levels of care provided by family members will have increased.
- Do a greater number of avoidable complications and readmissions occur if the required equipment has not been provided?
- Whether psychological profiles and QOL vary between paraplegic and tetraplegic individuals.
- Whether the perception of control over care influences perceived locus of control.

In the next chapter the methodology for investigating these questions will be proposed, appropriate measures selected and the research process piloted and evaluated. Additionally, clear definitions will be given of variables to be evaluated and timescales to be measured in order to ensure that comparisons may be made with results from this study and other research.

## **CHAPTER 4: The Research Methodology, Measures and Procedures**

### **Overview**

In this chapter the development of the methodology of the research project will be discussed. The measures that will be used in the project will be presented. Clear definitions of the variables and timelines to be measured will be developed. In addition, the results from a Pilot Project will be presented along with the changes that were made to the project structure following evaluation. Finally, the methods and procedure of each phase of the actual research project will be discussed.

#### **4.1 Introduction**

In the previous chapters the context of SCI in the UK was identified. SCI is a lifelong condition which has wide ranging implications for the SCI individual and their immediate network (Joyeux and Spinal Injuries Association, 2002; Grundy and Swain, 2002; Oliver *et al.*, 1988). The available research regarding outcomes following SCI along with factors which may influence these outcomes were reviewed. It was identified that there are gaps in our knowledge regarding the outcomes for an SCI individual and factors which may influence these outcomes. This presents difficulties for healthcare service planners when identifying service requirements, for SCIC professionals when lobbying for service and resource provision and most importantly for SCI individual as they attempt to reintegrate in to the society without some resources or support that are required. This chapter will present the methodology and measures for a research project to attempt to fill some of these gaps in our knowledge.

#### **4.2 Identifying the Research Objectives**

The overall purpose of this research is to investigate rehabilitation and reintegration outcomes in a cohort of SCI individuals both on discharge and at one year post-discharge and identify factors which may influence those outcomes. Through a review of the available research the outcomes to be evaluated in this thesis have been identified. Some are healthcare system outcomes which evaluate the injury to discharge 'pathway' but may also have an impact on the outcomes for the SCI individual. These outcomes are: Functional Improvement, Length of Stay, Discharge Delays, and Readmissions. The other identified outcomes are outcomes for the SCI individual and are: Community Reintegration and Participation, Vocational Status, Quality Of Life and Accommodation/Residential Situation. Using the ICF model of disability the majority of the SCI individual specific outcomes can be viewed as measures of participation (World Health Organisation, 2002). Quality of life is more difficult to classify according to the ICF as it is suggested to be a reflection of participation and engagement however it could also be classed as a personal contextual factor. In this thesis it will be considered to be an outcome measure for successful reintegration and engagement in society. Additionally, some contextual factors were identified which may influence these outcomes. The personal contextual factors are: individual demographics, coping strategies, locus of control and social support. Environmental contextual factors were identified as the provision of resources such as equipment and care provision. Accommodation although classed as an outcome measure of successful reintegration in to the community is also an environmental contextual factor that may affect levels of participation. Lack of accommodation or inaccessible and inadequate accommodation

due to delays in provisions of adaptations will impact upon the ability of the individual to engage in their community (World Health Organisation, 2013).

From this a research objective is proposed of:

- To establish, through a variety of measures, if both rehabilitation and reintegration outcomes are influenced by contextual factors.

In this thesis the term resources will be considered to mean provision of specialist healthcare through admission to an SCIC bed as well as potential environmental contextual factors such as accommodation, care and equipment provision. The issue of provision or non-provision of resources has also been discussed along with the potential for impaired outcomes with delayed provision. SCI individuals who have access to private funds or an interim personal injury payment may be able to secure resources more quickly. As delays in provision of resources frequently occur due to budgetary restrictions the identification of individuals with access to alternative funds may provide an opportunity to investigate if outcomes vary with an 'ideal' provision of resources on discharge. Therefore where possible information regarding the timing and source of provision of resources will be examined in relation to outcomes achieved.

Therefore an overall null hypothesis for this project is proposed of:

- Timely provision of accommodation, care and equipment does not make a difference to the speed of discharge once rehabilitation is completed, or on reintegration outcomes once discharged.

In the following sections the methodology of the research and location at which the research will be undertaken will be discussed.

### **4.3. The Location:**

#### **4.3.1. Single Site versus Multiple sites**

As previously discussed SCI is recognised as a 'low incidence' condition (NHS England, 2013a) and therefore the numbers of potential subjects may be small. However performing a multi-site research would increase the opportunity for confounding variables to occur due to variations in SCIC services and rehabilitation pathways (New *et al.*, 2013b). Therefore, a decision was made to restrict sampling to one centre in order to eliminate the possibility that differences in pathways and outcomes observed between SCI individuals could be due to differing treatment and management protocols at other SCIC.

### **4.3.2. The London SCIC**

The London Spinal Cord Injury Centre (LSCIC), based at the Royal National Orthopaedic Hospital (RNOH), Stanmore, is the site of this research project. It is one of the 11 designated specialised SCIC in the United Kingdom (NHS England, 2013a) and provides both acute treatment (including surgery) and rehabilitation for those who have sustained an SCI by either traumatic or non-traumatic means. It is a regional facility essentially covering London and the South East of England; however SCI individuals may be referred to the SCIC from other areas.

#### **4.3.2.1. Rehabilitation at the LSCIC**

An SCI individual admitted to the LSCIC is deemed to be ready for rehabilitation when acute medical care is complete, that is, when spinal surgery or stabilisation (if required) had been performed, the individual was medically stable and rehabilitation was the major reason for them remaining in hospital. Rehabilitation formally commences at the point that the SCI individual has been mobilising in their wheelchair for approximately 4 hours. The form and principles of SCI rehabilitation have been discussed previously in Chapter 1.

#### **4.3.2.2. Care pathway**

Progress through rehabilitation at the LSCIC is monitored via an Integrated Care Pathway (ICP). ICPs have been used in SCI rehabilitation for many years as a process map to identify interventions and achievements that occur during an episode of care, the variations in these that may occur and the reasons for the variation (Goodwin-Wilson, Watkins and Gardner-Elahi, 2010; Playford, Sachs and Thompson, 2002). The ICP provides a means of audit and evaluation of service outcomes and potential issues. It is essentially a 'when, what and who' guide to the progress that the SCI individual will be expected to have made at various points in their rehabilitation, the interventions they will have received and who will have actioned or provided those interventions.

The LSCIC uses an ICP that was developed on site and is designed to work with 7 injury groupings with varying lengths of stay (LOS) of between 6 and 16 weeks (See Appendix C). It was implemented in 2008 and is still in use on the LSCIC, although the document and pathway has been adjusted over time following further evaluation and review. It commences at the point of mobilisation or admission to LSCIC (whichever is the later of the two) and continues until the SCI individual is discharged, with notes made regarding the completion of rehabilitation and delays to discharge.

#### **4.3.2.3. Completion of Rehabilitation and Discharge Delays**

Rehabilitation is deemed to be complete when the individual has achieved all of the goals that they are capable of achieving that require an inpatient stay. If the SCI individual is not able to be discharged due to community issues then rehabilitation activities will cease. The individual will remain on the LSCIC, but they will be classed as a delayed discharge. Care and treatment will continue to be provided as required but active therapy and supported social community activities will cease.

#### **4.4. Selecting the Research Approach**

As no research interventions are being planned in this research and the variables measured will be the progression of the subject through the admission and rehabilitation pathway and the outcomes following rehabilitation and reintegration an observational study will be performed.

A longitudinal design was utilised in order to be able to evaluate outcomes and make between and within subject comparisons. Longitudinal collection of data permitted repeated psychological measures to be incorporated in to the process and the observational monitoring of when provision of resources or issues occurred and for outcomes to be viewed in relation to this. A decision was made that, other than in the initial stages when retrospective collection of baseline data would be required, data would be collected on a prospective, longitudinal basis.

##### **4.4.1. Establishing the Data Collection Points**

In order to monitor the rehabilitation and reintegration outcomes following SCI successfully it is necessary to clearly identify the period over which data will be collected and the points in time at which measures will be taken.

Two phases of data collection were proposed for this research. The first phase covers the point of injury to discharge from the LSCIC and will incorporate measures of healthcare system evaluation. The second phase then evaluates outcomes at one year post-discharge in relation to the potential influencing environmental and personal contextual factors.

Variable	Measure	Taken On Admission	Taken On Discharge	Taken At One Year Post-Discharge
Baseline Measures	Demographics	✓	✓	
Other Medical Conditions	Presence of other medical conditions	✓	✓	
Healthcare Systems Outcomes	Referral and admission data	✓		
	LOS and discharge data including reasons for delay		✓	
	Type of complication on admission and impact on pathway	✓	✓	
Functional Improvement	Neurological level and AIS grade	✓	✓	✓
	Goal achievement		✓	
Readmissions	If readmission planned		✓	
	Readmissions occurred			✓
Sequelae Of SCI	Type and impact			✓
Community Reintegration And Participation	Number and form of community outings		✓	✓
	Driving/Car owner or access to public transport		✓	✓
Vocational Status	Form of vocational activity and details	✓	✓	✓
Accommodation And Residential Situation	Residential situation and issues with accommodation	✓	✓	✓
	Details of outstanding adaptations		✓	✓
Social Support	Frequency and importance ascribed to social contacts			✓
Care	Care levels and funding		✓	✓
	Issues with care			✓
Equipment	Outstanding equipment		✓	✓
Psychological Variables	Coping strategies and Locus of Control	✓		✓
QOL	QOL measure			✓

Table 4.1 Proposed Data to Be Collected and Points of Collection

#### 4.4.1.1 Phase I: Inpatient Phase

The first phase of the research is the most active in terms of data collection. It concerns not just the baseline measurement at injury but also collects data throughout the

preadmission and admission pathways of the SCI individual including the period prior to LSCIC admission, their rehabilitation and preparation for discharge. Details of the specific data that will be collected and the time points for collection are shown in Table 4.1.

*Baseline: Point of Injury*

The aim of this project is to establish outcomes following SCI and identify factors that may affect those outcomes as well as the extent to which this occurs. Retrospective baseline measures are taken at this point identifying the SCI individual's situation at the point of injury, against which subsequent outcomes can be measured.

*Process: Injury to Discharge*

Benchmarks	Phases Recorded	Data Obtained
Injury	Injury to referral ↓	Number of Days from Injury to Referral
Referral	Referral to admission ↓	Number of Days from Referral to Admission and from Injury to Admission
Admission to LSCIC	Admission to mobilisation ↓	Pre mobilisation LOS
Date of mobilisation	Mobilisation to Completion of Rehabilitation ↓	Rehabilitation LOS (= No of days from mobilisation to discharge – No of discharge delay days)
Date completed rehabilitation	Completion of Rehabilitation to Discharge	Time over/under target LOS (=Rehabilitation LOS - Target LOS)
Date of discharge		Number of Discharge Delay Days
		Overall LOS = No of days from admission to discharge including discharge delay days

Table 4.2 Milestones on the Admission and Rehabilitation Pathway

Prior to admission, delays in either referral or admission may have occurred which could alter the progress of a SCI individual. A delayed admission is defined as an admission that does not occur within the first 72 hours of injury and a delayed referral is one that is not made within the first 72 hours of injury. This measure is very important as the point of referral indicates the point at which the referring hospital commenced liaising with the SCIC team and may influence the occurrence of avoidable complications (National Specialised Commissioning Group, 2010; South of England Spinal Cord Injury Board, 2010; Wing, 2008). Additionally, if a referral has not happened within 72 hours then it is not possible for the SCI individual to be admitted within 72 hours and this reason for delay in admission should be acknowledged in this study.

Various other points from injury to discharge are of particular interest as either benchmarks from which other time points will be measured (for example date of mobilisation) or as a target to be achieved, (for example discharge date). As noted in research lack of clarity of definitions of the rehabilitation pathway presents difficulties not only in evaluating outcomes but also in making comparisons between studies. Therefore this research will endeavour to clearly identify the significant milestones in the admission and rehabilitation pathway with clear definition of when each of these commences and finishes. These milestones are detailed specifically in Table 4.2 and a full definition of these time points and phases is given in Appendix C.

#### *Point of Discharge*

The first set of outcome measures concern rehabilitation outcomes and therefore discharge is the appropriate point at which to take these measures. At discharge details of the SCI individual's situation and rehabilitation outcomes will be taken. These measures are detailed in Table 4.1.

#### **4.4.1.2. Phase 2: One Year Post-discharge**

In the interests of using a consistent point in time for measurement of outcomes, a decision was made to collect data at one year post-discharge. Although SCI individuals will have been injured for varying lengths of time they will have all been in the Community for approximately one year which gives a consistent benchmark to compare outcomes. Collecting data at one year post-discharge would also permit collection of any unreturned data forms when the SCI individual attended their one year outpatient review. Through this it was hoped that better response rates would be obtained than might normally be seen in a postal survey (Kennedy *et al.*, 2010b; Chevalier, Kennedy and Sherlock, 2009).

## **4.5. Selection of Measures**

In order to be able to identify and measure outcomes appropriate measures were required; some of which would identify a baseline, some would identify changes and others would measure outcomes. The chosen variables are as listed in Table 4.1. For some variables there are identified standardised, recognised, measures which will be discussed in relation to the relevant variables.

### **4.5.1. Standardised Measures**

#### **4.5.1.1. Spinal Cord Injury Measurement and Classification**

The International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) are the internationally recognised system to establish the level of spinal cord injury and the degree of neurological impairment (ASIA/ISCOS, 2011). A copy of this form is available in Appendix A. As the measure utilised on LSCIC to classify functional ability was proposed to change from FIM to SCIM during the period of this research data for these measures could not be utilised. Therefore the measures of functional improvement utilised in this research were ISNCSCI and rehabilitation goal attainment.

#### **4.5.1.2. Psychological Variables**

As discussed in Chapter 3, the psychological variables of locus of control and coping strategies may significantly influence both the level of emotional distress that the SCI individual experiences and outcomes following SCI. In order to identify the individual's psychological profile and if this may promote better outcomes, or be influenced by the situation which the SCI individual finds themselves in, measures of locus of control and coping were taken during admission and at one year post-discharge. Due to the potential that individuals may be willing to contribute data to the project but unwilling to contribute data from the psychological measures subjects would have the option of not completing the psychological questionnaires. Those completing psychological questionnaires comprise a cohort permitting further comparisons of outcomes and influencing factors.

#### *Locus of Control:*

This research aims to observe the outcomes in subjects across a variety of areas in their lives, over which they may have varying levels of control. The Spheres of Control Questionnaire (SOCQ) (Paulhus, 1983) measures locus of control as a multidimensional construct, evaluating perceptions of control in different domains of an individual's life. Since the original scale was devised revisions have been made (Paulhus and Van Selst, 1990; Paulhus, 1983) and the version used here is one proposed by Spittal et al (Spittal *et al.*, 2002) which produced greater reliability and a more robust factor structure. The

SOCQ scale in both forms has been used and validated in a variety of fields (Spittal *et al.*, 2008; Bonito *et al.*, 2006) including those with ambulatory disabilities (Allen and Blascovich, 1996), but not, to the author's knowledge, with an exclusively SCI population.

The questionnaire has three scales which measure the individual's perception and expectation of control in three distinct spheres of their life. These spheres are:

- Personal Control: the individual's sense of their personal achievement and abilities. This scale also incorporates elements of the individual's perception of self-efficacy.
- Interpersonal control: reflects the sense of control in social interactions, for example the amount that the individual feels that they are able to present and defend their position and requirements, develop and maintain social relationships, or work with others as part of a team. Paulhus (Paulhus, 1983) also suggested that this scale may identify the level of social skills of the individual.
- The final scale measures the individual's sense of SocioPolitical Control which is the extent to which they feel that they can influence government and national policy through activities such as protest, voting or lobbying.

The SOCQ contains 30 items, 10 items on each of the three scales relating to each sphere. Subjects are given 30 statements and asked to rate how much they agree or disagree with them, for example.

	Disagree		Neutral		Agree		
1. I can usually achieve what I want if I work hard for it.	1	2	3	4	5	6	7

Each statement/question carries a minimum of one point and a maximum of seven points dependent on the answer given. Five statements for each scale are positively loaded, that is the subject would score seven for circling '7 Agree' through to one for '1 Disagree' and five statements are negatively loaded in that the subject would score one for circling '7 Agree' though to seven for '1 Disagree'. The maximum that the subject can score in each scale is 70 and the minimum is 10. Each Sphere has a scoring continuum of perceived externality of control (low score) to internality of control (high score). As with most locus of control scales, scores at the extreme ends of the scale are not desirable. Scores for each scale are not combined as their meaning is as an individual scale score not as a whole 'Questionnaire score' Normative scores for this measure have been given as: Personal control: 50.56, Interpersonal Control: 48.19 and SocioPolitical Control: 35.94 (Spittal *et al.*, 2002) .

### *Coping Styles*

The concept of detachment in coping is novel, although not new. It is the opposite of emotional coping and allows the individual to emotionally distance themselves from the stressor as a means of processing and dealing with the events. Detachment differs from avoidance, in which the individual does not acknowledge the stressor, is suggested to promote resilience (Roger, Jarvis and Najarian, 1993) and may reflect the adaptive denial identified by Dorsett (Dorsett, 2010). Only one questionnaire was found that investigates the concept of detachment as a coping style; the Coping Styles Questionnaire (CSQ) (Roger, Jarvis and Najarian, 1993).

The CSQ is a measure of coping traits and so a measure of a stable element of an individual's personality. Since the initial development of the questionnaire it has been extensively validated and used in a variety of non-healthcare (Xuereb, Ireland and Davies, 2009; Lawrence, Ashford and Dent, 2006; Ireland, Boustead and Ireland, 2005; Lyne and Roger, 2000) and healthcare environments (Pinto-Gouveia *et al.*, 2012; Borrill, Fox and Roger, 2011; O'Connor and Elklit, 2008). An earlier form of the questionnaire has been used in SCI research (Stougaard Nielsen, 2003) which identified that the use of emotional coping increased slightly (and conversely the level of detached coping reduce slightly) as the individual progressed through their rehabilitation and the first few months of discharge. During this time the levels of Rational and Avoidance coping decreased (Stougaard Nielsen, 2003).

In the current version of the scale, (provided by the scale's author (Roger, 2003)), detached and emotional coping are viewed as opposite ends of a bipolar scale, the other two scales in the questionnaire are rational and avoidance coping. Rational coping and detached coping are viewed as adaptive coping styles, whilst emotional and avoidance coping are viewed as maladaptive coping styles. The questionnaire was used as provided by the author other than one statement, Q33. 'Just take one step at a time.' was changed to: 'Just take one thing at a time.' The questionnaire contains a list of 41 statements and subjects are asked to rate if they feel or behave that way in a stressful situation Always (A), Often (O), Sometimes (S), or Never (N). For example:

1. Feel overpowered and at the mercy of the situation.                    A    O    S    N

Questions score a maximum of three and a minimum of zero and each question relates to one of the following three scales:

Detached/Emotion Focussed Coping Scale: 22 items measure this coping style, twelve are negatively loaded so the subject will score zero points for A through to three points for N and 10 items are positively loaded so the subject will score three points for A through to zero points for N. A high score on this scale (66) indicates a tendency toward more detached coping styles and a low score (0) indicates more emotion focussed coping.

Rational Coping Scale. There are 9 items measuring the use of rational coping, each is positively loaded and so the subject will score three points for A through to zero points for N. High scores on this scale (27) indicate a tendency to utilise rational (adaptive) coping styles rather than maladaptive, less rational coping.

Avoidance Coping Scale. There are 10 items measuring the use of this form of coping style each is positively loaded and so the subject will score three points for A through to zero points for N (Never). High scores on this scale (30) indicate a tendency toward avoidant (maladaptive) coping styles and a low score less use of avoidant styles and so more adaptive coping.

Scores for each scale are not combined as their meaning is as an individual score not as a whole 'Questionnaire score'. Normative means have not been reported for this scale but mean scores have been reported as Avoidance coping 11.78 (Std Dev.4.79), Rational coping 16.82 (Std. Dev.4.50) and Detached/emotion coping 36.84 (Std. Dev.8.11) in the non-self harming student population (Borrill *et al.*, 2009)

#### **4.5.1.3. Pain Measurement**

The perception of pain and the amount that pain affects the ability to do things will be measured at one year post-discharge to identify if it has limited the SCI individual's ability to participate in community or vocational activities.

A well established means of measuring pain is the visual analogue scale (VAS). This method of measurement has been found to produce reliable and consistent results (Johnson, 2005) in a variety of research areas. A VAS is simply a line on which a respondent is asked to indicate their position along a continuum of presence or non-presence of a variable, for example pain – no pain or agree-disagree. Although the use of a 10 cm scale VAS has often been discussed as the ideal, successful use of a VAS across a variety of lengths and modalities (Reips and Funke, 2008) such as mobile phones, computers, etc suggests that it is not the ultimate size of the scale that matters so much as consistency in the interpretation of the results.

Subjects were asked three questions to establish their experience of pain:

**How would you rate your level of pain today?**

Place a cross on the line to indicate.

None	Moderate to severe 	Extremely bad
------	---------------------------	------------------

**Please rate the worst pain that you have experienced in the last 24 hours.** Place a cross on the line to indicate.

None	Moderate to severe 	Extremely bad
------	---------------------------	------------------

**How much do you feel that your pain limits your ability to do things?** Place a cross on the line to indicate.

No limitation	Occasionally limits abilities 	Extremely limits abilities
------------------	--------------------------------------	-------------------------------

Copying of the research materials was carefully monitored to ensure that the VAS consistently measured 12cm. The point at which the individual placed the cross on the line was measured and the rating of pain taken as the point that the cross was made to the nearest 0.5cm.

**4.5.1.4. Spasm Measurement**

The individual's perception of spasm and the amount that it affects the ability to do things will be measured at one year post-discharge to identify if it has limited their ability to participate in the community. As with pain measurement the issue of interest is the individual's perception of spasm and how they feel it influences their ability to do things a VAS was used as a simple, reliable measure of the subjective experience of spasm.

Individuals were asked three questions to establish their experience of spasms:

**How would you rate the level of your spasms today?** Place a cross on the line to indicate.

None	Moderate to severe 	Extremely bad
------	---------------------------	------------------

**Please rate the worst spasm that you have experienced in the last 24 hours.** Place a cross on the line to indicate.

None	Moderate to severe 	Extremely bad
------	---------------------------	------------------

**How much do you feel that your spasm limits your ability to do things?** Place a cross on the line to indicate.

No limitation	Occasionally limits abilities 	Extremely limits abilities
------------------	--------------------------------------	-------------------------------

As with the pain measurement, copying of the research materials was carefully monitored to ensure that the VAS consistently measured 12cm and the rating of pain taken as the point on the line at which the cross was made.

#### 4.6. Non-Standardised Measures

##### 4.6.1 Quality of Life Rating

There are many different concepts of QOL and many standardised tools that can be used to measure it (Hill *et al.*, 2010; Alexander *et al.*, 2009). An alternative method of establishing subjective QOL ratings is to ask the individual what they perceive their QOL to be (McKevitt *et al.*, 2003). As QOL was one of many factors to be measured in this research and subjective perception of QOL was the variable of interest a decision was made to ask subjects two overt questions:

- On the scale below please rate the level that you feel your general quality of life was before your injury
- On the scale below please rate the level that you feel your general quality of life is now

Subjects were asked to indicate on a scale of 1-10 their rating of QoL with notations indicating that 1 rated 'Very Poor' and 10 rated as 'Extremely good'

Whilst it is acknowledged that the retrospective view of QOL prior to injury could be artificially inflated, the difference between how QOL life is perceived to have been prior to injury and how QoL is perceived to be at the time of answering the question (the *perceived difference* in QOL) may yield important information.

##### 4.6.2 Demographic and Outcome Measures Data

In addition to the data from standardised measures a range of data related to both the outcome measures and potential influencing factors will be collected as detailed in 4.1. Some of this information is overt, such as mode of injury or marital status, and so is

easily identified or obtained, whereas some information, such as details of provision of adaptations or source of care provision, is more complex with multiple levels or factors.

Unfortunately the concepts of reintegration and participation are as difficult to measure as they are to define (Eng *et al.*, 2010b). Although tools have been designed to measure social engagement and participation they do not take account of many of the variables of interest in this study; particularly provision of resources and the UK funding systems and therefore these questions would need to be asked in addition to the questionnaire. Due to these issues a decision was taken to take overt measurements of the factors and outcomes being investigated in this research through data collection tools specifically designed to ensure that the required information was consistently obtained.

#### 4.6.2.1 Data Collection Tools Development

Outcome Measures	Measure	Taken On Admission	Taken On Discharge	Taken At One Year Post-Discharge
Pathway Issues	Referral and Admission Data	✓		
	Discharge Data		✓	
Functional Improvement	Neurological Level and AIS Grade	✓	✓	✓
	Goal Achievement		✓	
Community Reintegration And Participation	Number Of Outings In Last Month Of Admission		✓	
	Number And Form Of Community Outings		,	✓
	Driving/Car Owner or Access to Public Transport		✓	✓
Readmissions	Is A Readmission Planned On Discharge		✓	
	Number Of Readmissions, Length And Reason			✓
Vocational Status	Form of Vocational Activity And Details	✓	✓	✓
Accommodation And Residential Situation	Residential Situation And Issues With Accommodation	✓	✓	✓
Quality of Life	Subjective Grading of QOL Pre- and Post SCI			✓

Table 4.3 Outcome Measure Data and Points of Collection

Once the data items of interest were identified and the time period at which they would be collected identified (Table 4.2. and 4.3.) data collection tools were devised. Two tools were developed for completion by the primary investigator and one was developed for completion by the subject. There was no intention to develop a measure for general use or a questionnaire to be utilised elsewhere. These tools were developed purely to be

utilised in this research to ensure that consistent information was collected for all subjects in the study. Details of the outcome measures and influencing factors investigated, the measures of them that were taken and when they were taken are given in Table 4.3 and 4.4. The VAS measures for pain and spasms were incorporated in to the subject survey tool to be used at one year post-discharge.

Influencing Factors	Measure	Taken On Admission	Taken On Discharge	Taken At One Year Post-Discharge
Demographic Variables	Demographics	✓	✓	
Sequelae Of SCI	Type And Impact			✓
	Pain VAS			✓
	Spasm VAS			✓
Complications On Admission	Type And Impact On Pathway	✓	✓	
Other Significant Medical Conditions	Significant Medical Conditions On Admission	✓		
	Significant Medical Conditions Diagnosed During Admission		✓	
Social Support	Perception of Social Network	✓		
	Number of Visitors		✓	
	Frequency and Importance Ascribed to Social Contacts			✓
Care	Amount, Reason for and Source of Care, and Funding		✓	✓
	Issues with Care			✓
Accommodation	Details Of Outstanding Adaptations		✓	✓
Equipment	Outstanding Equipment Including Wheelchair		✓	✓
Locus Of Control	SOCQ	✓ at consent		✓
Coping Strategies	CSQ	✓ at consent		✓

Table 4.4 Influencing and Contextual Factors Data and Points of Collection

#### 4.6.2.2 Admission and Discharge

It was anticipated that data would be collected prospectively for the inpatient phase from the medical, occupational therapy and case management notes by the primary investigator and tools were developed to facilitate consistent data collection. Details of

the data collected are given in Tables 4.3 and 4.4. Sources of this data are listed in Table 4.5. Copies of these tools are included in Appendix E.

Data type	Where information was obtained from	Who obtained information and how
SCI individual Demographics	Medical notes, Case Management notes	Primary Investigator. Manual collection
Injury demographics and Complications on present admission	Medical notes.	Primary Investigator. Manual collection
Information on accommodation and socioeconomic status. Perceived social network Level of Education achieved and vocational status.	Medical notes, Case Management notes	Primary Investigator. Manual collection
Time Points: injury, referral, admission, mobilisation, completion of rehabilitation, discharge.	Medical notes, Case Management notes, Occupational Therapy notes, SCIC referral folder.	Primary Investigator. Head OT. Manual collection.
Goals outstanding on discharge	Goal planning folder notes, Medical notes, Case Management notes.	Primary Investigator. Manual collection
Information on discharge delay and reason for this	Medical notes, Case Management notes	Primary Investigator. Manual collection
Information on outings and visits from Family/Friends prior to discharge	Medical notes, Case Management notes, verbally provided by Ward Staff.	Primary Investigator. Manual collection

Table 4.5 Inpatient Data Collected and Source of Information

The Admission Data Collection tool collected information on demographics, injury details, socioeconomic situation, and residential situation as well as the pathway to admission and commencement of rehabilitation. The Discharge Data Collection Tool collected this information again but also collected information on the outcome measures of vocational activity, LOS, discharge delays and discharge accommodation. Full details of the data collected in this phase are given in Tables 4.2 and 4.3 as well as Appendix E. The measure of community participation at this stage was the number of outings from the LSCIC during the last month of admission. Information was also obtained on the potential influencing factors of resource provision, sources of funding, including, where available, costs, as well as whether the individual was able to drive or had access to a vehicle. Additionally, note was made of whether an interim payment from a compensation claim or small insurance policy had been received, and whether this was used to secure accommodation or other resources.

To gather meaningful information on discharge delays the number of discharge delays and the number of days of delay were recorded. In the author's experience discharge

delays are usually due to housing or care funding issues and occasionally due to a range of other potential issues. The reasons for discharge delay were categorised into 3 groups: 1) Housing/Adaptations Discharge was delayed as suitable accommodation was not available or the adaptations required for the subject to be able to access their accommodation were not completed. 2) Care/Placement funding or Other Care issues. Discharge was delayed because the funding required for the costs of their required care and/or Nursing Home placement was delayed. This group includes subjects who did not have accommodation in the community suitable for them to be discharged to and, due to their high level of care needs required an interim nursing home placement until accommodation was available. There were also some who did have accommodation to be discharged to but experienced lengthy delays in securing funding for the required care package. For both of these sub-groups of subjects the delay in discharge is primarily due to the funding issues rather than accommodation issues. 3) Other. Discharge was delayed due to 'one off' issues such as provision of a grant to purchase essential furniture or subject/family refusal to be discharged on the day planned.

#### **4.6.2.3 One Year Post-Discharge Data Collection Tool**

Information gathered in the final phase of the research identified the situation of the individual in relation to the stated outcome measures, information on social and community activities, details of provision and outstanding provision of resources and additionally whether the subject had experienced significant SCI related complications since discharge.

In this phase of the research a self-administered survey was developed for subjects to complete independently. This data collection tool will be referred to as the Post-Discharge Booklet. Care was taken when devising the Post-Discharge Booklet to ensure that questions were unambiguous and did not contain professional jargon. Formatting of the document was done in such a way to ensure that the space for answers was sufficient that individuals with impaired hand function would not have difficulties entering their answers. Appendix E contains a copy of this form but formatting has been revised to permit the questionnaire to be presented within the margins and page area of this thesis.

In addition to the outcome measures and potential influencing factors already discussed, details of community activities and social contact were measured by the form and frequency of these occurrences as well as the importance that the individual ascribed to them (Table 4.3 and 4.4). Details of visits and readmissions to hospital that were not part of a scheduled review or planned prior to discharge were also taken, as a factor

which may influence reintegration outcomes and indicate significant health issues. As well as the non-standardised measures, the Post-Discharge Booklet incorporated the VAS measures of spasm and pain, the QOL measures and copies of the psychological questionnaires for those subjects who consented to complete them.

#### **4.7 Ethical Committee Applications**

Ethical committee approval for the project, data collected and questionnaires used was sought and obtained from both the local NHS ethics committee and the Brunel University ethics committee in December 2003 and May 2004 respectively. Amendments were submitted for, and gained, approval from the NHS ethics committee in September 2006 and May 2008. Both amendments received a favourable response and details of amendment and response were forwarded through to Brunel University ethics committee for information. Full details of revisions are available in Appendix C.

#### **4.8 Pilot Project**

Following the creation of the data collection tools and identifying standardised measures to be used a pilot project was undertaken. The purpose of this pilot was to establish:

- Identify issues with data collection for the Admission and Discharge Data Collection Tool.
- Identify subject difficulties, subjects experience completing the Post-Discharge Booklet and the nature of these difficulties.
- Establish if the psychological questionnaires were appropriately phrased for the population to be surveyed.
- Whether the data collected was easily entered into SPSS tables and able to be meaningfully analysed.
- Identify, through subject feedback, if additional data that should be collected.
- Develop the research protocol

##### **4.8.1 Pilot Method:**

###### **4.8.1.1 Subjects:**

All subjects were inpatients of the LSCIC service or attending outpatient clinics between December 2006 and February 2007. The sample was a convenience sample of the first six subjects consented for each phase/group of the study. Following consenting to take part in the research subjects were allocated to the appropriate one of three groups (Admission, Discharge or Post-discharge) depending on the phase of their rehabilitation or reintegration. Twelve subjects were current inpatients of the service and six were outpatients. These group names were applied purely for clarification during the Pilot Study and will not be utilised in the main project.

### *Inpatient Phase Groups*

The Admission group mimics the data that collected at the Snapshot 1 point of the project. The Discharge Group mimics the data collected at Snapshot 2: Discharge. Those who were in the 'Admission' group had been on the LSCIC for less than one month. The SCI individuals included in the 'Discharge' group were the first 6 SCI individuals approached who consented to be part of the study and were due to be discharged within the next month. Unfortunately 2 subsequently suffered significant delays to their discharge and so it was several months before data collection could finally be completed.

### Post-Discharge Group

The 'Post-Discharge' group consisted of six outpatients who consented to take part in the study either when then they attended an outpatients clinic appointment, or during a brief, pre-planned, readmission.

#### **4.8.1.2 Materials/tools**

##### *Tools:*

The Admission and Discharge data collection tools and the Post-Discharge Booklet discussed previously as well as the CSQ and SOCQ psychological questionnaires were used in this pilot study (See Appendix E).

#### **4.8.1.3 Procedure**

The pilot study took place between December 2006 and February 2007. A cross-sectional study was performed as a means of examining subject responses at the three proposed intervals whilst ensuring that data could be collected within a short time period.

The Admission and Discharge Groups both completed the two psychological questionnaires with assistance if required. The primary investigator collected the demographic, process and discharge data from medical and case management notes. Full information on the sources and means of collection of the data are given in Table 4.5. The Post-Discharge group completed the two psychological questionnaires and all data items in the Post-Discharge Booklet. Comments were requested from subjects in all three groups regarding ease of completion and understanding of the questionnaires as well as any issues with data collected.

## **4.8.2 Results**

Summary data from the data collection tools or psychological questionnaires will not be presented as the focus for this pilot was on whether subjects were able to complete the tools and whether the resulting data could be successfully analysed. However feedback from the subjects and issues identified with data analysis will be discussed. Due to the small number of SCI individuals available on the LSCIC and the average length of stay the pilot project would only be likely to contain a small number of subjects if it were to be completed within a reasonable amount of time therefore any interactions observed are unlikely to be significant. As the purpose of this pilot was as a 'trial run' of the data collection and methodology for the main project this was not a cause for concern.

### **4.8.2.1 Subject Demographics**

18 subjects participated in the pilot projects, six had recently been admitted, six were approaching discharge and six had been discharged for over one year. Mean age of subjects was 41 (Std Dev: 15.2) years. 13 subjects were male (72%). Length of time since discharge in the post-discharge group ranged from one to six years. Subjects represented four of the injury groupings used in the LSCIC Integrated Care Pathway. SCI demographics and subject numbers are: High tetraplegic (C3-5 AIS A-C) N=6, Low tetraplegic (C6-8, AIS A-C) N=5, Incomplete tetraplegic (C1-8, AIS D) N=1, Paraplegic (T1-12, AIS A-C) N=6. There were no SCI individuals with ventilator dependent tetraplegia, incomplete paraplegia (T1-12, AIS D) or ambulant cauda equina amongst the subjects. Further comparisons of demographics were not performed as it would not provide any meaningful information.

### **4.8.2.2 Feedback on the Data Collection Tools and Post-Discharge Booklet**

#### *Psychological Measures*

All subjects were able to complete the psychological questionnaires and found the instructions and questions easily understandable.

#### *Phase I: Admission and Discharge*

Although the information for the Admission and Discharge data forms were generally easily obtained from medical and case management notes, some information to be collected was not consistently available in either source. The following strategies were proposed to deal with these issues:

Date of Referral - The primary investigator to obtain date of referral from LSCIC staff, medical notes or referral folder. In the case of subjects with non-traumatic SCI where a date of 'injury' was not clearly defined, the date of onset was taken to be the first day of the month in which the symptoms were recorded.

Cost of care package or interim placement - If information was not able to be obtained from the subject's Case Manager, the cost of care for a cross-matched subject was used, or national average figures of £17.60/hour (Great Britain. The NHS Information Centre, Social Care Statistics, 2011) utilised.

In the main research project the following information was obtained from the subject directly: type of vocational activity prior to injury, if applicable job title and number of hours working or studying per week, religious beliefs, level of education obtained and perception of social network. Revised sources of data are given in Table 4.6.

#### *Phase II: One Year Post-Discharge*

Some elements of missing data were noted in the Post-Discharge Booklet, in many cases the data was missing for the same questions. When questioned subjects advised that they had not noticed/realised there were additional sub-questions. This was concluded to be an issue with tables being used to contain several questions, rather than an issue with the question in itself. Revisions were made to the Post-Discharge Booklet to reflect this.

#### *Data entry and analysis*

Whilst going through setting up SPSS tables and entering data it became apparent that some changes need to be made to the way in which questions were phrased so that the data collected could be structured in a way that could be analysed easily (Appendix G).

#### **4.8.2.3 Summary of Outcomes of Pilot Project**

- All subjects completed the psychological questionnaires and stated that they felt the measures were appropriate.
- The study highlighted that a proportion of subjects needed to be reminded to complete psychological questionnaires if they were left to complete them independently. This could present difficulties in ensuring that subjects completed the questionnaire.
- Although two of the discharge phase subjects experienced significant delays to their discharge this was useful for ensuring that information regarding the reasons for delay was obtained and entered in to SPSS tables in a way that ensured meaningful analyses could be performed.
- The pilot project assisted in identifying issues that would have made interpretation of the data difficult. This information was invaluable in ensuring that questionnaires and SPSS data tables were set up in such a way that data could be easily extracted and entered for statistical analysis in a meaningful manner.

- Questionnaire sheets were also adjusted so that subjects should not inadvertently 'miss' questions in the forms and to ensure that questions are easily understandable and meaningful to subjects.
- Some issues were identified in the sources of data that would be collected by the primary investigator. The revised sources of data to be used in the project procedures are given in Table 4.6.

<b>Data type</b>	<b>Where information was obtained from</b>	<b>Who obtained information and how</b>
SCI individual Demographics	Medical notes, Case Management notes	Primary Investigator. Manual collection
Injury demographics and Complications on present admission	Medical notes.	Primary Investigator. Manual collection
Perceived social network Level of Education achieved and vocational status.	Verbally provided by SCI individual	Primary Investigator. Verbal request at the time consent obtained.
Information on accommodation and socioeconomic status	Medical notes, Case Management notes	Primary Investigator. Manual collection
Time Points: injury, referral, admission, mobilisation, completion of rehabilitation, discharge.	Medical notes, Case Management notes, Occupational Therapy notes, SCIC referral folder.	Primary Investigator. Head OT. Manual collection.
Goals outstanding on discharge	Goal planning folder notes, Medical notes, Case Management notes.	Primary Investigator. Manual collection
Information on discharge delay and reason for this	Medical notes, Case Management notes	Primary Investigator. Manual collection
Information on outings and visits from Family/Friends prior to discharge	Medical notes, Case Management notes, verbally provided by Ward Staff.	Primary Investigator. Manual collection

Table 4.6 Revised Sources of Data Collected

Following evaluation of results and feedback from the Pilot Project revisions to the procedure and form of some of the data collected were proposed to address issues raised. Ethical approval for these revisions was sought and obtained, as detailed in Appendix C. The revised data collection tools and Post-Discharge Booklet are included in Appendix G. The six SCI individuals included within the 'Admission Phase' group of the pilot study were included in the main research at their request. This was possible due to only minor changes being made to the way that data items were collected for this period.

#### **4.9 Main Project Methods**

Copies of the data collection tools used in all phases of the research are included in Appendix G.

#### 4.9.1 Phase I: Inpatient Phase

Phase 1 of this research project took place on the LSCIC between February 2007 and February 2010.

##### 4.9.1.1 Recruitment

*Inclusion criteria:* The following individuals were considered potential research subjects:

- SCI individuals who were inpatients on the LSCIC, AND
- Admitted for more than 18 days for their first episode of specialist SCIC rehabilitation in the UK, AND
- Due to be discharged in the three years between Feb 2007 and Feb 2010.

SCI inpatients were identified from LSCIC ward lists during their admission. *Exclusion criteria:* The following groups of potential subjects were excluded from taking part in the research project.

- Under 18
- Diagnosed with an enduring mental health condition that the LSCIC treating team felt would impact on their ability to participate in the research project or would result in them experiencing distress.
- Diagnosed with a significant and enduring cognitive impairment that made the individual unable to consent for them self.
- Terminally ill.
- Deemed to be unable or unsuitable to take part in the research project by their treating team.
- Likely to be transferred to another rehabilitation facility or hospital prior to the completion of their rehabilitation.

During the period of the research a total of 154 SCI individuals met the inclusion criteria (Table 4.7). Six of these were excluded as they were transferred to another SCIC or repatriated to their home country to complete their rehabilitation. 28 were excluded as they fell in to one of the remaining exclusion categories (cognitive deficits or mental health issues that may impact on their ability to consent). A further exclusion was applied to those completing the psychological questionnaires. Subjects were excluded from this option if their ability to speak English fluently was limited to the point that they would have required an interpreter to be able to complete the psychological questionnaires. This was to ensure that nuances in the phrasing of the questions were not lost in translation.

The remaining 120 SCI individuals were considered to be the potential study population (Table 4.7).

Inclusion and Exclusion Criteria Stages	Number of Potential Subjects
Falls within the inclusion criteria	154
Completed rehabilitation in this SCIC	148
Do not fall in to one of the exclusion criteria	120

Table 4.7 Inclusion and Exclusion Criteria Application

Prior to approaching any potential subjects the primary investigator confirmed with the LSCIC nursing staff on duty that the individual did not fall in to an exclusion category, was aware of their SCI diagnosis and was fit and well enough to be approached on that day.

Potential subjects approached were given a brief verbal description of the research project and its purpose. If they expressed an interest in taking part they were given a copy of the Patient Information sheet (as in Appendix G) and advised that there were two levels of participation possible in the study:

- 1) Permit data to be collected via their hospital notes during their inpatient stay and complete a questionnaire on their situation at one year post-discharge.
- 2) As option 1 but also complete 2 questionnaires investigating locus of control and coping strategies during admission and at one year post-discharge.

The primary investigator visited them approximately 1 week later to confirm if they wished to take part. If, on this subsequent meeting, the individual consented to take part in the research a copy of the signed consent form (as in Appendix G) was placed in the medical notes as per NHS Research Governance requirements.

#### **4.9.1.2 Phase I Procedures**

Data was collected by the primary investigator as detailed in Tables 4.3, 4.4 and 4.6 using the Admission and Discharge Data Collection Tools (Appendix G). The standardised measures of CSQ, (Roger, Jarvis and Najarian, 1993) and SOCQ (Spittal *et al.*, 2002) were utilised as discussed earlier.

#### **4.9.1.3 Phase 1 Data Collection**

Data was retrospectively collected from the point of injury to the point of admission to the LSCIC and attempts were made to ensure that the remaining data were collected from the subject's medical and case management notes during the admission to avoid

the need for further retrospective data collection. Where this was not successful retrospective data collection was required. This process could be particularly time consuming and involve several sets of medical and case management notes in addition to LSCIC databases. Details of the information collected and the source of the information is detailed in Tables 4.3, 4.4 and 4.6.

Subjects who agreed to also contribute psychological data were given the psychological questionnaires at the time of consenting to take part in the study. Arrangements were made to collect the completed questionnaires between an hour and one week later, depending on the subject's schedule. If subjects required assistance to complete the psychological questionnaires they were offered the option to receive assistance from the primary investigator or to be set up to complete the questionnaire on a computer.

Data collected were checked and confirmed prior to data analysis being performed. Full details of data handling procedures, including handling of missing data and forms of data analysis are given in Appendix F.

#### **4.9.2 Phase II: One Year Post-Discharge**

In this phase of the research data were collected from subjects at approximately one year post-discharge. Although it had been anticipated that the Post-Discharge Booklet survey would be mailed to the subjects and then either sent back or collected from them when they attended their one year post-discharge outpatient appointment, a change in the follow-up procedure meant that discharged SCI individuals would be seen at approximately 9 or 15 months post-discharge. Therefore it was necessary to issue and receive questionnaires purely via postal or electronic mail survey. Additionally the measurement of SCI level and AIS grade would not be able to be repeated at one year post-discharge.

##### **4.9.2.1 Procedure – Phase II**

The Post-Discharge Booklet was posted to subjects along with a stamped addressed envelope. A full copy of the discharge booklet is available for information in Appendix G. Where subjects had given an email address for communication a digital copy of the Post-Discharge Booklet was sent. Reminders were sent if a reply had not been received within one month. No further reminders were sent after this second attempt to contact non-responding individuals.

The subjects who were contributing psychological data were sent these with the Post-Discharge Booklet. The order in which the psychological questionnaires and data

collection tool were presented in the Post-Discharge Booklet was randomly rotated to ensure that the order in which the questionnaires were presented did not bias the responses.

#### **4.9.2.2 Data Collection – Phase II**

Phase II of this research project took place between February 2008 and February 2011. Questionnaires returned by subjects were checked for missing data prior to data analysis being performed. Full details of data handling procedures, including handling of missing data and forms of data analysis are given in Appendix F.

#### **4.10 Summary**

Following on from the literature reviews in the preceding chapters the areas of interest in this research project have been formally identified. Gaps in the current knowledge of outcomes in SCI, particularly in the UK have highlighted areas that require further investigation. This research project aims to investigate rehabilitation and reintegration outcomes following SCI. From available research, potential outcome measures of successful rehabilitation or reintegration have been proposed. A range of environmental and personal contextual factors have been proposed which may influence these outcomes. Additional healthcare systems outcome measures were also identified related to the subject pathway from injury to admission and ultimately discharge. From this a principle research objective has been proposed of:

- To establish, through a variety of measures, if both rehabilitation and reintegration outcomes are influenced by contextual factors.

The research project proposed to investigate these outcomes is a single site study utilising an observational, longitudinal methodology with prospective collection of data regarding a cohort of newly injured SCI individuals. In this chapter the data to be collected and procedures for this research project were identified and outlined. This included:

- Clear definitions of the factors, variables and timelines which will be measured including clear identification and definition of the milestones in the admission and rehabilitation pathway.
- The identification of the standardised and non-standardised measures for measuring the proposed outcomes and contextual factors.
- Identification of the time points at which the data will be collected.
- The development of the data collection tools incorporating the standardised and non-standardised measures including a self-administered survey to be completed by subjects at one year post-discharge.

A pilot project confirmed the appropriateness of the data being collected and the standardised measures for use in this research. Issues were identified with some of the questions on non-standardised measures and revisions to the project tools were implemented as a result of this.

The pilot also identified that the procedure for the research was appropriate and therefore the main research project commenced in February 2007. In the early stages of the research a change in outpatient follow-up resulted in the self-administered survey having to be sent and returned as a postal survey.

Methods of data handling, analysis and methods for managing missing data were developed in response to the data collected and are presented in Appendix F. These methods will be referred to in the presentation of results which will occur in the next three chapters.

## **CHAPTER 5 Results Phase 1 - Injury to Discharge**

### **Overview**

This Chapter will present the results of the first phase of the main research project. This incorporates information from the inpatient phase of the study and includes the baseline measures on admission and the evaluation of the proposed healthcare systems and rehabilitation outcomes. In addition to presenting a range of descriptive and outcome measure related data that has previously not been reported in the UK this chapter will present a scene against which the proposed reintegration outcomes can be evaluated in chapter 6. The results presented will be discussed in the context of the current research on outcomes following spinal cord injury (SCI) as well as current provision and funding of care, equipment and accommodation in the UK. Potential implications for subjects in the final stage of the research will also be discussed.

*“When you reach the end of your rope, tie a knot and hang on.”*

— Abraham Lincoln

## 5.1 Introduction

In Chapters 1-3 the available literature was reviewed and gaps in SCI research identified. Potential healthcare systems and rehabilitation outcomes were proposed along with environmental and personal contextual factors which may influence these outcomes. As a result of this the objectives and areas for investigation in this research project were identified. The potential healthcare systems outcome measures which relate to this phase of the research project are: Functional Improvement, Length of Stay and Discharge Delays. The rehabilitation outcomes which will be investigated in this phase of the study are: Community Participation, Vocational Status and Accommodation/Residential Situation. The impact of environmental and personal contextual factors on these outcomes will be evaluated in this chapter.

The aim of this first phase of the research project is to establish the situation and demographics of subjects at the point of injury, monitor their progress through the pathway from injury to discharge, and identify their situation at discharge. The process and procedure for this research project have been detailed in Chapter 4 along with data handling and analysis procedures.

## 5.2 Subjects

74 (61.7%) of those eligible inpatients of the London SCIC between February 2007 and February 2010 consented to participate in the study.

### 5.2.1 Representativeness of Sample

Over the three years of inpatient data collection 120 potential subjects were admitted to the SCIC and eligible to be approached to take part in the research. To identify if those who consented to take part in the research project were representative of the total eligible population the two groups 'consenting' and 'non-consenting' patients were compared on a number of factors and full details of these between group comparisons can be found in Appendix H. In summary, no significant differences were found between the consenting and non-consenting groups on all but two of the factors. Those who consented to take part in the study had a significantly longer length of stay than those who did not consent ( $U= 2.135.5$ ,  $z=2.34$ ,  $p=0.019$ ,  $r=0.214$  indicating a small effect, Median consented=88.0, Median not consented= 72.5). There were also significant differences between the two groups for injury grouping, ( $\chi^2(6)=16.230$ ,  $p=0.009$ ) with a significant moderate association (Cramers  $V=0.368$ ,  $p<0.009$ ) between whether an individual consented or not and their injury group.

### 5.3 Results:

Data management, handling and analyses methods utilised are as discussed in detail in Appendix F. For the sake of parsimony only significant or notable non significant results will be presented.

#### 5.3.1 Profile of Subjects

74 eligible subjects consented to take part in the study; of these 27 subjects contributed only demographic and pathway data during this phase of the study. The remaining 47 subjects consented to contribute data from the psychological measures in addition to demographic and pathway data.

75.7% (N=56) of subjects were male. The mean age of subjects at the time of injury was 43.93 years (Skewness= 0.577,  $z=2.1$ ), median=43 (IQR=33) with a modal age of 24 (Range 18-87). On discharge 44.6% (N = 33) of subjects were married compared 47.3% (N = 35) at time of injury. Four more subjects were single than at the point of injury. Of the 58 subjects discharged to the Community 55.2% (N=32) lived with their children and/or partner and 8.6% (N=5) lived with their parents or other family members (Appendix I, Table I.4). 17 subjects (23%) were diagnosed with an additional condition during their rehabilitation admission (Appendix I, Table I.10) and these additional conditions limited progress in rehabilitation in 9.5% (N=7) of cases. Full details of subject demographics and interactions are included in Appendix I.

#### *Mode of Injury*

The most frequent cause of injury (26%, N = 19) was falls (Figure 5.1) followed by road traffic accidents (RTA) at 23% (N = 17). 16.2% (N=12) of injuries were of non traumatic origin (NTSCI).

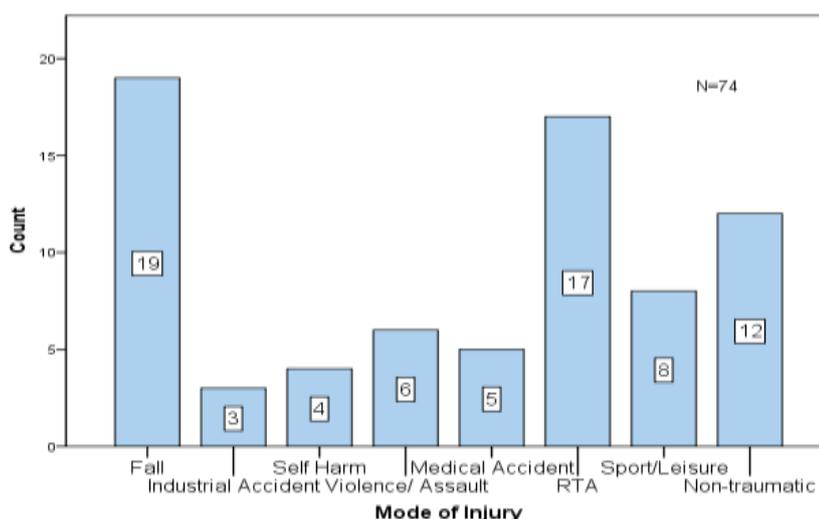


Figure 5.1 Mode of Injury

### *Complications Present on Admission*

27% (N=20) of subjects overall and 36.5% of those who were delayed in admission, were admitted with complications which may have been avoided if they had been admitted to a specialist SCIC service earlier. 70% (N=14) of complications (18.9% of subjects overall) were pressure sores, one individual had contractures, one had multiple issues and four had a range of other avoidable complications.

### *Injury Grouping and AIS Grade*

The majority of subjects were tetraplegic at both admission (N=43, 58.1%) and discharge (N=42, 56.7%). Due to changes in neurological classification over the period of admission the C6-C8 (AIS A-C) group contained only 4 subjects at discharge (Appendix I, Table I.3). In order to permit meaningful statistical analyses to be performed the ICP injury groups were revised to the four injury groups illustrated in Table 5.1. These revised classifications were used in all analyses regarding discharge situation unless otherwise stated. Full group details are shown in Appendix I. On admission a target length of stay was estimated for the subject based on their SCI level and AIS grade (Appendix D). Changes in SCI level and grade noted during rehabilitation may have impacted on the length of rehabilitation the subject actually had. Therefore the target lengths of stay which relate to the subjects' discharge neurological level and AIS grading will be used in calculations involving timescales from the point of mobilisation.

Revised Injury group	Frequency (N)	Percent
Tetraplegic A-C	26	35.1%
Paraplegic A-C	25	33.8%
Tetraplegic D	16	21.6%
Paraplegic D	7	9.5%

Table 5.1 Revised Injury Group at Discharge

Functional improvement is an outcome measure of this phase of the research and changes in all AIS grade and injury groups were noted during the admission period. The number of subjects with AIS A and B grade injuries reduced from 34 and 10 respectively to 32 and 7 respectively. Whereas the number of subjects with AIS C and D grade injuries increased from 11 and 19 subjects to 12 and 23 respectively. No significant differences were found between those who were admitted within 30 days of injury and those who were admitted later in terms of changes in AIS grade over admission (U=653.00, z=-0.347, p=0.728).

### 5.3.1.1 Demographic interactions

Age was not found to be significantly related to actual neurological level of injury ( $H(df17) = 14.090$ ,  $p=0.661$ ) but significant differences in age at injury were identified between injury groupings, AIS grades and modes of injury with moderate to strong associations (Table 5.2). Typically those who were older sustained their SCI through non-traumatic means and had AIS C or D grade injuries.

Interaction	Kruskal-Wallis (H) Test and Jonckheere's (J) Post Hoc Test Results	Median Age in Group Categories (Descending order)
Age: Injury Group	$H=10.73$ ( $df4$ ), $p=0.03$ $J=1,258$ ( $z= 2.828$ ) $r=0.33$	Paraplegic (AIS D) = 58.67 years, Tetraplegic (AIS D) = 57 years, C1-C5 Tetraplegic (AIS A-C) = 36.0 years, Paraplegic (AIS A-C) = 34.0 years, C6-C8 Tetraplegic (AIS A-C) = 27.5 years
Age: AIS Grade	$H=10.73$ ( $df4$ ), $p=0.03$ $J=1,278.5$ ( $z=3.432$ ) $r=0.4$	C = 58 years, D = 51 years, B = 37 years, A = 29 years
Age: Mode of Injury	$H=20.3$ ( $df7$ ), $p=0.005$ $J=1,607.5$ ( $z=4.519$ ) $r=0.5$	Non-traumatic causes = 61.0 years, Medical accident = 47.0 years, Falls = 47.0 years, RTA = 34.0 years, Self-harm = 35.0 years, Industrial accident = 34.0 years, Violence/assault = 28.0 years, Sport/leisure activities = 24.0 years

Table 5.2 Analyses With Significant Variations In Age Across Injury, Neurological Groups and Mode Of Injury Groups.

Although there was no statistical significance in the presence of complications on admission between injury groups ( $\chi^2=(df4)3.683$ ,  $p=0.427$ ) there was a clinically significant trend as 93.3% admitted with sores had an AIS A-C grade injury, 53.3% of who were paraplegic.

### 5.3.2 Process: Injury to Discharge Pathway

To allow for meaningful interpretation of data and interactions the inpatient process was divided into four stages: Injury to admission, Pre-mobilisation length of stay (LOS), Rehabilitation LOS and Discharge Delay.

#### 5.3.2.1 Healthcare Systems Outcome Measure: Time from Injury to Referral and Admission

Information on the date of referral was missing for 9 subjects. Comparison of the groups with or without referral date found no significant differences (Appendix I, Referral Information) across the two groups. Therefore the missing data was treated as missing completely at random (Graham, 2009) and a complete case analysis conducted. Where

a subject had a NTSCI the date of injury was taken as the first day of the month in which symptoms were reported.

Table 5.3 illustrates that the data for these variables was significantly skewed with a cluster of subjects at the lower end of the scale as exhibited by low modes and significant outliers. Three subjects had a substantially delayed admission and nine subjects had times to mobilisation of between 53 and 313 days. Four of those with lengthy pre-mobilisation LOS (Subjects 28, 34, 39, 50) were admitted with pressure sores, two (Subjects 4, 33) were admitted with polytrauma, one (Subject 71) had pressure sores and polytrauma, the remaining two (Subjects 4, 55) were high level subjects who were initially ventilated on admission and took a substantial period of time to wean. Controlling for these outliers via log transformation (Field, 2009) did not yield different results in the correlations or analyses below. For this reason the data will be used in the original form. To identify if the time to referral and admission were influenced by other variables or resulted in particular outcomes the following analyses were performed.

	Days from Injury Referral to Admission	Days from Referral to Admission	Days from Injury to Admission	Pre-mobilisation LOS
N	65	65	74	74
Mean (95% Confidence Interval)	29.4 (18.6, 40.3)	29.9 (19.0, 40.9)	61.4 (42.2, 76.7)	22.4 (9.6, 22.6)
Std. Deviation	43.82	44.05	85.13	50.09
Median	12.00 (IQR 42)	10.00 (IQR 34)	34.50 (IQR 84)	6.50 (IQR 19)
Skewness	2.67 (z=8.98)	1.96 (z=6.6)	3.05 (z=10.9)	4.33 (z=15.5)
Minimum	0	.00	0	0
Maximum	223	177	514	313
Mode	0	1	1	0

Table 5.3 Information on Injury to Discharge 'Pathway' data 1: Injury to Mobilisation

#### *Time to Referral*

The date of referral was available for 65 (87.8%) subjects. 66.1% (N=43) did not achieve the outcome measure of being referred to the SCIC within 72 hours and 53.8% (N=35) were not referred for more than 10 days post injury. The median time to referral was 12 days with a maximum of 223 days. Of the 55 TSCI subjects who had a known date of referral, 60% (N=33) were not referred for over 72 hours post injury and 45.4% (N=25) not referred for over 10 days.

### *Time to Admission*

Time to admission ranged from 0 to 514 days (Table 5.3) with a median of 34.5 days across all subjects (mean 61.4 days). 71.6% (N=53) of subjects did not achieve the outcome measure of being admitted within 72 hours of injury, with 50% of these delays in admission being due to delays in referral. Only 4.1% of delays in admission were due to subject health and 1.4% due to bed availability. 55% of subjects (N=41) were not admitted within 30 days of injury. A highly significant correlation was identified between the time from injury to referral and the time from referral to admission ( $\tau=0.355$ ,  $n=65$ ;  $p<0.000$ ). This suggests that a delay in referral would lead to a longer delay in admission following this, compared to when there was no delay in referral.

Five subjects were injured outside of the UK. Time to admission for these subjects ranged from 15 to 122 days (mean=68). One was admitted with significant pressure sores that necessitated a prolonged period of bed rest and, subsequently, a lengthy admission (341 days, 247 of which were pre-mobilisation). Two subjects were admitted from their home, having been discharged from their referring hospital at the time of admission.

### *Presence of Complications on Admission*

Comparison of whether subjects were admitted with complications or not showed highly significant differences in both the number of days from injury to admission and the number of days from referral to admission with moderate to strong group effects (Table 5.4). No significant difference was found in the number of days from injury to referral between those admitted with or without complications, suggesting that there is no statistical difference between the two groups for when they are referred to the SCIC. However, although there is no statistical difference this analysis was approaching significance ( $p=0.052$ ) and those who were admitted with complications were referred on average 11 days later than those admitted without complications. This is clinically significant, additionally the small to moderate effect size of  $r=0.24$  suggests that there is a difference between the two groups and this is not likely to be a type II error (Field, 2009).

Although overall, a longer period to referral led to a longer time from referral to admission, there was a moderate and highly significant positive correlation between number of days from injury to referral and number of days from referral to admission ( $\tau=0.452$ ,  $n=47$ ;  $p=0.000$ ) for those who were admitted without complications. However

for those who were admitted with complications there was a very weak non-significant *negative* relationship between the number of days from injury to referral and number of days from referral to admission ( $\tau=-0.060$ ,  $n=18$ ;  $p=0.732$ ). This suggests that the time from referral to admission may be shorter for those who are admitted with complications compared to those admitted without complications. This highlights that the relationship between time to referral and time to admission is neither straightforward nor consistent.

Interactions with Presence of Complications on Admission	Test statistic (U)	z	p and effect size	Median Number of Days
Number of Days to Admission (N=74)	840.5	3.407	0.001 $r=0.40$	Admitted with Complications=63.5 days Admitted Without Complications=22.0 days
Days From Injury to Referral (N=65)	555.0	1.944	0.052 $r=0.24$	Admitted with Complications= 17 days Admitted Without Complications = 5 days
Days From Referral to Admission (N=65)	690.5	3.939	0.000 $r=0.49$	Admitted with Complications = 35 days Admitted Without Complications = 4 days

Table 5.4 Significant Interactions between Times to Referral or Admission and Presence of Complications

### 5.3.2.2 Healthcare Systems Outcome Measure: Pre-Mobilisation LOS

Pre-mobilisation LOS was examined for all subjects to identify if particular demographics or issues that occurred prior to admission impact upon this outcome measure. Table 5.3 demonstrates that there was a range of over 300 days in pre-mobilisation LOS across subjects. The total number of pre-mobilisation bed days was 1657 days, with a mean of 22.4 days. Significant mild negative correlations were found between the pre-mobilisation LOS and the length of time from injury to admission ( $\tau=-0.252$ ,  $n=74$ ;  $p=0.002$ ), the length of time before referral was made ( $\tau=-0.326$ ,  $n=65$ ;  $p=0.000$ ) and the time from referral to admission ( $\tau=-0.249$ ,  $n=65$ ;  $p=0.005$ ). This suggests that both delays in referral and longer time to admission will not result in a significantly longer pre-mobilisation LOS. However these findings need to be interpreted with caution as will be discussed in the following section.

### 5.3.2.3 Pre-Mobilisation LOS and Demographic Interactions

Pre-mobilisation LOS was significantly related to injury grouping on admission in the order shown in Table 5.5. Separate analyses of data for the 53 subjects who were delayed in admission found a significant relationship between pre-mobilisation LOS and whether complications were present on admission ( $U=471.5$ ,  $z=2.485$ ;  $p=0.013$ ,  $r=0.34$

indicating a moderate effect); those admitted with pressure sores were likely to have a significantly longer pre-mobilisation LOS.

Interaction	Kruskal-Wallis (H) Test and Jonckheere's (J) Post Hoc Test Results	Median Pre-Mobilisation LOS in Group Categories (Descending order)
Pre-Mobilisation LOS : Injury Group on Admission	$H=9.772$ ( $df4$ ), $p=0.044$ $J=684.00$ , ( $z= 2.829$ ) $r=0.33$	C6-C8 Tetraplegic (AIS A-C) = 12 days, Paraplegic (AIS D) = 8 days, C1-C5 Tetraplegic (AIS A-C) = 8 days, Paraplegic (AIS A-C) = 8 days, Tetraplegic (AIS D) = 4.5 days
Pre-Mobilisation LOS : Type of Complications on Admission	$H=15.197$ ( $df4$ ), $p=0.004$ $J=217.50$ ( $z= 2.998$ ) $r=0.41$	Multiple Issues = 0 days, Other Issues = 2 days, Nil Issues = 2 days, Contractures = 6 days, Pressure Sores = 34.0 days

Table 5.5 Significant Analyses Of Variations in Pre-mobilisation LOS across Injury Groups and Types of Complications on admission.

No significant relationship was identified between pre-mobilisation LOS and whether an additional condition was diagnosed during rehabilitation ( $U=553$ ,  $z= 0.884$ ;  $p=0.337$ ) or whether the individual had a significant pre-existing condition on admission ( $U=650.0$ ,  $z=-0.182$ ;  $p=0.856$ ) and was not correlated with age at time of injury ( $\tau= -0.020$   $n=74$ ;  $p=0.807$ ).

#### **5.3.2.4. Healthcare Systems Outcome Measure: Rehabilitation and Overall Length of Stay**

The following section investigates factors which may influence or be influenced by overall LOS or rehabilitation LOS. The overall LOS is the total number of bed days that the subject spent on the SCIC from their admission to discharge (Table 5.6) including both pre-mobilisation LOS and any discharge delay. Table 5.6 illustrates that all data items regarding LOS measurement are significantly skewed. Log transformations were applied to correct for the impact of outliers (Field, 2009) and analyses were performed with both the original and transformed data. The corrected version of number of days under or over target length of stay was still found to have two significant outliers therefore categorical data was utilised as if the subject completed their rehabilitation over or under target LOS where possible. Where no differences in results for the original or corrected versions of data were detected the analyses of the data in the original form is presented.

Only one subject had the exact rehabilitation LOS that it was estimated they would have, 40 subjects (54.1%) completed their rehabilitation in less time than their target

rehabilitation LOS and the remaining 33 (44.6%) had a longer rehabilitation LOS than expected.

	Rehabilitation LOS	Days over/under Target LOS	Overall LOS
Mean	96.2 (CI 87-106)	2.4 (CI -8.4-13)	140.8(CI 123-159)
Median	89.5 (IQR 40.25)	-1.5 (IQR 60.25)	122.0 (IQR 84)
Std. Deviation	41.7	46.3	76.7
Skewness (z)	1.1 (3.99)	0.7 (2.48)	1.6 (5.81)
Minimum	18	-94	24
Maximum	238	154	462
Mode	82 (Range 220)	-29 (Range 248)	96 (Range 438)
Key: LOS = length of stay IQR = Inter-quartile range Negative values are days under planned length of stay			

Table 5.6 Information on Injury to Discharge 'Pathway' data 2: Rehabilitation and Length of Stay

Very weak non-significant relationships were identified between Rehabilitation LOS and both number of days to admission ( $\tau = 0.001$   $n=74$ ;  $p=0.993$ ) and the number of days from referral to admission ( $\tau = 0.094$   $n=65$ ;  $p=0.280$ ). No significant relationship was found between number of days to referral and either Rehabilitation LOS ( $\tau = 0.003$   $n=65$ ;  $p=0.968$ ) or Overall LOS ( $\tau = -0.105$   $n=65$ ;  $p=0.968$ ). This suggests that delays in referral or admission do not impact upon rehabilitation or overall LOS but, as mentioned earlier, these delays were both mildly negatively related to pre-mobilisation LOS.

Interactions with Rehabilitation LOS	Test statistic	z	p
Complications Present on Admission	U=735.5	-2,147	0.032 ( $r=0.25$ )
Additional Condition Diagnosed During Admission	U=670.0	-2.384	0.017 ( $r=0.28$ )

Table 5.7 Significant Differences in Rehabilitation LOS across Demographic Groups

Analyses were performed in order to identify if demographic variables impact upon LOS outcomes. Table 5.7 illustrates that subjects who had an additional condition diagnosed during admission had a significantly longer rehabilitation LOS (with a small to moderate effect) as did subjects who had complications on admission (with a moderate effect). When seen in combination with earlier findings this last result suggests that although a delay in admission *per se* may not lead to a longer LOS they can lead to complications which do lead to a longer LOS, both in the pre-mobilisation and rehabilitation phases. Subjects with contractures and pressure sores also had a significantly longer rehabilitation LOS than subjects admitted with other forms of complications (Table 5.8).

These subjects also had an almost twice as long overall LOS (Median overall LOS without pressure sores = 111 days, Median overall LOS with pressure sores = 208 days). The results suggest that the impact of these complications carries on throughout the whole period of the admission, not just the pre-mobilisation LOS.

No significant correlation was identified between age at injury and rehabilitation LOS ( $\tau=-0.081$ ,  $n=74$ ;  $p=0.313$ ).

Subjects with Tetraplegia AIS A-C injury group had significantly longer rehabilitation and overall LOS than subjects in other injury groups (Table 5.8). There was also a highly significant relationship between injury group at discharge and whether rehabilitation was completed within or over the target Rehabilitation LOS ( $\chi^2(df6)=20.942$ ;  $p=0.000$ , Cramers  $V=0.368$ ,  $p=0.001$ ). Typically those with A-C AIS grade injuries exhibited a greater level of variation both over and under target LOS, those with AIS grade D injuries tended to complete their rehabilitation within the target rehabilitation LOS.

Interaction	Kruskal-Wallis (H) Test and Jonckheere's (J) Post Hoc Test Results	Median Number of Days In Group Categories (Descending Order)
Rehabilitation LOS : Types Of Complications	$H=11.043$ (df4) $p=0.026$ $J=241.5$ (z= -2.549) $r=0.35$	Contractures (N=1)=165 days, Pressure Sores=113.0, Nil Issues=84 days, Multiple Issues (N=1)=78 days, Other Issues=77.5 days
Rehabilitation LOS : Injury Group On Discharge	$H=410.14$ (df3) $p=0.017$ $J=633.5$ (z= -3.280) $r=0.38$	Tetraplegic (AIS A-C) = 98.5 days, Paraplegic (AIS A-C) = 91 days, Paraplegic (AIS D) = 82 days, Tetraplegic (AIS D) = 69.5 days
Overall LOS : Injury Group On Discharge	$H=26.71$ (df3) $p=0.000$ $J=426.0$ (z= -5.318) $r=0.62$	Tetraplegic (AIS A-C) = 173 days, Paraplegic (AIS A-C) = 107 days, Paraplegic (AIS D) = 98 days Tetraplegic (AIS D) = 80.5 days,

Table 5.8 Significant Differences in LOS Variables across Injury Groups on Discharge and Types of Complications Present on Admission

### 5.3.2.5 Outcome Measure: Discharge Delays

	Discharge Delay Days
Mean	22.15 (95% CI 13-32)
Median	0.5 (IQR 30)
Std. Deviation	40.4
Skewness (z)	2.8 (9.996)
Mode	0 (Range 0-198)
Total	1639

Table 5.9 Discharge Delay Days

50% (N=37) of subjects experienced a delay to their discharge. As shown in Table 5.9, the total number of discharge delay days over the period of the study was 1639 days (15.7% of the 7120 overall number of bed days used by these subjects). In this SCIC this equates to 1.5 SCIC beds lost for the period of the study due to delayed discharges and is the equivalent of an extra 22.15 bed days for every subject. 17 subjects were delayed due to lack of housing or adaptations and 16 were delayed due to care or placement funding delays, five of whom had suitable accommodation to be discharged. The remaining four were delayed due to a range of other issues. Although lack of housing or delays in completion of adaptations was the most frequent reason for discharge delays (Figure 5.9) the greatest number of discharge delay days (1054 days) occurred for those whose discharge was delayed due to Care/Placement Funding issues (Table 5.10).

Whether or not a subject completed their SCI rehabilitation in less than their proposed rehabilitation LOS was not significantly related to whether or not their discharge was delayed ( $\chi^2(df2)=1.083$ ;  $p=0.816$ ) suggesting that shortened rehabilitation LOS did not necessarily result in a delay to discharge.

Interaction	Kruskal-Wallis (H) Test and Jonckheere's (J) Post Hoc Test Results	Median Discharge Delay Days in Group Categories (Descending order)
Discharge Delay Reason : Discharge Delay Days	$H=63.932$ (df3) $p=0.000$ $J=1,645.5$ ( $z=8.223$ ) $r=0.95$	Care/Placement Funding Issues = 37.5 days, Housing Adaptations = 22 days, Other issues = 11.5 days
Source Of Care Or Placement Funding : Discharge Delay Days	$H=15.493$ (df7) $p=0.030$ $J=454.0$ ( $z=-3.872$ ) $r=0.49$	Joint CHC and SSD (N=1) = 43 days, SSD = 30 days, Joint SSD and Private funding = 11 days, CHC = 4.5 days, Private Funds only = 4 days, Interim Funds = 1 day, Other Public Funds (N=1) = 0 days
Injury Group on Discharge : Discharge Delay Days	$H=11.305$ (df3) $p=0.010$ $J=634.0$ , ( $z=-3.503$ ) $r=0.41$	Tetraplegic (AIS A-C) = 24.5 days, Paraplegic (AIS A-C) = 4 days, Tetraplegic (AIS D) = 0 days, Paraplegic (AIS D) = 0 days

Table 5.10 Analyses of Discharge Delay Days across Discharge Variables and Injury Groups on Discharge (Significant Differences)

Tetraplegics experienced significantly longer discharge delays than subjects in other injury groups (Table 5.10). The reason for discharge delay was also found to be significantly related to injury group on discharge ( $\chi^2(df9)=20.242$ ;  $p=0.005$ , Cramers  $V=0.306$ ;  $p=0.012$ ) with a moderate association. For tetraplegics (AIS A-C) the main reason for delay was funding issues, in other injury groups the main reason for this delay was issues with accommodation. Injury grouping on discharge was found to be

significantly related to the number of discharge delay days (Table 5.10) with AIS A-C. The relationship between funding issues and discharge delays was confirmed in analysis with a highly significant relationship (Table 5.10). The source of funding for care/placement was also significantly related to number of discharge delay days with those awaiting either Joint CHC (NHS funding) and SSD or sole SSD funding having the greatest number of discharge delay days (Table 5.10).

### **5.3.3 Discharge**

All 74 subjects were able to be discharged. The following sections will identify subject situations in relation to the outcome measures identified for this phase of the research project.

#### **5.3.3.1 Outcome Measure: Discharge Destination**

A detailed breakdown of discharge destination and numbers of subjects is given in Appendix I, Figure I.4. Due to small group numbers and to allow for meaningful statistical analyses the discharge destination groups were categorised into four groups of New Home (N=31), Previous Home (N=27) and nursing home (N=15). A fourth group of NHS transfer remained. This was a group containing only one subject who was transferred to another NHS facility by his Primary Care Trust due to a lack of suitable accommodation for discharge. This data could not be combined into the other three groups without compromising the data of these 3 groups and so this single subject group remained. This simplified grouping for discharge destination was used in all analyses unless otherwise stated.

20.3% (N=15) of subjects did not achieve the outcome measure of being discharged to the community and instead were discharged to a nursing home and 66.7% of these subjects (13.5% overall, N=10,) had no potential 'follow-on' accommodation in the community identified. Of the 58 subjects able to be discharged to the Community, 32.7% (N=19) were discharged to temporary accommodation. Only 39.2% of subjects were discharged to a property owned by the subject or their family (Appendix I, Figure I.5) and 21.6% of subjects were discharged to a property provided by the public or voluntary sector.

Adaptations were not deemed to be necessary on discharge if the individual was able to function independently in the home environment without adaptations, but with aids (bath board and grab rails for example) if required. 14 subjects did not have a property identified at the time of discharge. Of the remaining 60 subjects 68.3% (N=41) did not require adaptations for discharge either because their property already met their needs

or because a property had not yet been identified (Figure 5.2). For 38.3% of these subjects (N=23) adaptations were required but outstanding, with the majority of these (N=17) requiring state funding. The cost of adaptations and amount of care required due to delays in adaptations was rarely in the subject's notes and so could not be included in analyses.

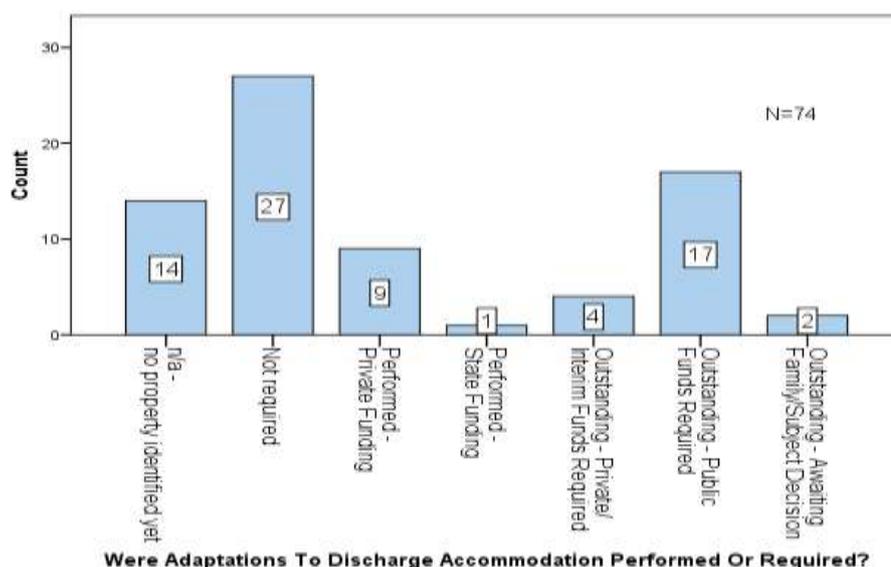


Figure 5.2 Whether Adaptations To Property Were Required and/or Performed.

A moderate, but highly significant relationship was found between the source of accommodation on injury and discharge destination (Table 5.11). 64.7% of subjects who were owner occupiers on injury returned to this accommodation on discharge. 42.9% of subjects living with their family on injury returned to this property on discharge but 28.6% were discharged to a nursing home. 33.3% of those who were in accommodation rented from a local authority or housing association on injury were discharged to a nursing home but 55.6% were discharged to a new property. 77.3% of those who were living in privately rented accommodation on injury were discharged to new accommodation.

	Discharge Destination
Injury Group on Discharge	$\chi^2=24.698$ (df9) $p=0.0001$ , Cramers V=0.344)
Source of Accommodation on Injury	$\chi^2=42.612$ (df15) $p=0.000$ , Cramers V=0.406

Table 5.11 Significant Interactions between Discharge Destination and a Range of Subject and Discharge Demographics

A highly significant relationship was found between injury group at discharge and the discharge destination groups (Table 5.11) with 42.3% of A-C tetraplegics being discharged to a nursing home. The mean age of those discharged to a Facility was 46.7 years (CI 35.9, 57.5); the youngest was 21 and the oldest 87. A significant relationship

( $H=15.046$  ( $df3$ ),  $p=0.002$ ) was identified between a subject's age and their discharge destination with a significant ( $J=508.5$  ( $z= -3.83$ )  $r=0.44$ ) trend for those who were discharged to their previous home to be older whilst those who were younger were discharged to a new property (Previous Home = 50 years, nursing home = 47 years, New Property =29 years).

Interaction	Kruskal-Wallis (H) Test and Jonckheere's (J) Post Hoc Test Results	Median Discharge Delay Days in Group Categories (Descending order)
Discharge Destination : Discharge Delay Days	$H= 17.096$ ( $df3$ ) $p=0.001$ $J=1,266.0$ ( $z=4.034$ ) $r=0.47$	Nursing home= 35 days, NHS Transfer (N=1) = 35 days, New Home = 1 day, Previous Home = 0 days

Table 5.12 Analyses of Discharge Delay Days across Discharge Variables and Injury Groups on Discharge (Significant Differences)

Subjects who were discharged to a nursing home had significantly longer discharge delays than those who were discharged to the community and those discharged to their previous home had significantly shorter discharge delays (Table 5.12) indicating a significant impact of discharge destination on the length of discharge delays.

#### **5.3.4 Outcome Measure: Vocational Activity**

Only 29.7% of subjects were employed on discharge, compared to 66.2% on admission, with only 9.4% actually having firm plans to return to work. Due to small subject numbers the following categories of vocational status were used: Employed/Self Employed/Full Time Care Giver (N=7), Employed – no date for return to work yet (N=15), Study/Retraining Being Considered (N=22), Retired Prior to or Since Injury (N=17), Unemployed – Declined Retraining (N=13). This simplified grouping was used in all analyses unless otherwise stated. The number of subjects who were retired had increased by only one at discharge. Only 12.3% of subjects who were not retired achieved the outcome measure of being vocationally active at discharge, with the potential that a further 65% may engage in vocational activity after discharge. Despite this only six subjects (8.1%) had contact with an advisor from the Department of Employment on discharge to assist with this transition.

No statistically significant relationship was identified between vocational status and either injury grouping on discharge, marital status on discharge or level of education attained prior to injury (Table 5.13).

Although no statistically significant relationship was identified between vocational status and whether adaptations to the subject's property were performed or were outstanding

(Table 5.13) 67.6% of those who had adaptations performed prior to discharge had either confirmed their return to work or were considering options to return to work or study, compared to 44.4% of those still awaiting adaptations.

	Vocational Status
Injury Group on Discharge	$\chi^2=15.058$ (df12) $p=0.182$
Discharge Delayed?	$\chi^2=5.888$ (df4) $p=0.614$
Marital Status on Discharge	$\chi^2=11.892$ (df12) $p=0.320$
Level of Education Attained Prior to Injury	$\chi^2=13.822$ (df12) $p=0.254$
If Adaptations Were Performed or Outstanding	$\chi^2=18.698$ (df24) $p=0.814$

Table 5.13 Non-Significant Interactions between Vocational Status and a Range of Subject and Discharge Demographics

### 5.3.5 Outcome Measure: Achievement of rehabilitation goals

A further indicator of the outcome measure of functional improvement is the achievement of rehabilitation goals. Although 62.2% of subjects successfully completed all of their rehabilitation goals, 37.8% (N=28) had goals outstanding on discharge. The majority of these were mobility goals which would typically focus on activities such as transfers or exploring options for driving or accessing public transport.

Whether a readmission was planned was found to be significantly related to whether goals were outstanding on discharge, type of goal outstanding and the reason for the outstanding goals with moderate to very strong associations (Table 5.14). In this last analysis a clear distinction is seen between reasons why goals were outstanding and plans for readmission. All subjects whose goal attainment was limited by wearing a brace or orthosis had a readmission planned and this group accounted for over two thirds of the planned readmissions at the time of discharge. Injury group on discharge was also found to be significantly related to whether goals were outstanding on discharge (Table 5.14) but as there was a notable but non-significant trend for A-C paraplegics not achieving mobility goals due to wearing a brace, this is likely to be a reflection of the relationships discussed above.

60.7% of those who had goals outstanding on discharge had a significant pre-existing condition on admission and this significantly impacted upon goal achievement, type of goals that were not achieved and the reason goals were outstanding with moderate associations (Table 5.14). When the data was examined more closely a split in the achievement of certain types of goals were noted as the majority (53.8%) of those with

mobility goals outstanding on discharge did not have a significant pre-existing condition whereas the majority of those with a self-care (75%) or education goal (100%) outstanding did have a pre-existing condition.

	If All Goals Were Attained	Type of Goal Outstanding	Reason Goal Outstanding
Injury Group on Discharge	$\chi^2=7.851$ ; (df3)	$\chi^2=20.864$ (df18)	$\chi^2=21.936$ (df21)
	<b><math>p=0.045</math></b> <b>Cramers V=0.332</b>	$p=0.142$	$p=0.297$
Significant Pre-existing Condition	$\chi^2=6.556$ (df1)	$\chi^2=11.476$ (df6)	$\chi^2=14.996$ (df7)
	<b><math>p=0.015</math></b> <b>Cramers V=0.298</b>	<b><math>p=0.040</math></b> <b>Cramers V=0.394</b>	<b><math>p=0.010</math></b> <b>Cramers V=0.462</b>

Table 5.14 Interactions between Goals Attainment and a Range of Subject Demographics (significant relationships are in bold)

### 5.3.6 Contextual Factors

At this stage of the research project it is unlikely that these contextual factors will significantly influence outcomes for the majority of subjects. However it is important to report the information given below as it is not widely available and therefore increases our knowledge of the situation of SCI individuals on discharge. It also identifies a benchmark of provision of resources, in the form of funds, care and equipment, against which we can begin to identify changes or differences which may influence outcomes at one year post-discharge.

#### *Alternative sources of funding*

58 (78.4%) subjects were seen by a solicitor from the SCIC's (free) Legal Support Service during their admission. 18 (31%) subjects seen by the legal service had a high likelihood of being able to make a claim for compensation (Appendix I, Figure I.10). A further five had the potential to be able to receive a small payment from personal insurance policies (household, travel, critical illness insurances) and four had a possibility of a claim that would need to be investigated further.

Five subjects not advised by the Legal Support service also declared that they had an active compensation claim. Out of all subjects with a potential claim, six made it known that they had received an interim/full payment prior to discharge, these payments were used to perform adaptations in one case and for multiple purposes (including private rental of property and some adaptations) in five cases. Three individuals were paraplegic (AIS A-C) and 3 tetraplegics (AIS A-C) and all were discharged to accessible properties.

### Care Provision

66.5% (N=64) of subjects required some level of assistance on discharge. Of the 58 subjects discharged to the Community 81% (N=47) received assistance with some element of their daily activities. 25.8% (N=15) of subjects were discharged to the community with a 24 hours/day care package. 34% of subjects would only receive a median of two hours per week informal assistance from friends or relatives.

Interaction	Kruskal-Wallis (H) Test and Jonckheere's (J) Post Hoc Test Results	Mean Care Hours Received or Cost of Care (Descending Order)
Injury Group on Discharge: Hours of Care on Discharge	$H(df3)=46.265$ ; $p=0.000$ $J=376.5$ , ( $z=-6.238$ ), $r=0.72$	Tetraplegic (AIS A-C) = 168 hours/week, Paraplegic (AIS D) = 0 hours, Paraplegic (AIS A-C) = 0 hours, Tetraplegic (AIS D) = 0 hours
Injury Group on Discharge: Cost of Care on Discharge	$H(df3)=40.724$ ; $p=0.000$ $J=396.5$ , $z=-5.809$ , $r=0.68$	Tetraplegic (AIS A-C) = =£1318.00/week, Paraplegic (AIS D) = £0, Paraplegic (AIS A-C) = £0, Tetraplegic (AIS D) = £0

Table 5.15 Significant Analyses of Variations in Mean Number of Formal Care Hours and Cost of Care across Injury Groups

The mean care package cost per week was £884.35, (Median weekly cost = £1000.00); this excludes any costs associated with provision of care by healthcare professionals such as District Nurses. The majority of care packages and nursing home placements (31.7%, N=20) were funded by Social Services (SSD) with NHS Continuing HealthCare (CHC) funding meeting the cost of 15.9% of cases. Private funds either partially or fully covered the cost of any care in 16.2% (N=12) of cases in addition to the statutory contribution that all care recipients make. The mean cost of a nursing home placement per week was £1429.31 (CI 1202.89), median £1489.00 (IQR=338.75). Tetraplegic (AIS A-C) subjects had a significantly greater number of paid care hours per week with an associated significantly higher cost (Table 5.15).

### Equipment Provision

85.1% (N=63) of subjects had one or more pieces of equipment outstanding on discharge. 5.4% (N=4) were awaiting provision of a stair lift and so would have been unable to access the upstairs of their property on discharge. 9.5% of individuals were awaiting provision of bathing equipment such as a shower chair, whilst 5.4% were awaiting a range of other types of equipment. 60.8% (N=45) of AIS A-C individuals were awaiting provision of standing equipment on discharge, but only 11 individuals had access to standing through an alternative source. Further analyses were not performed as the high number of subjects with outstanding equipment on discharge could cause the interactions to be artificially significant.

72.9% of subjects were still awaiting provision of their permanent wheelchair on discharge. Two subjects were discharged without a wheelchair. One of these subjects was an elderly Tetraplegic (AIS D) who fatigued easily and required a wheelchair to mobilise for anything other than short distances indoors. The other was a Paraplegic (AIS A-C) for whom the use of a wheelchair was essential for all mobility, provision of a loan SCIC wheelchair enabled this subject to be discharged. 80.8% (N=21) of AIS A-C Tetraplegics were discharged with only a temporary manual wheelchair, which would be likely to result in mobility restrictions.

#### **5.4 Discussion**

The outcome measures that relate to this phase of the study are LOS, discharge delays, functional improvement, vocational status on discharge and discharge destination. Additionally this phase of the study has a further healthcare systems outcome measure of timely referral and admission which will be included in the discussion of LOS. Prior to discussing these outcomes it would be beneficial to recap the information gained regarding subject demographics.

The incidence of tetraplegia in this study reflects trends reported internationally (Cripps *et al.*, 2011; van den Berg *et al.*, 2010; Ahoniemi *et al.*, 2008; Wyndaele and Wyndaele, 2006). The mean age also reflects international trends for increasing age at injury (Ahoniemi *et al.*, 2008; Wyndaele and Wyndaele, 2006) as well as a tendency for motor incomplete C or D AIS grade injuries and NTSCI in those with a greater age at injury (Schonherr *et al.*, 1996). These demographics suggest that this sample is representative of the SCI population in these respects.

Some variations were noted however as falls were the most frequent cause of SCI in this research although this does reflect the increasing numbers of fall related SCI being reported both in the UK and internationally (Apparelyzed.com, 2011; Spinal Injuries Association, 2011; Couris *et al.*, 2010; Divanoglou and Levi, 2009; Ahoniemi *et al.*, 2008; Amin *et al.*, 2005) and is representative of the patients admitted to the SCIC over this period. The lower percentage of subjects with NTSCI than previously reported in UK based figures (Barr and Spinal Injuries Association, 2009) is likely to be reflective of the admission policy of the SCIC which, generally, favours those with TSCI. The low numbers of NTSCI subjects meant that between group analyses could not be performed due to the grossly unequal sizes of the NTSCI/TSCI groups.

In the following section the results obtained will be evaluated in relation to these proposed outcome measures.

#### **5.4.1 Healthcare Systems Outcome Measure: Length of Stay**

A proposed area for investigation in relation to this outcome measure was the clarification of acute and rehabilitation LOS and examination of factors which may result in variations in rehabilitation LOS. The phases of the injury discharge pathway will be examined in turn.

The first 72 hours following SCI are a crucial period during which appropriate specialist management is required, however there is little UK-based evidence detailing the implications if provision of this appropriate management is delayed. This research identified that over 47% of subjects had not been referred to the SCIC at 10 days post injury and this will have resulted in a delay in the referring teams receiving specialist advice and support in the appropriate management of a new SCI. Several pieces of UK Department of Health guidance (National Spinal Cord Injury Strategy Board, 2011; NHS Clinical Advisory Group, 2011; Great Britain. Department of Health Long Term Conditions NSF Team., 2005, QR 3 and 4.) stress the requirement for early liaison and, where possible, transfer to an SCIC for the newly injured SCI individual if issues and complications are to be avoided. However this research indicates that this is not occurring. Additionally there is a clinically significant (but not statistically significant) trend for those admitted with complications to have been referred later and subjects admitted without complications typically had a shorter time to referral. The small to medium effect size present in this analysis suggests that a larger study may find a statistically significant difference. The time from referral to admission was also negatively related to time from injury to referral for those with complications present on admission, suggesting that a) delay in referral and so delay in receipt of specialist advice is associated with complications on admission and b) SCIC teams endeavour to admit those with issues sooner. This also supports the need for pro-active support from SCIC team members to provide specialist advice and support to referring hospitals in an attempt to ensure that newly injured patients can be admitted without avoidable complications. There is no similar research with which to compare these findings and so further research is required to confirm or dispute these findings.

Over half of the delays in admission in this study were due to a delay in referral, rather than subject health or bed availability. Although this contrasts with findings from an earlier study at the same SCIC (Amin *et al.*, 2005) this variation is likely to be due to

differences in the definitions of reasons for delay in admission. In this study if a referral had not been made within 3 days then the delay in referral was defined as the primary reason for any subsequent delay in admission; the study by Amin et al did not make this distinction. Additionally this research identified that a delay in referral could result in a significantly longer period from referral to admission than would occur if there was no delay in referral. There is no comparable research to confirm whether this reflects occurrences elsewhere or is a reflection of the admission processes in this particular SCIC; however referring institutions need to be aware of this relationship and the potential impact on their ability to transfer the SCI patient on to a SCIC if they delay in initiating a referral.

Although it is commonly suggested that delays in admission could potentially lead to longer lengths of stay (Wing, 2008; Grundy and Swain, 2002; Harrison, 2000; DeVivo *et al.*, 1990; Yarkony *et al.*, 1985), for the majority of subjects in this study a greater number of days to admission was actually accompanied by significantly shorter pre-mobilisation LOS and no impact was identified on rehabilitation LOS. This suggests that those subjects who were delayed in their admission may have been more 'rehabilitation ready' than those who were admitted more quickly. However there is an important exception to this in that those admitted with pressure sores had a significantly longer pre-mobilisation LOS, longer rehabilitation LOS, echoing other UK findings (Barr and Spinal Injuries Association, 2009). They also went significantly over their target LOS more than those admitted either without complications or with other forms of complications. This finding suggests that the benchmark of completion of rehabilitation within the target LOS is impacted upon by the presence of pressure sores in those who experience a delay in admission. It also suggests that appropriate management prior to admission may result in a shorter LOS due to reduced periods of pre-mobilisation. At a time when there is suggested to be an increasing incidence of SCI (van den Berg *et al.*, 2010; Wyndaele and Wyndaele, 2006), and therefore an increasing demand on SCIC beds this is particularly important and would bear further investigation.

In relation to the potential impact of demographics on LOS this study confirmed results reported elsewhere (Wolfe, Hsieh and Mehta, 2012; Barr and Spinal Injuries Association, 2009) that the subject's injury group on discharge was significantly related to both the rehabilitation and overall LOS. However, in this study those with AIS D tetraplegia had a shorter LOS than those with AIS D paraplegia, this difference may be explained by the small number of AIS paraplegic subjects (N=7) compared to those with AIS D tetraplegia (N=16). Neither pre-mobilisation nor rehabilitation LOS varied significantly with age. This is contrary to published research (Wolfe, Hsieh and Mehta,

2012), however as the definition of commencement of rehabilitation varies significantly between SCIC facilities and research studies so this variation may account for the differences in findings. Additionally this may reflect the use of age as a continuous variable in analyses rather than an 'older/younger' split as seen in some other studies (Wolfe, Hsieh and Mehta, 2012; Aito *et al.*, 2007; Cifu *et al.*, 1999). The increased use of common definitions of the acute and rehabilitation period through the SCI common data set (DeVivo *et al.*, 2006) or in the UK through the formalisation of the SCI Care Pathways (National Spinal Cord Injury Strategy Board, 2011) and associated collection of data may help in the future to identify causes of any disparities.

This research also aimed to investigate the impact of complications on admission on LOS and rehabilitation outcomes and identified that 27% of subjects were admitted with complications. As the occurrence of complications was not significantly related to any particular mode of injury they are likely to be a reflection of post-injury management rather than injury related issues (Regan *et al.*, 2012; Wing, 2008). This incidence of pressure sores is higher than the complication rate of 24% reported in another UK-based study; this may be because Barr (Barr and Spinal Injuries Association, 2009) included complications sustained during admission whilst this study only considered complications sustained prior to SCIC admission in the analysis.

Although injury group on admission was not statistically significantly related to either the presence or type of complications there was a clinically significant higher incidence of pressure sores on admission in those with AIS A-C injuries, echoing findings elsewhere that those who are more dependent are more at risk of developing pressure sores (Regan *et al.*, 2012). This highlights the need for SCIC advice and support to the referring hospital (such as through an Outreach service) to advise on appropriate management of the acute SCI. Further investigation of this with a larger number of subjects is required.

Longer periods of pre-mobilisation and rehabilitation LOS were found in those admitted with pressure sores but not with other avoidable complications. This is contrary to other, recent, UK based findings (Barr and Spinal Injuries Association, 2009) which, unfortunately, gave little information on the analyses other than the level of significance. Therefore the reason for the differing findings can only be speculated and may be a reflection of the differing forms of measurement of LOS or classification of complications used by Barr (Barr and Spinal Injuries Association, 2009) compared to this research. What this research clearly identifies is that whilst the impact of some forms of complications may resolve relatively quickly, pressure sores sustained prior to

admission have a significant impact throughout the admission period resulting in longer lengths of stay. This potentially impacts on SCIC bed availability and the ability to admit newly injured individuals quickly.

#### **5.4.2 Healthcare Systems Outcome Measure: Discharge Delay**

The total number of bed days lost due to delays in discharge meant that 1.5 beds on the SCIC (11% of available beds) were unavailable for the entire period of the study due to 'bed blocking'. In line with reports from other research both accommodation and funding issues were the main causes of discharge delays (Barr and Spinal Injuries Association, 2009; Anzai *et al.*, 2006; Forrest and Gombas, 1995). However the greatest number of discharge delay days was due to delays in the funding of care packages or nursing home placements that were essential for discharge. Tetraplegic (AIS A-C) subjects were not only significantly more likely to have a delay to discharge and a significantly longer delay, but this was also significantly more likely to be due to care or placement funding issues, particularly if the source of funding was Social Services (SSD). This is likely to be a reflection of funding mechanisms and processes in the UK which (in the author's experience) often results in an adversarial approach being taken by the NHS and SSD leading to delays in funding and subsequent care or placements being secured. Delays to discharge for paraplegics (AIS A-C) tended to be due to lack of accommodation issues or delay in provision of adaptations. These findings indicate a distinction between different injury groups not just on reasons for discharge delay but also the length of those discharge delays with tetraplegic (AIS A-C) individuals having more discharge delays and longer discharge delays. If the increasing incidence in tetraplegia noted elsewhere (Cripps *et al.*, 2011; van den Berg *et al.*, 2010; Wyndaele and Wyndaele, 2006) is also occurring in the UK then this information is extremely important for service planners and budget holders.

The finding that the largest number of discharge delay days occurred when subjects were discharged to a nursing home is contrary to both what has been found in other research (Tooth, McKenna and Geraghty, 2003) and commonly held discharge planning beliefs (Joyeux and Spinal Injuries Association, 2002, pg. 4.5.); the impact of delays in securing funding on this result needs to be considered. All subjects who were delayed in their transfer to a nursing home experienced delays in securing SSD or NHS funds for the placement and therefore would have been affected by the funding issues discussed above. A novel finding was identified that the length of discharge delays also varied according to injury group. As those who were AIS A-C Tetraplegic had a greater chance of being delayed due to funding issues, which in itself was associated with longer

discharge delays this finding is likely to be a reflection of the issues affecting plans for discharge in this injury group rather than an issue specific to the SCI itself.

The group of individuals who were delayed due to funding issues included both subjects who were discharged to the community with a care package and those who went to a nursing home. The subjects discharged to nursing homes tended to have high level care, and so high funding needs, and would have still had these needs if they were discharged to the community. Therefore high level of funding obtained from NHS or Social Services for the nursing home placement would also have been required for care in a home environment had the subject been able to return home, although the actual cost may have been slightly different. Therefore these delays due to funding issues are likely to have still occurred to these subjects if they were discharged to the community; in other words it is the cost and funding mechanisms not destination that is the primary cause of delay for these subjects. This research provides evidence of the potential impact of current issues with Health and Social Care funding cuts, the breakdown of joint working agreements and disputes over responsibility (Samuel, 2011) often resulting in an assessment funding process that is protracted or, at best, lengthened.

#### **5.4.3 Rehabilitation Outcome measure: Functional improvement and Goal Attainment**

Change in AIS grade was utilised in this research as the measure of functional improvement and increases in the number of functionally incomplete AIS C or D subjects was noted across the inpatient phase, however contrary to the findings of Scivoletto et al (Scivoletto, Morganti and Molinari, 2005) no significant differences in neurological change was noted between those who were admitted within or after 30 days post-injury.

A measure of functional improvement was the achievement of rehabilitation goals and although the majority of subjects achieved all of their rehabilitation goals some did not. The lack of significant differences in age between those who did or did not achieve their rehabilitation goals may reflect the use of age as a continuous variable as previously discussed (Wolfe, Hsieh and Mehta, 2012). The proportion of subjects with a significant pre-existing condition prior to admission echoes levels reported elsewhere (Barr and Spinal Injuries Association, 2009) and in line with findings elsewhere there was an impact on achievement of rehabilitation goals (DeVivo, 2012; Aito *et al.*, 2007; Cifu *et al.*, 1999). That these goals tended to be the domains of self-care and education suggests that those with pre-existing conditions may benefit from a differing approach in their rehabilitation. It also suggests that although the expectation of achievement in

some elements of rehabilitation may not have been lowered and LOS was not changed, actual goal achievement was reduced for these subjects. Further investigation may be warranted to establish why the pre-existing conditions affected goal attainment in these particular domains and whether increasing LOS would impact upon this.

Conversely, those subjects who had another condition diagnosed during admission did not have goals outstanding on discharge but did have a significantly longer rehabilitation LOS. The longer rehabilitation LOS is likely to reflect a period of time when diagnoses and possible treatment of the additional condition was occurring; in addition to the temporary slowing down of rehabilitation that will occur with conditions such as pulmonary emboli, and heterotrophic ossification. 23% were diagnosed with an additional condition during admission, slightly lower than the 28% reported in other UK based research (Barr and Spinal Injuries Association, 2009), suggesting that approximately a quarter of SCI individuals will require a significantly extended LOS, which will then have an impact on how quickly a newly injured individual may be admitted into that bed. Better rehabilitation outcomes in this situation compared to those with a significant pre-existing condition possibly reflect the transient impact of some of these additional conditions. Equally, better outcomes may have occurred due to an adjustment of expected outcomes from rehabilitation due to the new condition. For example self-care and transfer goals may have been adjusted to reflect the restrictions in hip range of movement due to heterotopic ossification.

Combined these findings suggest that outcomes in rehabilitation including LOS are affected differently by pre-existing conditions and new conditions that are diagnosed during rehabilitation. Further investigation is required into why particular types of goals were not achieved with pre-existing conditions, whether rehabilitation outcomes might have been improved if LOS was extended for these SCI individuals (Cifu *et al.*, 1999) and if the diagnosis of particular forms of condition during admission has differing impacts on rehabilitation progress and outcomes. When the reported increased incidence of SCI and the changing demographics of the SCI population are also considered then these issues require further investigation to identify the potential impact of pre-existing and newly diagnosed secondary conditions on the rehabilitation pathway.

The main injury group who had outstanding rehabilitation goals at discharge were paraplegics (AIS A-C) and the goals outstanding tended to be mobility goals that were restricted due to a brace/orthosis. These subjects also tended to have lengths of stay below the target LOS for their injury group and to have a readmission already planned at the point of discharge. Although not all of these relationships were statistically

significant, combined they present a picture of subjects whose rehabilitation is paused until the issue that is limiting their progress is resolved; in this case they are cleared by surgical teams to mobilise without their brace/orthosis (Barr and Spinal Injuries Association, 2009; Young *et al.*, 2006). Other research presenting similar findings has not been identified and therefore there are no comparisons that can be drawn. Although this suggests an effective use of bed resources as the specialist SCIC rehabilitation bed will now be available for an SCI individual who is able to participate in rehabilitation; this situation can only occur if the home environment can facilitate the SCI individual returning there. Additionally there will need to be an adequate provision of equipment and care support for the individual who will not have achieved all of their rehabilitation goals and will be more dependent on others for assistance than would normally be expected (Somers, 2010; Kirshblum *et al.*, 2007; Grundy and Swain, 2002).

#### **5.4.4. Rehabilitation Outcome Measure: Accommodation/Discharge Destination**

The provision of accommodation and residing in the community are significant outcome measures that potentially could impact upon the ability of the SCI individual to participate in the community. This research identified that over 78% of subjects were discharged to the community; this is a slightly higher rate than previously reported in a UK study (Aspire, 2009) but still suggests that a notable proportion of subjects did not achieve the target of being discharged to the community. Those who owned their property on admission tended to be married and older and were more likely to be discharged to that property. Those who were in privately rented accommodation on injury were more likely to go to new accommodation. However, as identified by Heywood (Heywood, 2004) those who are discharged to the community may experience serious limitations on their community participation due to lack of adaptations to the home. This research identified that 38.3% of subjects with an identified property were awaiting adaptations with 80% dependent on state funding. Potentially these subjects will have experienced greater difficulties in participating in community activities due to environmental limitations (Kennedy *et al.*, 2010a) and may have required extra assistance which would not have been required had adaptations been performed (Heywood, 2004). The potential impact of poor access in the home environment on psychological well being and quality of life has been widely acknowledged particularly if this situation is sustained for a prolonged period (Mortenson, Noreau and Miller, 2010; Heywood, 2004). In the next phase of this research project the potential impact of the delay in provision of adaptations on the reintegration outcome measure of community participation will be investigated.

In line with findings elsewhere the lowest numbers of discharge delay days occurred in those individuals who returned to their previous home (Tooth, McKenna and Geraghty, 2003); combined with the significant relationship between discharge to a nursing home and delays to discharge this suggests that some commonly held discharge planning beliefs need to be reviewed (Joyeux and Spinal Injuries Association, 2002, pg. 4.5.) and strategies for the curtailment of discharge delays revised.

As noted by DeVivo (DeVivo, 1999), tetraplegics (AIS A-C) were significantly more likely to be discharged to a nursing home. Whilst the overall numbers of subjects discharged to a nursing home (21.6%) is lower than the 25% reported by Aspire (Aspire, 2009), it is significantly higher than the figures reported elsewhere (Spinal Injuries Association, 2011). Unlike other research findings, age (Greenwald *et al.*, 2001) was not related to discharge to a nursing home. Those with a greater age were more likely to be discharged to their previous property and the youngest to a new property. It is a positive finding that all of those discharged to a nursing home/facility viewed this as only temporary accommodation, however it is concerning that only five (31.3%) of these subjects had onward accommodation identified at the time of discharge.

#### **5.4.5. Rehabilitation and Reintegration Outcome Measure: Vocational Status**

Vocational status is another identified rehabilitation and reintegration outcome to be evaluated in this research. This research identified that the numbers of subjects employed on discharge is less than half of that employed at injury, with only seven subjects (9.4%) actually having firm plans for when and how they would return to work. This low level of vocational activity is of concern and below previously reported UK figures of 38% in employment (Kennedy, Lude and Taylor, 2006). Additionally only six individuals actually had contact with a Department of Employment Advisor (Great Britain. Department for Work and Pensions, 2012a), along with access to vital information on their options for return to work and the support available to facilitate this. Research suggests that the availability of advice and support regarding training, changes to the work environment or hours and assistive equipment or care normally provided by a DEA are facilitators overcoming potential barriers to work (Noreau *et al.*, 2010; Schonherr *et al.*, 2004). In the UK Quality Requirement 6 of the National Service Framework for Long Term Conditions (Great Britain. Department of Health Long Term Conditions NSF Team., 2005) stresses that vocational rehabilitation and support should be available to individuals with long term conditions but this standard is clearly not being met. The next phase of this study will identify if this input becomes more commonly available once the subject has been discharged to the community. The low rate of return to work and lack of availability of support to facilitate this is also a concern when

the potential link between vocational status and mortality is considered (Krause, Saunders and Acuna, 2012). The next phase of the study will identify if this situation is rectified at one year post-discharge.

Contrary to findings in other research vocational status was not related to level of education attained (Marti *et al.*, 2012; Noreau *et al.*, 2010; Fiedler *et al.*, 2002) and the number of non significant relationships identified in analyses suggests that the low numbers with plans to return to work is a general issue for all subjects and not a particular sub-group. It must be acknowledged that the small subject numbers in some of the statistical analyses may be an issue and potentially significant results could be obtained with a larger sample. However it is notable that although vocational status on discharge was not found to be significantly related to whether or not adaptations to the home were outstanding, over 67% of those who were in a property that had been adapted or already met their needs had either confirmed their return to work or were considering options to return to work or study at the point of discharge. The next phase of the study will identify if this trend is maintained.

#### **5.4.6 Contextual Factors: Provision of Funds, Care and Equipment on Discharge**

81% of those discharged to the Community received some formal support on discharge, with 24.1% receiving 24 hour care. In line with findings elsewhere those with a Tetraplegia (AIS A-C) received a greater number of care hours per week and had higher care costs (Cohen *et al.*, 2012; Boucher, Ballantyne and Boschen, 2012; DeVivo *et al.*, 2011) but this level of support was also associated with a higher likelihood of a delay to discharge.

This research also hints at the significant role played by friends and family who provide informal care, with approximately 32% of subjects receiving a median of two hours per week informal support. At the point of discharge the level of informal support is only an estimate of what will be provided; at one year post-discharge the subject should have a greater awareness of the support provided therefore it is possible that the amount of informal support provided will be significantly higher than that formally recorded at discharge. The next phase of the study will attempt to clarify if this is the case.

That two subjects who required a wheelchair had still not received this essential equipment by discharge is a concern and may have impacted significantly on the ability of these individuals to participate in the community. Over 80% of AIS A-C tetraplegics injury group were discharged with only a temporary manual wheelchair and so are likely to be dependent on another person to propel their wheelchair for most if not all mobility

(Hastings *et al.*, 2011) potentially due to changes in procedures for the provision of powered wheelchairs (Rose and Ferguson-Pell, 2002). Delays in provision of other equipment were common with outstanding equipment ranging from a stair lift (which necessitated the subject sleeping, toileting and washing in a communal downstairs room) to standing equipment. This outstanding equipment may have a significant impact on the overall well-being of the individual concerned due to their inability to mobilise independently or engage in self-care tasks and potentially limit their ability to participate and reintegrate into the community. Increasing budget cuts are likely to have had an impact on the provision of these resources (Lungu-Mulenga *et al.*, 2013; Spinal Injuries Association, 2012; Loughborough University, Public Relations Office, 2012; Aspire, 2009; Kennedy, Lude and Taylor, 2006) however the lack of equipment will often lead to a need for additional support or alternative equipment which will often be funded from the same budget (Brangwyn, 2007). Unfortunately details of care provision required due to lack of equipment or adaptations were not available and therefore this line of investigation could not be pursued. In the next stage of the project outcomes will be identified, including incidence of complications and analysis of potential causes of this, including lack of equipment provision.

Although there were not enough subjects with a compensation claim to fully investigate whether the impact of interim funds could facilitate a speedier discharge, this study has identified that potentially there are alternative sources of funding available for some individuals that they require assistance to identify. Alternative sources of funding were made available, or could potentially have been so, for 30% of subjects. 21.4% of the 28 cases with potential compensation or insurance claims received payments from these sources prior to discharge and often utilised these to make adjustments to or provide accommodation. All subjects provided with an interim payment were discharged to accommodation that met their needs and provided with all the equipment and care that they required, which may potentially lead to improved outcomes at one year post-discharge; however these subject numbers are too small to be able to facilitate meaningful analyses. For some subjects payments were from personal or household insurance policies which are options that may not have been pursued by the subject if they had not received legal advice. Although often small these payments may financially assist the subject or their family during admission or assist in funding adaptations which the individual may have required a loan or state funding to obtain otherwise. As funding limitations are becoming more prevalent the potential availability of another source of funding is an option that many with SCI may wish to pursue but will need support to do so. This is an area which may benefit from further research to establish if a positive trend can be confirmed with larger subject numbers. There is no UK based research

with which to compare these findings and so conclusions drawn here are based on the trends evident in only a small sample of subjects.

## **5.5 Summary**

This first phase of this study has identified the subject's situation at the point of injury and at discharge. Relevant outcome measures for this phase of the study have been monitored. Some of these outcome measures are specific to the subject's situation on discharge, such as vocational activity, and will be evaluated again in the next phase of the study. Other outcome measures discussed reflect healthcare systems outcome measures, such as lengths of stay or delays in discharge. These outcomes will not be reassessed in the next phase of the study. Several meaningful or significant findings have been identified in this phase of the research project. Some support established findings, whilst others contest them. Some findings are novel and challenging or refining commonly held concepts in SCI care and management and in many cases are worthy of further investigation.

### **5.5.1 Limitations**

A limitation of this phase of the study is the lack of measure of social network as perceived by the subject. A further limitation is that data was not obtained on the actual number of independent outings and overnight stays performed by the subject prior to their discharge as this may be a measure of 'discharge preparedness' of the subject and their social network which may impact on their outcomes pre- and post- discharge. That is, if an individual has regular overnight leave prior to discharge they will have had more opportunities to practice skills acquired during rehabilitation and troubleshoot problems with or without the assistance of SCIC team members prior to discharge; as will those who have had regular day outings with friends and family, although probably not to the same level. This could potentially have an impact on the speed of their reintegration post discharge.

The lack of information regarding levels of care required due to non-provision of equipment or access issues within the home, as well as the cost of this care, means that one of the objectives of this research project, the evaluation of increased costs due to poor provision was not possible. In the next phase of the study it is hoped that it will be possible to evaluate if outcomes have been influenced by this lack of provision.

Smaller than anticipated subject numbers has meant that some analyses may not have achieved significance but would have done so in a larger group. However, as discussed in Chapters 1-4, the relatively low incidence numbers of SCI means that large sample

numbers cannot be achieved. Additionally the facility in which this study was undertaken had, at the time, only 14 rehabilitation beds and therefore would yield a small sample population.

### **5.5.2 Notable Findings**

Results presented in this phase of the study have assisted in identifying the situation of a cohort of SCI individuals at both injury and discharge. In addition, identification of clear and defined milestones in the pathway from injury to discharge will contribute to the knowledge of these pathways and factors which may hinder or facilitate progress along them. Due to the level of detail in the data collected it has not only been possible to clearly identify issues within the health and social care systems which may also impact upon both the SCI individual's progress through that pathway but also their rehabilitation and reintegration outcomes.

In summary this research has identified that both pre-mobilisation and rehabilitation LOS are affected by a range of factors. Functional improvement in the form of neurological improvement and goal achievement were noted in this group of subjects regardless of age. However subjects who had a pre-existing secondary condition on admission were less likely to achieve all of their rehabilitation goals, particularly in the self-care and education domains but they did not have an increased LOS. In contrast, subjects with a diagnosed with a new condition after admission achieved all of their rehabilitation goals but had a longer LOS.

In this research a clinically significant trend was identified for subjects who experienced a delay in referral to have complications, particularly pressure sores on admission. Subjects with A-C AIS grade injuries were also more likely to sustain pressure sores prior to admission. Over 47% of subjects had still not been referred to the SCIC at 10 days post-injury. This research demonstrates that SCI individuals who were referred more quickly to SCIC services had a subsequent shorter time to admission than those who were referred more slowly. However delays in admission are not significantly related to longer pre-mobilisation LOS in those who are admitted without avoidable complications as SCI individuals who are admitted to the SCIC earlier but without avoidable complications had a significantly longer pre-mobilisation LOS than those who were admitted later. SCI individuals sustaining pressure sores prior to admission were shown in this research to have significantly longer pre-mobilisation and rehabilitation LOS and to have an overall LOS that is almost twice as long as those admitted without pressure sores. Although in this research neither pre-mobilisation nor rehabilitation LOS varied with age they did vary significantly with injury group.

A shorter rehabilitation LOS was not significantly related to the occurrence of a discharge delay. Discharge delays were identified in this research to be significantly more likely to happen to tetraplegic (AIS A-C) individuals due to funding issues and paraplegic (AIS A-C) individuals due to accommodation issues. Additionally tetraplegic (AIS A-C) subjects awaiting a nursing home placement funded by SSD were significantly more likely to experience a delay to discharge. Discharge to a nursing home was significantly more likely to occur to a tetraplegic (AIS A-C) subject and significantly related to the occurrence of discharge delays. In contrast SCI individuals who were discharged to their previous home were least likely to have a delay to discharge.

A notable proportion of subjects did not have an identified permanent property at the point of discharge. Many who did have a property were still waiting for adaptations to the property on discharge. However a notable but non-significant finding was that subjects who were discharged to an environment that had been adapted or did not require adaptations (in other words a physically enabling environment) were more likely to be vocationally active on discharge.

Lower levels of vocational activity were reported in this group at discharge than have been reported elsewhere and few individuals had access to support in the community on discharge to facilitate return to work. The results of the next phase of this research project will identify if this relationship is sustained at one-year post discharge.

In summary the null hypothesis of: *'Timely provision of accommodation, care and equipment does not make a difference to the speed of discharge once rehabilitation is completed, or on reintegration outcomes once discharged.'* It appears that delays in the provision of accommodation and care do make a difference to the speed with which discharge occurs and so the null hypothesis is partially disproved. The provision of equipment was not noted as a significant delay to discharge, whether this or any other factors impact on reintegration outcomes will be investigated in the following chapters.

## **CHAPTER 6: Results Phase 2 – Outcomes at One Year Post-Discharge**

### **Overview**

This Chapter will present the results of the second phase of the research project, the aim of which is to examine the reintegration outcomes achieved by a cohort of SCI individuals at one year post-discharge. Additionally the potential for contextual factors to have impacted on these outcomes will be examined. Interactions between the outcomes and influencing factors will also be examined and discussed in relation to the current research on outcomes following spinal cord injury (SCI) as well as current provision and funding of care, equipment and accommodation in the UK.

*“Do not go gentle into that good night.  
Rage, rage against the dying of the light.”*

Dylan Thomas.

## **6.1 Introduction**

The aim of this second phase of the study is to examine the reintegration outcomes achieved by this cohort of subjects at one year post-discharge. This Chapter will also evaluate the interactions between these outcome measures and some of the previously identified contextual factors. The potential impact of the additional personal contextual factors of coping and locus of control will be examined in Chapter 7 along with the outcomes in relation to perceived quality of life.

## **6.2. Subjects**

Of the 74 subjects who consented to take part in the research project two died during their first year of discharge and one subject was lost to follow-up. This left a total of 71 subjects available to contribute data for this phase of the project. 48 completed surveys were received giving a response rate of 67.6%. Chapter 7 will contain discussions for those subjects who contributed psychological data.

### **6.2.1. Representativeness of Sample**

The majority of subjects (N=48, 67.6%) contributed data at one year post-discharge however subjects who did not contribute data constitute a significant amount of missing data which may influence the representativeness of this sample. In order to establish if the reduced numbers were due to some selective bias or attrition, comparative analyses of the groups who did and did not contribute data were performed. Full details of significant and non-significant between group analyses can be found in Appendix J. Those who did and did not contribute data at one year post-discharge did not vary significantly on a number of factors (Appendix J, Table J.1). However subjects who did or did not contribute data did significantly vary in terms of age. Subjects who contributed data were older (median age=44.5, mode =24) although the effect size of this difference was small ( $r= 0.242$ ) and the median age of all available 71 subjects was 43.0. There were also significant differences in vocational status at injury and level of education attained; discharge destination and source of accommodation on discharge (Appendix J, Table J.2).

### **6.2.2 Demographics**

48 subjects contributed data at one year post-discharge. 72.9% were male and mean age at injury was 47 years (Table 6.1). The mean time since discharge was 59.87 weeks and mean time since injury was 83.71 weeks. 46.5% of subjects were single at the time of discharge and 43.7% were married or cohabiting. 41.7% had a professional qualification or diploma/degree at the point of injury. 52.1% of subjects were tetraplegic and 62.5% had a functionally complete AIS grade A or B SCI, compared to 54.7% of

subjects on discharge. The proportion of subjects with an AIS A-C paraplegia and AIS D tetraplegia in this sample had increased (Appendix K, Table K.1), although this was not a significant difference. The majority had sustained their SCI due to road traffic accidents (25%) followed by both falls and non-traumatic causes. 54.9% of subjects completed their rehabilitation in less than the target rehabilitation LOS for their injury group. 43.8% experienced a delayed discharge which was slightly less than the 50% seen in the larger group of subjects, the main reason remained as housing related issues. Full demographic information is given in Appendix K.

	Age at Injury	Weeks Since Discharge	Weeks Since Injury
Mean	47 (CI 41.15, 52.85)	59.87 (CI 57.75, 61.99)	83.71 (CI 79.59, 87.83)
Std. Deviation	20.14	7.3	14.19
Median	44.5 (IQR=36)	59.00 (IQR=11.75)	81 (IQR=22.75)
Skewness	0.465 (z=1.35)	0.460 (z=1.34)	0.660 (z=1.92)
Minimum	21	50.00	61
Maximum	87	76.00	129
Mode	24	55	72

Table 6.1 Descriptive Statistics of Demographic Data at One Year Post-Discharge

### 6.3. Results:

Data management, handling and analyses methods utilised are as discussed in detail in Appendix F. The number of subjects who contributed data at one year post-discharge is lower than was anticipated, and has resulted in small group numbers in many of the analyses performed. The potential impact of small subject numbers needs to be considered as this has potential to cause false positive or negative results. Due to this trends in the data will also be examined where group numbers are small and unexpected significant or non-significant results have been obtained. For the sake of parsimony only significant and non-significant results which are contrary to previously published research will be discussed, however much of this data is novel in the UK and therefore the presentation of some descriptive data is necessary as this has the potential to contribute to the knowledge of issues affecting individuals with SCI in their first year of community reintegration.

#### 6.3.1 Outcomes Following Discharge from SCIC

The following section will identify the subject's situation in relation to the reintegration outcomes measures proposed for this phase of the research. These are: Community Participation, Vocational Activity Readmissions and Accommodation/Residential Status

### 6.3.1.1 Community Participation

In order to explore levels of participation subjects were asked to state the frequency with which they engaged in a range of community and social activities, the issues that they faced in doing this and the importance that they ascribed to these activities. Full details of community activity engaged in and the importance ascribed to this by subjects are detailed in Appendix K, Tables K.2 to K.3. Access issues were highlighted by subjects as barriers to many community facilities. 17.4% were unable to access their local shops (N=8 of 46). 22.7% stated that they were unable to access leisure facilities at all and 11.4% stated that they were unable to access any shopping facilities at all.

Overall low levels of community activity are reported by subjects despite the majority rating these activities as medium or high level of importance (Appendix K, Tables K.2 to K.3). Additionally 50% (N=19) of subjects stated that they only left their home once a week or less frequently (Table 6.2), 12 of who lived alone. 45.4% (N=10) stated that this was due to transport issues and 18.2% (N=4) that they did not have the level of assistance required to leave the house more frequently. Other reasons given were: health issues 13.6% (N=3), poor access 13.6% (N=3) and personal choice 9.1% (N=2).

How often does the subject leave their home?	Who lives with at one year post-discharge			Total
	Family (parents, etc)	Partner and/or children	Alone	
Daily/Every few days	3	14	7	24
Once a week or less	0	12	12	24
Total	3	26	19	48

Table 6.2 Frequencies of Community Outings of Any Form Compared to Who Subjects Live With

### 6.3.1.2 Readmissions

41.7% of subjects were re-admitted to hospital within their first year of community reintegration. None of the subjects who had a readmission planned at discharge (N=3) had a further admission to hospital. Six subjects had multiple admissions one of who was admitted six times during their first year following discharge (Appendix K, Table K.4). The available data gives a total number of readmission bed days over the first year post-discharge was at least 222 days (Appendix K, Table K.4), an average of at least 4.6 days per subject. Information on length of readmission was only collected for the longest admission regardless of how many admissions occurred therefore it is unknown how many more readmission days may have occurred. Without detailed admission records it is difficult to say which readmissions were avoidable and which were unavoidable. Therefore it is not possible to evaluate how many subjects achieved the outcome measure of not having an avoidable readmission to hospital. Skin issues are, perhaps, the exception to this and constituted 15% of admissions. Full details of

numbers of admissions, reasons for admissions and LOS are illustrated in Appendix K, Table K.4.

### 6.3.1.3 Accommodation/Residential Situation

At one year post-discharge 20.8% of subjects (N=10) were still living in temporary accommodation and 8.3% (N=4) of these subjects were still awaiting identification of permanent accommodation. 47.9% of subjects were living in a property that they owned (Appendix K, Figure K.5) but the number of subjects living in a public sector rented property increased by 64% compared to the point of injury (Housing Association or Local Authority).

The accommodation that subjects were living in at one year post-discharge was significantly related to the source of their accommodation at the point of injury ( $\chi^2=41.226$  ( $df16$ ),  $p=0.000$ ) with a moderate significant relationship indicated (Cramer's  $V= 0.500$ ,  $p=0.000$ ). However, as can be seen from Appendix K, Table K.5 there was notable changes in all but one group; the group of subjects who owned their property. Therefore the strength of this relationship may, in some part, be due to the robustness of the large group of subjects who were living in property that they owned at both time points.

Although no significant relationship was identified between the subject's injury grouping at discharge and where they were living at 1 year post discharge ( $\chi^2=14.889$  ( $df12$ ),  $p=0.118$ ), all of the four subjects (8.3%) who were still residing in a nursing home at one year post-discharge were A-C Tetraplegics. Two of these subjects (ages 21 and 61) did not have a property identified at one year post-discharge.

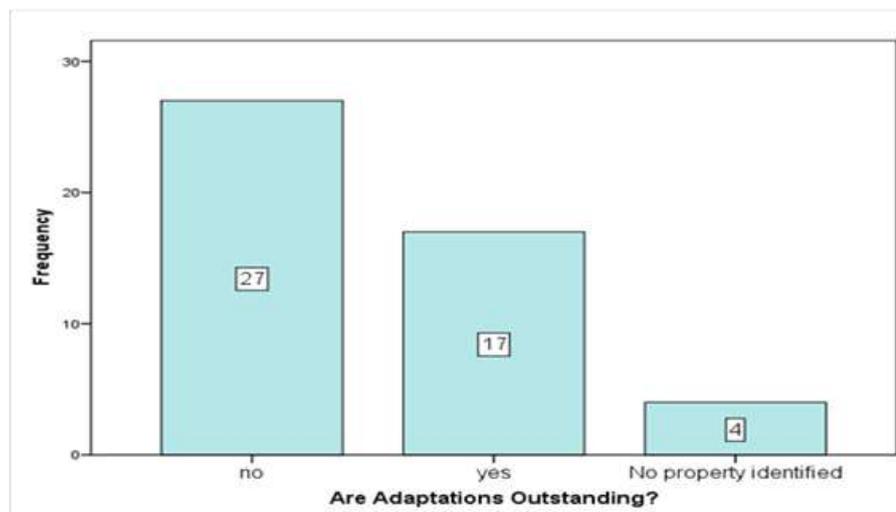


Figure 6.1 Subjects With or Without Outstanding Adaptations At 1 year Post Discharge

23.9% of subjects stated that they were unable to access the whole of the inside of their home (including with some assistance, if necessary) and 15.2% stated that they were unable to access the outside of their home. When the subjects who did not have a property identified at one year post-discharge were excluded the results identified 35.42% of subjects reported that their property still had outstanding adaptations (Figure 6.1). Only six of these subjects had outstanding adaptations on discharge. In order to identify the cause of this disparity the data was examined more closely and revealed that, of the 17 subjects requiring adaptations at one year post-discharge, three had been discharged to temporary accommodation but were now awaiting adaptations to their 'permanent' accommodation. Three of the remaining eight subjects had been discharged to a property where privately funded adaptations had been performed prior to discharge and five had been discharged to a property that community and hospital professionals stated did not require further adaptations. This indicates that these subjects deemed that further works to their property were required in order that it could meet their needs, not that adaptations had been formally prescribed and were outstanding.

#### **6.4.1.4 Vocational Status**

Two subjects did not give details of their vocational status at one year post-discharge. 32.6% of contributing subjects were vocationally active at one year post-discharge compared to 66.2% at the point of injury. In order to permit meaningful analyses of data the vocational status groups were simplified to three groups of: Vocationally Active, Vocationally Inactive and Retired (Figure 6.2) and these simplified vocational status categories will be used in remaining analyses unless otherwise indicated. Subjects were only classed as vocationally active if they were actively engaged in some form of paid or unpaid vocational activity, including studying/retraining or full time care giver. Two subjects stated that, although still officially employed, they did not have a planned date to return to work at one year post-discharge; these subjects were classified as vocationally inactive.

11 subjects gave the number of hours that they were engaged in work or study and the mean number of hours worked per week was 25.77 hours (Std Dev.=13.04, Minimum=1 hour, Maximum=40 hours). Four subjects stated that they were engaged in full-time vocational activity. Eight of the 15 vocationally active subjects declared that they worked from home and 60% of subjects who had a place of work/study stated that they were unable to access it. Two subjects stated that they had not yet returned to work due to access issues. Only 4.2% (N=2) of subjects stated that they had contact with a UK

Department of Employment advisor at one year post-discharge, despite 26.1% not being vocationally active.

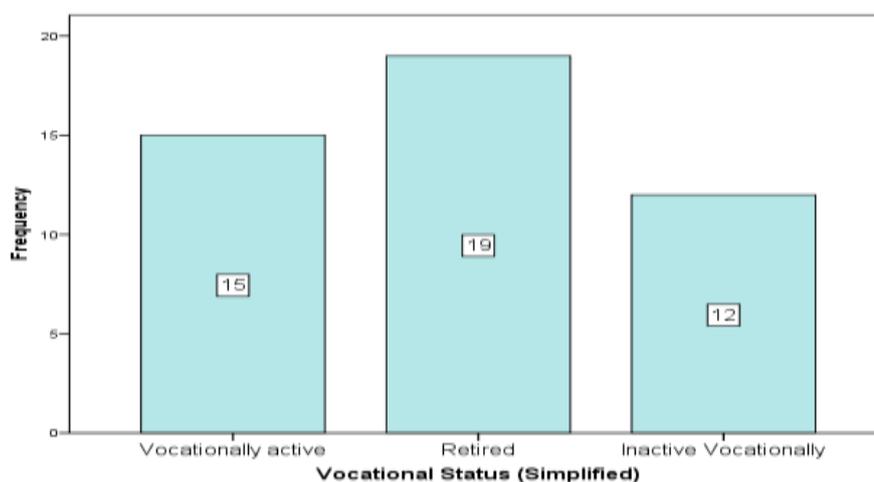


Figure 6.2 Simplified Categories of Vocational Status at 1 year Post Discharge

Further examination of the data identified that the minimum age at injury of subjects in the retired group was 36 years and 28.3% were younger than the standard UK retirement age of 65. Assuming a potential time from injury to survey completion of approximately two years, those who were 47 at the time of injury could be approaching 50 at the time of survey. Those over 50 may face greater challenges in securing new employment or retraining for what may be a comparatively short new career. However, those who were under 47 at the time of injury could be able to seek new employment, including retraining if required and therefore these subjects were reclassified as vocationally inactive if not employed (N=2). The remainder of the subjects who classed themselves as retired were over 47 at the time of injury. All of the following analyses were performed with these reclassifications.

The mean ages in the respective vocational groups were: Retired=67.74 years, (Std Dev. 12.73), Vocationally Active=30.67 years (Std Dev. 8.61) and Vocationally Inactive=35.08 (Std. Dev 10.11). 55.5% of those who were not retired were vocationally active. A highly significant relationship was identified between vocational status at the point of injury and vocational status at one year post-discharge ( $\chi^2=31.693$  (df6),  $p=0.000$ ) with a strong association (Cramers V= 0.593,  $p=0.000$ ).

To attempt to identify personal attitudes toward work, subjects were asked to state the level of importance they ascribed to the activity of going to work or college. 14 (30.4%) subjects omitted to answer this question (Table 6.3). Due to the number of subjects who did not answer this question and the near full completion of other similar questions, this was deemed likely to be a deliberate omission rather than an oversight. The ages of the

non-respondents ranged from 24 to 87, two of these subjects were female, one subject was employed and one had failed to give information on their employment status. The remainder were either unemployed and were not considering options for retraining (N=2) or considered themselves to be retired. There is a possibility that retired subjects did not answer this question as they did not feel that the question applied to them. There is also the possibility that those subjects who did not answer the question vary in some significant way from the responding subjects, and therefore the answers that have been obtained may not be representative of the group as a whole. For this reason only simple analyses will be performed with this data.

Importance Ascribed to Vocational Activity	Vocationally Inactive	Vocationally Active	Retired	Total
Low importance	4	1	5	10
Medium importance	1	4	4	9
High importance	2	9	2	13
Declined to answer	5	1	8	14
Total	12	15	19	46

Table 6.3 Subjects Stated Perceived Importance of Vocational Activity across Simplified Vocational Status Categories

40.6% of the 32 subjects responding to this question reported that going to work or college was a moderately or highly important activity (Table 6.3). The perceived importance of engaging in a study or work activity was found to significantly vary across the vocational status groups ( $\chi^2= 15.225$  (df6)  $p=0.012$ , Cramers V= 0.415,  $p=0.012$ ), with (60%) of vocationally active subjects identifying going to work/college as a highly important activity. 16.6% of those who were vocationally inactive also classed going to work/college as a highly important activity. This suggests that a significant percentage of those who are vocationally inactive may prefer to be vocationally active but are unable to be so for a variety of reasons. As low numbers had contact with a DEA advisor they will have been lacking information on options for work and training.

Those who were retired either prior to or since their injury represent a group in their own right and the demographics of this group may influence the results of analyses regarding vocational status in a manner that is contrary to the trends present in the other two groups. Additionally the presence or absences of a variety of factors are not as likely to influence the vocational status of this group. For these reasons those in the Retired category were excluded from the following interactions, unless otherwise indicated.

The vocational status of subjects at one year post discharge was not significantly related to whether the subject experienced a delay to their discharge ( $\chi^2=1.302$ (df9);  $p=0.218$ ).

It was also not related to the subject's age ( $t(df25)=1.226$ ,  $p=0.232$ ,  $F=1.594$ ,  $p=0.218$ ,  $N=27$ ) or a range of other non-modifiable demographics including injury group, gender or ethnicity, It was also not related to their level of education at the time of injury (Appendix K, Table K.6). However paraplegics did work notably more hours than tetraplegics (30.00 compared to a median of 20.00 hours for tetraplegics). Additionally subjects who were vocationally active were younger (median=27.5 years) than those who were vocationally inactive (median=33.5 years).

Although the source of the accommodation that the subject was living at one year post-discharge was significantly related to their vocational status ( $\chi^2=18.369$  ( $df8$ )  $p=0.003$ ) with a moderate to strong significant relationship (Cramers  $V=0.484$   $p=0.045$ ), this relationship was not sustained when those who were retired were discounted from the analysis ( $\chi^2=5.750$  ( $df4$ )  $p=0.168$ ). This suggests that where the subject lived indicated whether the subject was retired rather than whether or not they were vocationally active.

Whether adaptations to the subject's home were outstanding at one year post-discharge was also not significantly related to vocational status ( $\chi^2=1.081$ , ( $df4$ );  $p=0.710$ ,  $N=26$ ). However, subjects who were *discharged* to a property that either had been adapted to meet their needs or did not require adaptations were significantly more likely to be vocationally active at one year post-discharge even when all three vocational groups were analysed together ( $\chi^2=19.742$  ( $df12$ )  $p=0.016$ ). A moderate to strong association was identified between the subject being discharged to a physically enabling environment and being vocationally active at one year post-discharge (Cramers  $V=0.439$   $p=0.010$ ).

#### **6.4.2 Contextual Factors**

In this section some of the contextual factors identified in Chapters 2 and 3 which may influence outcomes will be reviewed and interactions with outcome variables will be examined.

##### **6.4.2.1 Social Situation & Social Support**

Levels of social contact were taken to be indicators of social engagement and potential social support in this research. Who the subject lived with at the point of injury was (highly) significantly related to who they lived with at one year post discharge ( $\chi^2=38.706$  ( $df6$ ),  $p=0.000$ ) with a strong, significant association (Cramers  $V= 0.647$ ,  $p=0.000$ ). However 40.4% of subjects lived alone at one year post-discharge and 63.2% of those subjects who lived alone at one year post-discharge only left their homes once a week or less frequently (Table 6.2).

The majority of subjects had a visit daily or every few days from family members or friends that they did not live with (Appendix K, Tables K.7 and K.8). Although a greater number of subjects did not have any visits from family than those who did not have any visits from friends potentially this result may have been influenced by the number of subjects who lived with family members (Table 6.2). 23.5% of those who lived alone at one year post-discharge only had visits from friends monthly or less frequently and 29.4% had weekly visits. 17.6% of had monthly or less frequent visits from family members and 11.8% had weekly visits. This suggests that despite the majority of subjects viewing social interaction in the home as important or highly important (Appendix K, Tables K.7 And K.8) a notable proportion of those living alone had little social engagement in their home. Potentially when combined with the findings discussed earlier regarding the low frequency of community activities this suggests that there may be potential for social isolation in those who are living alone at one year post-discharge. However information was not available regarding other forms of contact such as online contact. Additionally further, more detailed, analyses would be required to support this assertion and discount other forms of social contact (for example vocational activity or live in carers) but the small subject numbers limits the analyses that can be performed.

#### **6.4.2.2 Mobility and Transport**

60.4% (N=29) of subjects owned a car at one year post-discharge, however only 31.3% (N=15) were able to drive and only 29.2% of subjects stated that they had access to a driver all of the time. 27.1% (N=13) of subjects stated that they were unable to access public transport, but 45.8% of subjects were able to access and used public transport. These findings highlight that although some subjects have easy access to transportation a notable proportion experience barriers to their community participation in the form of transport.

The subject's vocational status was not significantly related to their car ownership, their ability to drive or their ability to access public transport (Appendix K, Table K.12).

At one year post-discharge four subjects (8.9% of 45 responding subjects) had still not received their permanent wheelchair. Four subjects (9.7% of 41 responses) stated that their local Wheelchair Service did not meet any of the cost of their permanent chair and a further four only received part of the cost. Due to the small number of subjects who had not received their permanent wheelchair at one year post-discharge further analyses will not be performed with this data as any results may be misleading, at best.

### 6.4.2.3 Care Provision and Costs

81.25% stated that they were receiving care support at one year post-discharge, an increase from 66.5% on discharge. This increase is despite the non-significant decrease in the number of the potentially more functionally dependent) AIS A-C tetraplegic subjects. Although the mean number of care hours received had reduced from 108.09 hours/week to 79.58 hours/week (Appendix K, Table K.16) the amount of care received on discharge was highly significantly related to the amount of care received at one year post-discharge ( $r=.90$ ,  $p=0.000$ ,  $R^2=0.81$ ). This suggests that although there are changes in the level of care received 81% of variation in the level of care received at one year post-discharge can be accounted for by the level of care received at discharge. 16 subjects were receiving 24 hour care. The most frequent reason subjects received care was for assistance with mobility (73.8%, N=31), followed by assistance with domestic activities (66.7%, N=28) and assistance with personal care tasks (59.5%, N=25). Nine (18.75%) subjects stated that they required care due to the limitations of their environment at home. The total number of care hours per week required due to environmental limitations was 78.5, with a cost of £153.51 per week. However, it is not clear from this data if this care was required due to outstanding adaptations or due to environmental issues overall.

A highly significant difference was noted in the number of care hours received at one year post-discharge across the different injury groups ( $H(df3)=21.365$ ;  $p=0.000$ , N=46). Jonckheere's test revealed a significant trend in the data ( $J=205.00$ ,  $z=-3.425$ ,  $p=0.001$ ) for those within the Tetraplegia AIS A-C group to have significantly greater number of paid care hours per week (Median=168) followed by Tetraplegic AIS D (Median=14.0), Paraplegic AIS D (Median=7) and finally Paraplegic AIS A-C (Median=5.5). On discharge all groups other than the Tetraplegia AIS A-C group had a median number of care hours per week of zero. This suggests that at one year post-discharge those in other injury groups are receiving notably more care than they were on discharge.

Of the of subjects receiving care 34.2% stated that this was solely provided by a member of their family or a friend compared to 27% on discharge (median hours=6.75 hours (IQR=12.0), minimum=2 hours, maximum=24 hours/day - one subject). A further 18.4% received care from a family member or a friend in association with carers or healthcare professionals (Figure K.4). This suggests that there is a greater acknowledgement of the level of informal support received by subjects at one year post discharge than there was on discharge. The median number of care hours received per week by the 13 subjects who only received informal care

The mean weekly cost of care had reduced by £207.64 since discharge. The source of care package funding was significantly related to who provided the care ( $\chi^2=35.695$  (df25)  $p=0.007$ ), indicating that formally funded care packages were provided by care professionals and care provided by friends or family was more likely to be funded from private means. However, although this association was moderate to strong, it was not significant (Cramer's  $V=0.452$ ,  $p=0.119$ ). The source of care package funding on discharge was significantly related to the source of care package funding at one year post-discharge ( $\chi^2=32.133$  (df25)  $p=0.025$ ), with a strong but non-significant association (Cramer's  $V=0.502$ ,  $p=0.062$ ). There are some notable changes, as a greater proportion of care packages are either partially or wholly funded through private funds (44.7% compared to 17.5% on discharge) and the percentage of packages funded by Social Services (SSD) has been halved to 28.9%. The percentage of care packages that were solely or joint funded by NHS Continuing Care has increased since discharge.

	Source of Care Funding (N=17)	Amount of Care Received (N=17)
Vocational Status at One Year Post-Discharge	$\chi^2=8.238$ (df4) $p=0.041$	$t(df18)= 1.584$ , $p=0.131$
	Cramers $V=0.713$ $p=0.061$	$F=2.539$ , $p=0.128$

Table 6.4 Significant Relationships/Differences of Care Factors and Vocational Status Groups

A highly significant relationship was identified between the source of care package funding at one year post-discharge and whether the amount of care received had been reduced since discharge ( $\chi^2=15.562$  (df4),  $p=0.001$ ) with a highly significant association (Cramer's  $V=0.743$ ,  $p=0.001$ ) indicating that subjects with reduced levels of care were more likely to be privately funding their care package (N=10). However, small subject numbers in these groups may have influenced the results.

Care factors had a varying impact on vocational status at one year post-discharge. Who provided care to the subject was not significantly related to vocational status ( $\chi^2=2.786$ (df5);  $p=0.964$ ) but the source of the care package funding was significantly related to the subject's vocational status with a strong but non-significant association (Table 6.4). This conflicting finding may be a reflection of the small group numbers as the total number of subjects in the analysis was 17, however a greater proportion of those who were privately funding their care were vocationally active. Vocational status was not significantly related to who provided the care with both groups of subjects receiving care from a variety of providers. The number of care hours received did not significantly vary with vocational status (Table 6.4). However those who were vocationally active received markedly less care hours (mean=45.33) compared to those who were vocationally inactive (mean=99.27).

#### 6.4.2.4 Equipment Provision

39.6% (N=19) of subjects reported that they had outstanding equipment at one year post-discharge. 38.2% (N=13) had not received standing equipment at one year post-discharge, ten of who did not have access to alternative standing facilities. Five subjects were still awaiting provision of essential bathing equipment, for example commode/shower chairs. 61.5% (N=8 of 13) of subjects who required an environmental control unit still did not have one at one year post discharge.

#### 6.4.2.5 Complications/ Sequelae Related Issues

The majority of subjects (93.7%) stated that they were experiencing complications or issues with the sequelae of SCI. Some of these issues and complications may have been avoidable whilst others were not. However defining these complications and issues in these terms would require a value judgment to be made which may be inaccurate without further information or access to medical records. Therefore only the type of issue or complication will be discussed. Pain issues were the most reported issues at one year post-discharge, followed by spasms, bladder, bowel and skin issues (Appendix K, Table K.9). 58.3% of subjects stated that they were experiencing problems with three or more issues related to their SCI.

The occurrence of skin issues during the first year of community reintegration was not significantly related to whether subjects had pressure sores on initial admission to the SCIC ( $\chi^2=2.551$  (*df*1),  $p=0.215$ ). However, 71.4% (N=5) of those admitted with sores had experienced frequent skin issues during the first year of community reintegration. If this result is viewed with the previous findings regarding the impact of pressure sores on LOS, it suggests that pressure sores sustained prior to admission can impact on both the admission period and the first year of community reintegration.

There was a non-significant difference in the number of care hours received ( $t(df44)=-1.225$ ,  $p=0.227$ , ( $F=1.594$ ,  $p=0.218$ ), N=46) between those who had experienced skin issues during the first year of community reintegration (mean=79.9) and those who had not experienced skin issues (mean= 51.82).

The sequelae of pain and spasms/spasticity were examined in greater detail and, in addition to a declaration of if issues were being experienced, the subject's ratings pain and spasms were recorded on visual analogue scales (VAS). 37 subjects (77.1%) reported that they had experienced issues with pain since discharge (Appendix K, Table

K.9) and 33 subjects (68.7%) reported that pain limited their ability to do things (Appendix K, Table K.10)

As no subjects had an SCI below T12 all had the potential to experience spasms. 70.1% reported that they had experienced issues with spasms (Appendix K, Table K.9) 56.2% reported that their spasms limited their ability to do things. The mean and median ratings for severity of spasms approximated those given for pain but the extent that spasms were felt to limit the ability to do things was markedly lower than the extent that pain was felt to limit the ability to do things (Appendix K, Tables K.10 and K.11).

N=48	Pain Rating Today	Worst Pain in Last 24 hrs	Extent Pain Limits Abilities	Spasm Rating Today	Worst Spasm in Last 24 hrs
Worst Pain in Last 24 hrs	$r=0.831$ $p=0.000$				
Extent Pain Limits Abilities	$r=0.725$ $p=0.000$	$r=0.724$ $p=0.000$			
Spasm Rating Today	$\tau=0.347$ $p=0.001$	$\tau=0.378$ $p=0.001$	$\tau=0.327$ $p=0.003$		
Worst Spasm in Last 24 hrs	$r=0.478$ $p=0.001$	$r=0.629$ $p=0.000$	$r=0.561$ $p=0.000$	$\tau=0.707$ $p=0.000$	
Extent Spasm Limits Abilities	$\tau=0.502$ $p=0.000$	$\tau=0.496$ $p=0.000$	$\tau=0.509$ $p=0.000$	$\tau=0.631$ $p=0.000$	$\tau=0.694$ $p=0.000$

Table 6.5 Correlation Matrix of Subject Ratings of Pain and Spasms

As shown in Figure 6.5 all subject ratings of spasms and pain were highly correlated. This suggests that the ratings of the presence and severity of pain are strongly related to the ratings of the presence and severity of spasms, with moderate to strong relationships.

No significant relationship was identified between whether the subjects had or had not received standing equipment and issues with spasms ( $\chi^2=1.087$  ( $df1$ ),  $p=0.462$ ,  $N=48$ ). Issues with pain were not significantly related to the frequency of visits from family ( $\chi^2=1.776$ , ( $df3$ );  $p=0.642$ ) or friends ( $\chi^2=2.175$ , ( $df3$ );  $p=0.642$ ), ( $df3$ );  $p=0.648$ ).

There was no significant relationship between vocational groups and whether the subject was experiencing frequent sequelae issues ( $\chi^2=1.298$ ( $df1$ )  $p=0.444$ ) although the high number of subjects (43/48) who stated that they had experienced issues/complications may have influenced this last result.

### 6.4.3. Community Reintegration, Access and Participation Interactions

		Test statistic	df	p
Relationships Between Subject Their Home More Often Than Weekly and:	If Able to Access Public Transport (N=35)	$\chi^2=13.836$	1	<b>0.000</b>
	If Vehicle Owner (N=47)	$\chi^2=5.226$	1	<b>0.005</b>
	If Discharge was Delayed (N=48)	$\chi^2=0.762$	1	0.561
	Pain Issues (N=48)	$\chi^2=2.087$	1	0.124

Table 6.6 Relationships with Frequency of Leaving the Home (Significant Results are in Bold)

Community and social activity and participation is a significant outcome measure for successful reintegration following SCI and the following section will explore issues that may have impacted upon this.

Significant relationships were noted between the frequencies that subjects left their home and whether they owned a vehicle or were able to access public transport (Table 6.6). The odds of leaving the house more frequently than weekly were 4.31 times higher for those who owned their own vehicle and Cramer's  $V=0.333$  ( $p=0.036$ ) confirmed a moderate significant association. Likewise the odds of leaving the house more frequently than weekly were 32.04 times higher for those who were able to access public transport with a strong, highly significant association (Cramer's  $V =0.629$ ,  $p=0.000$ ) between the frequency that subjects left their home and the ability to access public transport.

Although no significant relationship was found between whether adaptations to the subject's home were outstanding and whether the subjects left their home only once a week or less ( $\chi^2=3.343$ , (df1);  $p=0.115$ ,  $N=42$ ) it is worth noting that 55% of those who were still awaiting adaptations left the house only once a week or less frequently. Additionally 60% of those who were discharged to a physically enabling environment left their home daily or every few days when viewed in association with the trend for improved vocational outcomes for subjects who were discharged to a physically enabling environment this is clinically significant.

		Test statistic	df	p
Relationship Between Frequency of Social/Leisure Outings and:	If Vehicle Owner (N=46)	$\chi^2=11.645$	3	<b>0.005</b>
	If Able to Access Public Transport (N=35)	$\chi^2=10.925$	3	<b>0.007</b>
	Skin Issues (N=47)	$\chi^2=7.092$	3	0.055
	Pain Issues (N=47)	$\chi^2=8.670$	3	<b>0.026</b>

Table 6.7 Relationships with Frequency of Community/Social Outings (Significant Results are in Bold)

The frequency of social or leisure outings was significantly related to whether subjects had their own vehicle or not (Table 6.7) with a significant moderate to strong association (Cramers  $V=0.519$ ,  $p=0.004$ ). Similarly, the frequency of social or leisure outings was significantly related to whether subjects could or could not access public transport (Table 6.7) with a significant strong association between greater frequency of social or leisure outings and being able to access public transport (Cramers  $V=0.572$ ,  $p=0.007$ ). Subjects' reported issues with pain were also significantly related to the frequency of social or leisure outings (Table 6.7) with a moderate to strong significant association (Cramer's  $V=0.439$ ,  $p=0.029$ ) for less frequent social and leisure outing in those reporting issues with pain.

Although no significant relationship was identified between the frequency of social outings and whether subjects were experiencing issues with skin issues (Table 6.7) this was approaching significance and Cramer's  $V$  indicated a moderate significant association between whether the subject had experienced skin issues over the past year and the frequency of their social outings (Cramer's  $V=0.405$ ,  $p=0.049$ ).

The frequency of community outings for social purposes was not significantly related to injury group or the frequency of visits from family members or friends (Table 6.7).

Interaction between Frequency of community outings and:	Test statistic	<i>df</i>	<i>p</i>
Frequency of Friends Visiting (N=47)	$\chi^2=2.769$	3	0.472
Frequency of Family Visits (N=47)	$\chi^2=5.436$	3	0.151
Injury group	$\chi^2=5.628$	9	0.831

Table 6.8 Non-significant Interactions between Vocational Status and Social Support/Interaction Variables

## 6.5. Discussion

Although the percentage of subjects who contributed data was reasonably high for a postal survey it was smaller than originally anticipated when the research project was developed, resulting in some small group sizes. This impacted on the ability to perform some analyses and could have influenced the results of some analyses that were performed. Where possible trends were discussed if analyses were not possible or results may have been biased by to small subject numbers in groups.

Overall the subjects who contributed data to this phase of the study contained higher proportions of subjects with AIS A-C grade injuries and tetraplegia than the whole group of 74 subjects on discharge although this difference was not significant. The increase in mean age in the group has resulted in an increase in the proportion of subjects with non-traumatic SCI as may be expected (McKinley *et al.*, 2001; McKinley, Seel and Hardman,

1999), along with the resulting greater proportion of females, and paraplegics (Wolfe, Hsieh and Mehta, 2012; McKinley *et al.*, 2001).

In Chapters 1 to 3 some particular areas of investigation were proposed in relation to outcomes at one year post-discharge and contextual factors which may influence outcomes. The relevant results and findings will be now discussed in relation to those.

### **6.5.1. Healthcare systems outcomes including the impact of delays to admission or discharge and readmissions.**

Delays to discharge have not been noted to have an impact upon any of the identified outcome measures in this phase of the study.

- The impact of complications sustained prior to admission on reintegration outcomes.

This point will be discussed in section 6.5.2.

- Readmission rates in the first year post-discharge and causes of readmissions.

Although the numbers of readmissions seen in this study is below that discussed in other literature (Wolfe, Hsieh and Mehta, 2012; Young *et al.*, 2006) a notable proportion of subjects were readmitted, mainly due to issues with the sequelae of SCI. Some subjects had multiple admissions but the readmission length of stay was only taken for one admission. The number of known readmission bed days averaged across the group equated to at least 4.6 days per subject, this is similar to figures reported in another UK study (Savic *et al.*, 2000), although potentially an unknown number of additional readmission bed days were required by these subjects. Unfortunately it was not possible to conclude how many of these admissions were avoidable, but none were planned readmissions. The impact that these readmissions may have had an impact on reintegration outcomes could not be evaluated due to small subject numbers.

### **6.5.2 Reintegration Measure: Community participation**

During this phase of the study the area of interest was what the levels of community participation at one year post-discharge were in this group of subjects and what factors felt were felt by subjects to limit or enhance the ability to participate in community activities.

Although accessing the community is a measure of successful rehabilitation and reintegration following SCI (Somers, 2010; McKinley and Meade, 2004; Forchheimer and Tate, 2004; Whiteneck *et al.*, 2004; World Health Organisation, 2001) over 48% of subjects stated that they left their home once a week or less frequently. A notable

proportion of subjects reported that they were unable to access community facilities which included shops or leisure facilities. Although during their rehabilitation the SCI individual will have been taught skills to assist in overcoming environmental barriers where possible (Somers, 2010), this study has identified that there are a significant proportion of subjects who have been unable to do this. However the subjects' injury grouping was not related to the number of social outings that subjects had, confirming findings elsewhere (Siosteen *et al.*, 1990) and potentially highlighting the impact of contextual factors above impairment on community participation (World Health Organisation, 2001).

Those who lived in a nursing home were as likely to have social or leisure outings in to the community as those living in the community. This contradicts the image of social impoverishment reported in some research (Eastwood *et al.*, 1999). However small subject numbers suggests that further investigation is required as meaningful conclusions regarding the impact of living in a nursing home on community participation cannot be drawn from this data.

An unexpected and novel finding in this study was that the ability to access public transport, and to a lesser extent owning a car, was significantly associated with subjects leaving their homes more frequently. This suggests that being able to drive may not be as important in facilitating community activity for SCI individuals as it may be perceived to be in the both the rehabilitation process and research (Somers, 2010; Siosteen *et al.*, 1990). The important issue appears to be the ability to access transportation in whatever form. Further research is required to confirm these findings but assisting SCI individuals to access public transport is potentially an area that rehabilitation providers need to ensure is addressed in rehabilitation programmes.

In relation to social interaction both in the home and community a notable proportion of subjects only had monthly visits from either friends or family or none at all and the vast majority only had visits either weekly or less frequently. If this is viewed in association with the finding that 39.6% of subjects lived alone at one year post-discharge and the low levels of community participation reported by some subjects, this highlights the potential for some subjects to experience social isolation as noted in a previous UK survey (Smith and Spinal Injuries Association., 1999).

As previously noted by Mortenson *et al* (Mortenson, Noreau and Miller, 2010) there was a shift in the perceived importance of support away from friends and towards family social support at one year post-discharge. In this group of subjects a greater frequency

of family visits in the home was reported and a greater level of importance attributed to them than to visits from friends. However this higher level of social support from family members does not appear to have transferred in to the greater levels of successful reintegration also reported by Mortenson et al as levels of family visits were not related to either vocational activity or levels of community participation.

In relation to the potential impact of sequelae overall on community participation investigations were not possible as nearly all subjects reported that they had experienced issues with the sequelae of SCI with bladder, bowel, skin and pain being the most frequent cause of issues in line with other research (Akkoç *et al.*, 2013; Ataoğlu *et al.*, 2012; Krassioukov, Eng and Venables, 2012; Regan *et al.*, 2012; Jensen, Hoffman and Cardenas, 2005; Barrett *et al.*, 2003). Although this may appear concerning, it is not necessarily surprising. Most subjects with SCI will experience issues with one or more of the sequelae of SCI at one time or other although they will generally manage them successfully.

In relation to the impact of individual sequelae, the majority of subjects experienced issues with pain and spasms. The highly significant correlations suggest that the impact and perception of the two issues are often inter-related, as reported in other research (Adams and Hicks, 2005). Although subjects who reported issues with pain did not have less frequent visits from friends and family or less frequent outings generally in to the community, they did leave their home for social or leisure engagements. Combined these findings suggest that although the frequency subjects leave the home or the frequency of social contact per se are not significantly related to pain, the frequency of leaving the home for social interactions does appear to be significantly related to pain; suggesting that there is potentially a complex relationship between pain and community and social participation. This highlights that although the impairment of SCI may not influence the ability to participate in community activities the sequelae of SCI can result in a further impairment which may impact upon the ability to participate.

The presence of complications on admission did not significantly influence levels of social interactions either in the home or community. However, a high proportion of those who had pressure sores on their admission to the SCIC experienced further skin issues during the first year of discharge, suggesting a potential longer term impact of sustaining skin issues during the early stages of management post injury. Additionally those who had experienced skin issues during the first year post-discharge reported fewer community outings and a higher level of care support than those who had not. Although this reduced activity and increased level of care is what would be expected during a

period of bed rest or poor skin tolerance (Regan *et al.*, 2012) the results from this study highlight the potential enduring impact of pressure sores sustained prior to admission. However due to small subject numbers further research is required to confirm or dispute these findings.

### **6.5.3 Reintegration Measure: Vocational status**

The highly significant relationship between vocational status at one year post-discharge and vocational status at the point of injury echoes other research results (Noreau *et al.*, 2010). 26% of subjects were actively engaged in paid employment or retraining/study. The removal of retired individuals from analyses revealed that 55.5% of subjects had achieved the reintegration outcome measure of being vocationally active. This is notably higher than the rates reported elsewhere for the UK (Kennedy *et al.*, 2010b; Tasiemski *et al.*, 2000) but this is likely to be at least partly due to differences in the definition of vocational activity and the potential inclusion of those who are retired in results from other studies. This highlights the need for clarity and consistency in research on the classification of vocational status and the clear identification of those subjects who are retired in study numbers.

The research reviewed in this thesis suggested that vocational activity may be affected by a range of personal contextual factors including marital status and educational levels (Noreau *et al.*, 2010) however the results obtained in this research did not support this. Although the high level of subjects with a degree/diploma or professional qualification in this group appeared to bode well for employment levels no significant relationship was identified. This result may have been influenced by the inclusion of all forms of vocational activity, including those who were full-time care givers or engaged in studying, in to one group and therefore is likely to be a false negative result. More detailed analysis was not able to be performed due to small subject numbers and therefore further UK-based investigation of this is required.

Greater levels of social support (as measured by reported social interaction with friends or family either at home or in the community) were not significantly related to vocational status. This is in contrast to a range of non-UK based research (Marti *et al.*, 2012; Noreau *et al.*, 2010). However, as many of the vocationally active subjects were working from home they will not have engaged in the social activities and potential social support that would normally be a consequence of going to work. Additionally the outcome in question in this analysis was vocational activity as a whole, whereas much of the previous research has focussed on paid employment, this may have resulted in the differing findings.

Although age at the time of injury has been noted in other research to significantly influence employment post-SCI with further reductions in employment levels from mid 40's (Noreau *et al.*, 2010) this research did not identify this relationship. This may be due to a range of factors including small group sizes, the use of age as a continuous variable, the imposed 'cut-off age' point at which subjects were classed as retired or the exclusion of those who were retired from analyses. This last factor will have been particularly important as the classification of those who were over 47 at the time of injury and unemployed as retired and then their exclusion from the analyses will have notably influence the proportion of older individuals in the vocationally inactive group. This highlights the need to take age and age at injury into account when investigating vocational outcomes post-SCI as the potential to be able to pursue an alternative career, with possible retraining, is a potentially important influencing factor for outcomes. Consistency in how individuals are classified will also assist in making meaningful comparisons.

Contrary to other research findings vocational status was not significantly related to injury group (Noreau *et al.*, 2010; Schonherr *et al.*, 2004; Krause, 2001), and although paraplegics did work more hours than tetraplegics this was not significantly more (Marti *et al.*, 2012). The inability to find a statistically significant result on this last analysis may again have been influenced by small subject numbers as a) only a small number of subjects contributed information regarding the number of hours that they were vocationally active per week and b) there was a small proportion of tetraplegics in that group. However the assertion that vocational status is related to the higher levels of functional independence (Noreau *et al.*, 2010; Schonherr *et al.*, 2004; Krause, 2001) may have been confirmed indirectly as those who were vocationally active received less care. However these findings need to be interpreted cautiously due to the small numbers of subjects. Causality is also difficult to determine as paraplegic subjects may work more hours due to greater functional ability, or tetraplegic subjects may work less hours due to their need to structure their working day around the availability of care providers. Although paraplegics have a higher level of functional ability and so receive less care, the finding that tetraplegic subjects were also vocationally active suggests that this is not the only potentially influencing factor. Those who were vocationally active tended to receive less care as well as privately funding their care and other analyses identified that those who privately funded their care tended to receive less care. The lack of relationship between vocational activity and care provider suggest that this is not just due to the more flexible care arrangements associated with privately funded care when provided by the family members or friends. In summary, although there appears to be

some, non-significant, associations between the amounts of vocational activity and whether a subject is a paraplegic or tetraplegic it appears that these findings may be influenced by a variety of factors, some of which may be discrete or unmeasured variables.

Although the personal contextual factor of a modified skill set has been suggested to influence vocational outcomes (Noreau *et al.*, 2010) and almost a third of subjects were vocationally inactive, only two subjects had contact with a UK Department of Employment advisor (DEA) at one year post-discharge. This is contrary to the guidance in the National Service Framework for Long Term Conditions, Quality Requirement 6 which stipulates that vocational rehabilitation and support should be available to individuals with a long term condition in the community (Great Britain. Department of Health Long Term Conditions NSF Team., 2005). There is no current UK-based research to compare with these findings and comparisons with research from non-UK based funding and support systems may not yield meaningful information.

Driving was not a skill that was significantly related to vocational status in this research. This is contrary to other identified research (Noreau *et al.*, 2010). However, this finding may have been influenced by the number of subjects who worked from home as transportation may not have been such a significant issue for these individuals. Further UK-based research would be of benefit to identify if this is an anomalous finding.

The environmental contextual factor of access has been noted to be a significant barrier to employment in previous studies (Noreau *et al.*, 2010; Schonherr *et al.*, 2004) and this study also identified that a notable proportion of subjects were unable to access their work place and worked at home. In line with findings in other research (Noreau *et al.*, 2010; Schonherr *et al.*, 2004; Siosteen *et al.*, 1990) some employers will have made environmental, job role, location or working hour adjustments, such as permitting subjects to work reduced hours or from home. As a DEA could investigate options to improve access in the workplace, this identifies a failing in the system and echoes the previously reported perceptions of SCI individuals that occupation is not fully addressed following SCI (Kennedy, Lude and Taylor, 2006). In addition to highlighting some interesting potential outcomes and associations that require further research this study also identifies that vocational activity in individuals post-SCI is not given priority by the very departments responsible for assisting in this process. No similar research has been identified with which to compare these findings. This suggests that it is important for these resources to be provided at an early stage if optimal outcomes are to be obtained.

Although the provision of adaptations was not related to vocational status whether the individual was discharged to a physically accessible, and therefore enabling, environment was significantly related to vocational status. This relationship was also identified on discharge and suggests that this variable may be an important facilitator of vocational activity. Further UK-based research is required to confirm or dispute these findings.

Finally there is also the possibility that a combination of many factors influence the outcomes of vocational activity and community integration. Unfortunately there is no comparable research to assist in drawing conclusions regarding the lack identified relationships with delays in admission and discharge. As previously noted elsewhere (Noreau *et al.*, 2010) predictors or facilitators of vocational activity have not been clearly established but there are indications of some potential relationship between vocational status and previous vocational status, being discharged to a physically enabling environment and adjustments to work patterns in the form of being able to work from home. However further UK-based research is required to confirm these findings.

#### **6.5.4 Reintegration Measure: Accommodation/Residential Situation**

This research identified a strong association between the source of accommodation at injury and one year post-discharge. Although this indicates a trend for those who own their accommodation at injury to do so at one year post-discharge it does not necessarily indicate that it is the same accommodation. A potential limitation of this data is that subjects were not asked if they had moved home since injury. Also the large size of the group who owned their accommodation masks notable changes in the other groups. The 64.3% increase in the number of subjects who were renting accommodation from either housing association or their local council indicates an increased demand on public sector housing stocks which needs to be met if these subjects are to be able to live in the community. There are no UK-based studies which could be used to confirm or dispute these findings. Further research is required to investigate the potential accommodation requirements of the SCI population. Contrary to suggestions in other UK-based research outstanding adaptations within the home was not related to vocational status at one year post-discharge (Oliver *et al.*, 1988).

This research aimed to identify if subjects discharged to a nursing home would still be there at one year post-discharge and if they would be tend to be tetraplegics. The significant relationship between injury group and place of residence, particularly nursing homes indicated in other research (Anzai *et al.*, 2006; DeVivo, Krause and Lammertse, 1999; Richards, 1982) and present on discharge was not noted at one year post-

discharge. Although this suggests that high level tetraplegics were as likely to be living in the community as those with other levels of injury, the small number of subjects who were living in a nursing home at one year post-discharge were all high level tetraplegics and therefore small subject numbers may have influenced the ability to obtain a significant result. Further UK-based research is required to identify the outcomes of SCI individuals discharged to a nursing home.

This research also aimed to investigate the levels of provision and requirement of adaptations at one year post-discharge in this subject group and the potential implications of this. A large percentage of subjects were residing in a property that required adaptations at one year post-discharge, as noted in other UK based research (Aspire, 2009). Additionally 23.9% stated that they were experiencing limitations to access inside of the home. Although suggesting difficulties with access, this did not translate in to significant relationships with outstanding adaptations to the home.

Subjects who had adaptations still outstanding at one year post-discharge did not leave their home significantly less frequently than those who did not have outstanding adaptations, however, a greater proportion of those waiting for adaptations left their home only once a week or less. In contrast subjects discharged to a physically enabling environment tended to leave their homes daily or every few days for both social and general reasons, although this was not a significant relationship. Once again small group numbers may be limiting the ability to establish the presence of significant differences between groups found in other research (Bergmark, Winograd and Koopman, 2008; Post *et al.*, 1997; Siosteen *et al.*, 1990; Boschen, 1988). Although, at one year post-discharge, outstanding adaptations to the home did not significantly impact on levels of vocational activity, if subjects were discharged to a physically enabling environment they were significantly more likely to be vocationally active at one year post-discharge in line with suggestions in earlier UK-based research (Oliver *et al.*, 1988) and undertook a higher level of community activities. This could suggest a combination of issues influence community participation not just physical access but also the time-frame in which access is facilitated in the form of provision of an accessible home environment.

Some subjects reported that further adaptations to their home were required than those prescribed on discharge. This confirms the suggestions in other research of high levels of dissatisfaction by SCI individuals at environments being deemed to be wheelchair accessible which they experience to be inaccessible (Manns and Chad, 2001). Dissatisfaction with the adaptations process has been reported in studies from the UK,

Norway and Sweden, along with a perceived or real need for further works in addition to those that they had been assessed as requiring (Heywood, 2004; Post *et al.*, 1997; Siosteen *et al.*, 1990). Potentially, as an SCI individual lives in a property they will become more aware of how the property does or does not meet their needs and it is at this point that the needs for further adaptations will become apparent. This may be what these results are demonstrating. Further investigation of the impact of the SCI individual's perception of access and barriers to access in relation to outcomes following SCI is required. These results also highlight the need to explore the satisfaction of the SCI individual with their home environment as well as to involve them in discussions regarding works to their home (Heywood, 2004; Manns and Chad, 2001; Post *et al.*, 1997; Siosteen *et al.*, 1990).

## 6.6. Contextual Factors

In addition to the findings in relation to the outcome measures the following additional results were also noted regarding the influence of contextual factors that warranted further discussion in relation to current research findings.

- The incidence of avoidable complications and readmissions when the required equipment has not been provided.

Delays in the provision of standing equipment were not significantly related to reported issues with spasms. There may be several potential explanations for why statistical significance was not achieved in this analysis. It is possible that the group numbers were too small to produce a statistically significant result. Equally, although the subjects were questioned on whether they had standing equipment they were not questioned on how frequently they used it. Arguably, equipment that is never used is no more beneficial than equipment that is missing and this may have influenced the results. Additionally, as noted in other research there are different forms of spasms and these require different forms of management (Adams and Hicks, 2005) which may or may not benefit from the use of standing equipment.

8.3% of subjects had still not received their permanent wheelchair (that is, the wheelchair that was assessed as being required to meet their needs) at one year post-discharge. Small subject numbers prevented analyses to identify if this contextual factor influenced the ability of the individual to participate in the community; although previous research in to this issue suggests that this may be the case (Chaves *et al.*, 2004; Rose and Ferguson-Pell, 2002) Additionally, several subjects were also still awaiting provision of essential pieces of equipment such as a shower/commode chair. Again, further analyses investigating whether higher levels of professional health interventions or readmissions occurred due to delays in the provision of suitable equipment, were not

able to be performed due to the small of subject numbers, Therefore, as previously noted (Bushnik, 2002; Joyeux and Spinal Injuries Association, 2002), the assertion that delays in the provision of equipment increases care requirements and the risk of health issues is unproven,.

➤ If levels and source of care received is changed at one year post-discharge.

The amount of care received had reduced for some subjects at one year post-discharge suggesting that following discharge from the SCIC the subject continued to improve in terms of functional abilities and so required less support. For the remaining subjects the amount of care received at one year post-discharge was generally the same as that received at discharge.

There was a notable increase in the number of subjects who were privately funding their care package compared to discharge. It is unclear if this is due to personal decisions or the result of SSD financial assessments being completed after discharge. There was also an increase in the number of subject who received NHS funded care in the community. In the author's experience, SCIC discharge teams are often accused of over-estimating the level of care required and of over-prescribing the need for NHS Continuing Healthcare, therefore this finding and the noted stability in care levels received by many subjects is reassuring and contradicts these assertions. No UK based research has identified these trends previously. Unfortunately there is no comparable UK based research to assist in drawing any further conclusions on the meaning of the above findings. Additionally, they may be of limited interest to any not engaged in securing or providing care to SCI individuals in the community.

At one year post-discharge there is a greater acknowledgement by subjects of the amount of assistance given by friends and family both in an ad hoc and formal capacity. However, it is a concern that friends and family members were not just giving small levels of support such as assistance with domestic activities, gardening, etc but in some cases giving a substantial amount of support, supporting findings in other countries (Boucher, Ballantyne and Boschen, 2012; Mattson-Prince, 1997). Although this has been acknowledged in some cases, how many subjects do not recognise this level of support can only be guessed at and may bear further investigation. How much this may impact on the health or career prospects of the family member/friend providing the care (Boucher, Ballantyne and Boschen, 2012) or the relationships and autonomy of the SCI individual (Bergmark, Winograd and Koopman, 2008) is beyond the remit of this research to establish.

As discussed in Chapter 5 the provision of interim and small insurance policy payments may have facilitated earlier provision of resources including accommodation and equipment but subject numbers were too small to facilitate any meaningful analysis and, in this phase of the research, too small to even facilitate a discussion of trends.

## **6.7 Limitations**

Some limitations have been identified in the research process and data collected in this phase of the research. Brief acknowledgement of these is appropriate at this point prior to more detailed discussion in Chapter 8. The limitations will be discussed in relation to the outcome measures they relate to.

### *Subject issues*

- Small subject numbers has prevented many analyses being performed and potentially influenced the ability to obtain significant results.
- Some significant differences were noted between the groups of who contributed data to this phase of the study and those who did not. However, some of these differences may be predominantly due to the effect of group sizes, as often the largest groups had the greater proportion of responders. However the potential for differences in demographics to influence outcomes needs to be acknowledged. The profile of those non-responders is typically a subject who was: younger, a student (75% were non-responders), with a Post-graduate qualification (60% were non-responders) and discharged to an ASPIRE property (100% were non-responders).

### *Measurement Issues*

- The follow-up period of one year post-discharge may have been too short for the identification of some outcomes including health issues relating to poor provision.
- Missing data was accepted, attempts were not made to return the questionnaire to the subject for full completion.

### *Readmissions*

- Information on the lengths of stay for each multiple readmission was not taken. This has resulted in an underestimation of the number of readmission bed days required by this subject group. The size of this underestimation is unclear.
- Information on whether the admission was or was not avoidable was not obtained.

### *Accommodation*

- Some subjects interpreted the question 'Are adaptations to your home still outstanding?' as a query of whether they feel that adaptations to their home are

required rather than the intended question of whether further adaptations had been assessed as required. This potentially has an impact on the relevance and validity of the findings discussed in relation to this hypothesis.

- Subjects who had received new accommodation or adaptations since discharge were not asked when these were provided. Variations in lengths of time since provision may have influenced the ability to obtain significant results.

#### *Vocational Activity*

- Information was not obtained to explain why subjects did not return to work and the subject's perceived barriers or facilitators of vocational activity, for example: what percentage of subjects did not return to work due to access issues or unwillingness on the part of employers to make necessary adjustments.

#### *Sequelae*

- Although information was requested on whether standing equipment had been provided information was not obtained on how frequently it was used. This may have influenced the ability to identify a significant relationship between the lack of standing and an increase in issues with spasms.

### **6.8 Summary**

The findings for the outcome measures proposed in Chapters 1-3 have been discussed in relation to the variables measured at one year post-discharge. These findings will be summarised in relation to these outcomes.

#### *Community Participation and Social Activity*

39.6% of subjects lived alone at one year post-discharge. Many subjects reported low frequency of visits from friends and family at one year post-discharge and low frequency of community outings. Combined with the findings regarding low levels of community activity this suggests that many subjects may be at risk of experiencing social isolation. 8.3% of subjects were still awaiting provision of their permanent wheelchair at one year post-discharge this which may have impacted upon their ability to participate in community activities.

That higher levels of social and general community activity are present in those who report lower levels of pain, are able to access public transport, have their own car and were discharged to a property which met their access requirements, in other words was a physically enabling environment emphasises the impact of not only the health and

disability issues of the SCI and sequelae on participation but also the contextual environmental factors of environmental access and access to transport.

### *Accommodation*

Over 20% of subjects were still living in temporary accommodation at one year post-discharge and more than 8% were awaiting identification of a permanent property. There was a notable increase in the levels of subjects who were living in public sector rental accommodation suggesting an increase in requirement for this form of accommodation following SCI; however subjects who had owned their property at the time of injury tended to own their property at one year post-discharge. Although accommodation at one year post-discharge is no longer significantly related to injury group, all of those still living in a nursing home are high level tetraplegics and 50% of them were still awaiting identification of a permanent property. 23.9% of subjects stated that they were unable to access the whole of the inside of their home. Although over 35% stated adaptations to their home were still outstanding although just under half of these subjects had been discharged to a property that was deemed by professionals to not require adaptations or had been adapted.

Those subjects who had been discharged to a physically enabling environment were more likely to be vocationally active and to engage in higher levels of community activities at one year post-discharge. This also emphasises the impact of contextual environmental factors (in the form of environmental access as well as delays in provision of adaptations or an accessible property) on participation levels but also highlights that these contextual factors can facilitate as well as limit participation (World Health Organisation, 2013).

### *Vocational Activity*

Vocational activity at one year post-discharge is significantly related to vocational status at injury, being discharged to a property which met their access requirements, having a privately funded care package and reporting lower levels of pain (non-significant relationship). The outcome measure of vocational activity is potentially being influenced by health and disability issues in the form of the SCI and sequelae but also contextual environmental factors in the form of care provision and an accessible environment. This highlights the multi-dimensional and dynamic interactions proposed in the ICF model of disability (World Health Organisation, 2013). Vocational activity it was not significantly associated to whether subjects could drive or access public transport but a large proportion of subjects worked from home. Vocational status at one year post-discharge was not significantly related to any other demographic or SCI related variable.

### *Readmissions and Sequelae*

93.7% of subjects reported issues with sequelae. The high number of subjects reporting issues with sequelae resulted in a failure to identify significant relationships or trends with many outcome measures. Many subjects admitted to the SCIC with pressure sores experienced frequent and persistent issues with pressure sores during the first year of community reintegration. They were less likely to engage in vocational and community activities than those who did not experience skin issues. They were also in receipt of a higher level of care.

As reported in other studies the subject's experience of pain and spasms are highly correlated. Issues with pain and spasm were noted with non-significantly lower levels of vocational activity. Issues with pain are suggested to significantly influence levels of social activity in the community.

A significant proportion of subjects were readmitted to hospital for a variety of issues, over the first year of community reintegration. The average number of bed days for these admissions was 4.8 days. Some subjects had multiple admissions.

In terms of the overall null hypothesis of: *'Timely provision of accommodation, care and equipment does not make a difference to the speed of discharge once rehabilitation is completed, or on reintegration outcomes once discharged.'* no impact is noted in this phase of the study of delays to discharge on any of the identified outcome measures. However the impact of delays in referral and admission are still apparent in the increased likelihood for those subjects admitted with pressure sores to have similar issues over the first year of community reintegration. Delays in provision of suitable accommodation however have had a significant impact on vocational activity and levels of community activities at one year post-discharge. Although some subjects were still awaiting the provision of their permanent wheelchair the subject numbers were too small to facilitate meaningful analyses.

In the following chapter these variables will be discussed in relation to quality of life as well as the psychological variables of coping strategies and locus of control and the associated hypotheses.

## **CHAPTER 7: Results for Quality Of Life and Psychological Measures**

### **Overview**

This Chapter will evaluate the identified reintegration outcome measure of quality of life (QOL) and the investigated psychological variables in relation to each other. Additionally potential relationships with the variables and outcomes discussed in the previous two chapters will be examined.

Initially the results from the psychological measures obtained during admission will be evaluated and potential relationships with subject demographics examined. Shifts in scores on psychological measures from admission to one year post-discharge will be examined along with subject perceptions of quality of life at one year post-discharge. Potential relationships between the psychological measures, QOL rating and outcome measures identified and analysed in previous chapters will be examined and evaluated in relation to the areas of potential investigation put forward in Chapters 1-3.

## 7.1 Introduction

In the two preceding chapters baseline and outcome measure variables were examined identifying the subject's situation at the point of injury through to one year post-discharge. The aim of this chapter is to examine the relationships between the outcome measure of quality of life (QOL) and the psychological variables that were measured in relation to each other. Additionally relationships between the QOL and psychological variables and the rehabilitation and reintegration outcomes discussed in Chapters 5 and 6 will also be identified.

In Chapter 3 potential areas for investigation were proposed in relation to QOL and the psychological variables measured in this study. In summary these are:

- Whether variations in perceived QOL are associated with variations in perception of locus of control and coping styles.
- If perceptions of current QOL will vary significantly between paraplegic and tetraplegic subjects.
- The impact of issues of sequelae on the psychological profiles and perceived QOL of subjects, particularly issues with pain and continence management.
- The impact of variation in provision of a range of resources is associated with variations in perceived QOL, locus of control or coping styles.
- If perceived current QOL is associated with other reintegration outcome measures.

The data collected will be evaluated in relation to these areas of investigations and the outcomes discussed in relation to the research currently available.

## 7.2 Subjects

47 subjects contributed psychological data during the admission phase. Two of these subjects died prior to one year post discharge and so were unable to contribute data to this phase of the research project. Of the 45 remaining potential subjects who had contributed psychological data during their admission, 30 responded to the one year survey, giving a response rate of 66.7% for subjects contributing psychological data. There is a potential for different relationships to be present in the group of 30 subjects contributing data at one year post-discharge compared to the original 47 subjects contributing data during admission. As this thesis aims to identify the relationships between the use of the coping styles and attribution of control in relation to the rehabilitation and reintegration outcomes only the data for the 30 subjects who contributed data at both time points will be considered. Data for the group of 47 subjects is included in Appendix I.

The 66.7% response rate for completion of psychological questionnaires is notably similar to the 67.6% overall response rate for the overall study at one year post-discharge, the results of which have been discussed in Chapter 6.

76.7% (N=23) of subjects contributing psychological data at one year post-discharge were male and 56.7% (N=17) were married at the time of discharge. 9 subjects (30% were admitted with complications. 30% (N=9) were vocationally active at one year post-discharge and 40% (N=12) retired. One individual did not give information on their vocational status at one year post-discharge. Demographics for the subjects who contributed data on perceived QOL are as given in Chapter 6.

All 48 subjects who completed the Post Discharge Booklet survey contributed data regarding their perceived quality of life QOL, barring one subject (2.1% of subjects) who neglected to answer these questions. Listwise deletion of data was performed to exclude this subject's data from relevant analyses. Chi Square analysis identified that subjects who completed the psychological questionnaires were as likely to contribute data at one year post-discharge as those who were not completing the psychological questionnaires ( $\chi^2 (df=1) 0.049 p=0.824$ ).

### **7.3 Results**

Data management, handling and analyses methods utilised are as discussed in detail in Appendix F. Results will initially be presented and discussed in relation to the phase of the study in which they were collected and then interactions and trends between the psychological variables and outcome measures from the two phases that have already been discussed in Chapters 5 and 6 will be discussed.

Normative data was not available for CSQ3 at the time of writing but mean scores have been reported as Avoidance coping 11.78 (Std Dev.4.79), Rational coping 16.82 (Std. Dev.4.50) and Detached/emotion coping 36.84 (Std. Dev.8.11) (Borrill *et al.*, 2009). High scores on the Rational and Avoidance coping scales indicate a greater use of that form of coping, a high score on the Detached/Emotional coping scale indicates a greater use of Detached coping styles and a low score indicates a greater use of Emotional coping styles. Normative scores for this version of the Spheres of Control Questionnaire (SOCQ) have been given as: Personal control: 50.56, Interpersonal Control: 48.19 and SocioPolitical Control: 35.94 (Spittal *et al.*, 2002). A high score on all SOCQ scales indicates an internal locus of sphere specific control and a low score indicates an external locus.

	CSQ RatCop Admiss.	CSQ D/EmCop Admiss.	CSQ AvCop Admiss.	SOCQ PC Admiss.	SOCQ IPC Admiss.	SOCQ SPC Admiss.	CSQ RatCop 1yr	CSQ D/EmCop 1yr	CSQ AvCop 1yr	SOCQ PC 1yr	SOCQ IPC 1yr
CSQ D/EmCop Admission	<b>r=0.577**</b> <b>p=0.001</b> <b>N=30</b>										
CSQ AvCop Admission	r=-0.341 p=0.065 N=30	r=-0.314 p=0.091 N=30									
SOCQ PC Admission	<b>r=0.414*</b> <b>p=0.025</b> <b>N=29</b>	r=0.109 p=0.573 N=29	<b>r=-0.394*</b> <b>p=0.034</b> <b>N=29</b>								
SOCQ IPC Admission	<b>r=0.501*</b> <b>p=0.006</b> <b>N=29</b>	r=0.319 p=0.092 N=29	<b>r=-0.627**</b> <b>p=0.000</b> <b>N=29</b>	<b>r=0.611**</b> <b>p=0.000</b> <b>N=29</b>							
SOCQ SPC Admission	$\tau=0.232$ p=0.089 N=29	$\tau=0.197$ p=0.146 N=29	$\tau=0.013$ p=0.925 N=29	$\tau=-0.048$ p=0.720 N=29	$\tau=0.025$ p=0.851 N=29						
CSQ RatCop 1yr	<b>r=0.676**</b> <b>p=0.000</b> <b>N=29</b>	<b>r=0.495*</b> <b>p=0.005</b> <b>N=30</b>	r=-0.270 p=0.149 N=30	<b>r=0.408*</b> <b>p=0.028</b> <b>N=29</b>	<b>r=0.500*</b> <b>p=0.006</b> <b>N=29</b>	$\tau=0.147$ p=0.281 N=29					
CSQ D/EmCop1yr	r=0.343 p=0.064 N=30	<b>r=0.591**</b> <b>p=0.001</b> <b>N=30</b>	r=-0.163 p=0.390 N=30	r=0.038 p=0.846 N=29	r=0.316 p=0.095 N=29	$\tau=0.218$ p=0.105 N=29	r=0.320 p=0.085 N=30				

Cont...../

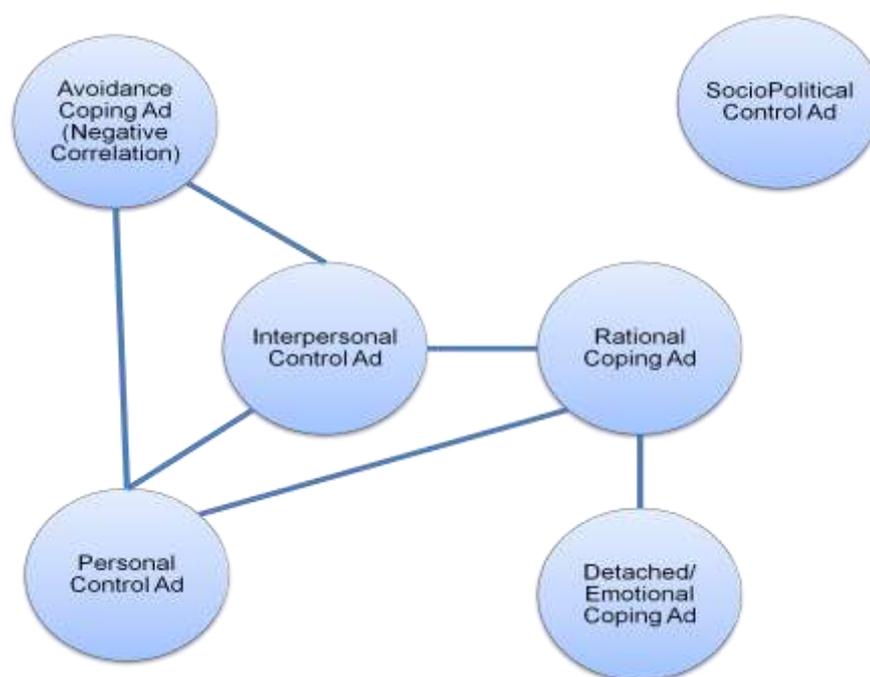
	CSQ RatCop Admiss.	CSQ D/EmCop Admiss.	CSQ AvCop Admiss.	SOCQ PC Admiss.	SOCQ IPC Admiss.	SOCQ SPC Admiss.	CSQ RatCop 1yr	CSQ D/EmCop 1yr	CSQ AvCop 1yr	SOCQ PC 1yr	SOCQ IPC 1yr
CSQ AvCop 1yr	$\tau=-0.162$ $p=0.234$ N=30	$\tau=-0.199$ $p=0.140$ N=30	<b><math>\tau=0.566^{**}</math></b> <b><math>p=0.000</math></b> N=30	$\tau=-0.121$ $p=0.374$ N=29	<b><math>\tau=-0.327^*</math></b> <b><math>p=0.016</math></b> N=29	$\tau=-0.015$ $p=0.910$ N=29	$\tau=-0.068$ $p=0.614$ N=30	$\tau=-0.137$ $p=0.305$ N=30			
SOCQ PC 1yr	$r=0.325$ $p=0.079$ N=30	$r=0.051$ $p=0.787$ N=30	<b><math>r=-0.394^*</math></b> <b><math>p=0.031</math></b> N=30	<b><math>r=0.796^{**}</math></b> <b><math>p=0.000</math></b> N=29	<b><math>r=0.598^{**}</math></b> <b><math>p=0.001</math></b> N=29	$\tau=-0.121$ $p=0.366$ N=29	$r=0.215$ $p=0.254$ N=30	$r=0.204$ $p=0.280$ N=30	$\tau=-0.192^*$ $p=0.151$ N=30		
SOCQ IPC 1yr	<b><math>r=0.511^*</math></b> <b><math>p=0.004</math></b> N=30	<b><math>r=0.445^*</math></b> <b><math>p=0.014</math></b> N=30	<b><math>r=-0.589^{**}</math></b> <b><math>p=0.001</math></b> N=30	<b><math>r=0.478^*</math></b> <b><math>p=0.009</math></b> N=29	<b><math>r=0.826^{**}</math></b> <b><math>p=0.000</math></b> N=29	$\tau=0.076$ $p=0.572$ N=29	<b><math>r=0.470^*</math></b> <b><math>p=0.009</math></b> N=30	<b><math>r=0.413^*</math></b> <b><math>p=0.023</math></b> N=30	<b><math>\tau=-0.358^{**}</math></b> <b><math>p=0.000</math></b> N=30	<b><math>r=0.607^{**}</math></b> <b><math>p=0.000</math></b> N=30	
SOCQ SPC 1yr	$\tau=0.161$ $p=0.228$ N=30	$\tau=0.007$ $p=0.957$ N=30	$\tau=-0.081$ $p=0.542$ N=30	$\tau=0.075$ $p=0.572$ N=29	$\tau=0.081$ $p=0.547$ N=29	<b><math>\tau=0.433^{**}</math></b> <b><math>p=0.001</math></b> N=28	$\tau=0.046$ $p=0.733$ N=30	$\tau=0.159$ $p=0.230$ N=30	$\tau=0.122$ $p=0.360$ N=30	$\tau=-0.061$ $p=0.641$ N=30	$\tau=-0.059$ $p=0.655$ N=30
Key:	$\tau$ =Kendall's tau correlation $r$ =Pearson's correlation coefficient      Admiss. = Admission N=Number of subjects contributing data to the analysis      Significant correlations are in bold. ** . Correlation is significant at the 0.001 level (2-tailed). * . Correlation is significant at the 0.05 level (2-tailed). CSQ= Coping Styles Questionnaire RatCop= Rational Coping D/EmCop= Detached/Emotional Coping AvCop= Avoidance Coping SOCQ = Spheres of Control Questionnaire PC= Personal Control IPC =Interpersonal Control SPC = SocioPolitical Control										

Table 7.1 Correlation Matrix of Psychological Measures

### 7.3.1 Admission Phase Results

Correlations for psychological variables during admission from the 30 subjects contributing data at both time points are detailed in Table 7.1. The significant correlations are summarised in Figure 7.1.

The significant CSQ correlations reflect the internal correlations reported by the scale's author (Roger, 2003). Significant moderate positive relationships were present between Rational coping and locus of Interpersonal of control as well as with locus of Personal control and Detached/Emotional coping (Table 7.1 and Figure 7.1). This relationship suggests that during admission an internal locus of Interpersonal control and a greater use of Rational coping styles are associated with a greater sense of self-efficacy (as measured by locus of Personal control) and lower levels of psychological distress (as measured by Detached/Emotional coping). Significant negative relationships were identified between Avoidance coping and the locus of Personal and Interpersonal control suggesting that high use of avoidance coping styles during admission was associated with a more external locus of Personal and Interpersonal control. Highly significant, but moderate, relationships were also identified between locus of Personal and Interpersonal control during admission. Locus of SocioPolitical control was not significantly associated with any of the psychological variables in the correlation matrix.



*Key: Ad=Admission*

Figure 7.1 Significant Correlations between Psychological Variables during Admission

As illustrated in Figure 7.1, there are two variables which are significantly correlated with most of the other psychological variables, including each other. These are locus of

Interpersonal control and Rational coping. Each of these variables has one exclusive correlation. Rational coping is exclusively correlated with Detached/Emotional coping but locus of Interpersonal control correlates (negatively) with Avoidance coping, as does locus of Personal control. This suggests that although Rational coping and locus of Interpersonal control have many similar relationships there are distinct differences between the two variables and, potentially, the actions they have in this situation. In summary during admission, a greater use of Rational coping styles and a more internal locus of Interpersonal control is related to a lesser use of both Emotional and Avoidance coping styles (and therefore less psychological distress) as well as a more internal locus of Personal control (and therefore a greater sense of self-efficacy). As these measures were primarily intended to be used to identify changes at one year post-discharge further analyses were not performed.

### **7.3.2 One Year Post-Discharge Results**

All results for psychological measures on admission were significantly correlated to the same measure at one year post-discharge (Table 7.1). Tables 7.2 and 7.3 give descriptive statistics for the psychological variables at one year post-discharge. Descriptive statistics regarding changes in the rating for each of the psychological variables between the two time points (admission and one year post-discharge) for the 30 subjects who contributed data at both time points are given in Appendix L, Tables L.6 and L.7. All of these data items were normally distributed (parametric) apart from SocioPolitical locus of control at both time points and Avoidance coping at one year post-discharge.

Contrary to findings in other research, including by the scale's original author (Spittal *et al.*, 2002; Paulhus and Van Selst, 1990; Paulhus, 1983), at one year post-discharge all measures of central tendency for Interpersonal control were slightly higher than those for Personal control. Additionally scores for Interpersonal control are higher and scores for the other two spheres of control lower than reported normative values (Spittal *et al.*, 2002) suggesting a greater trend toward an internal locus of Interpersonal control in this group of subjects than in the general population. The subjects also utilised higher levels of Detached coping and lower levels of both Avoidance and Rational coping styles than have been reported in another UK based study (Borrill *et al.*, 2009).

	Coping Styles Questionnaire (CSQ) 1yr			CSQ Rating Difference (1 year – Admission rating)		
	Rational Coping	Detached/ Coping	Emotional/ Avoidance Coping	Rational Coping	Detached/ Coping	Emotional/ Avoidance Coping
Mean	19.30 (CI 17.45 – 21.15)	41.43 (CI 37.93 – 44.93)	9.03 (CI 7.0 – 10.98)	0.60 (CI -1.27 - +2.47)	1.10 (CI -2.72 – +4.92)	-0.37 (CI -2.41 – +1.67)
Std. Deviation	4.94	9.38	5.22	5.02	10.22	5.47
Median	20.0 (IQR 7)	42.0 (IQR 13)	7.50 (IQR 6)	0 (IQR 7.5)	0 (IQR 14.5)	0 (IQR 8.25)
Mode	18	30	5	0	-12	0
Minimum	7	24	2	-9	-21	-10
Maximum	27	62	22	+10	+22	+13
Skewness (z)	-0.303 (-0.71)	0.117 (0.27)	1.119 (2.62)	-0.001 (-0.002)	0.232 (0.54)	0.569 (1.33)
Key:	IQR = Inter-quartile range CI = 95% Confidence Interval Items in italics are non-parametric data					

Table 7.2 Descriptive Statistics for Coping Styles Questionnaire Rating During Admission and At One Year Post-Discharge

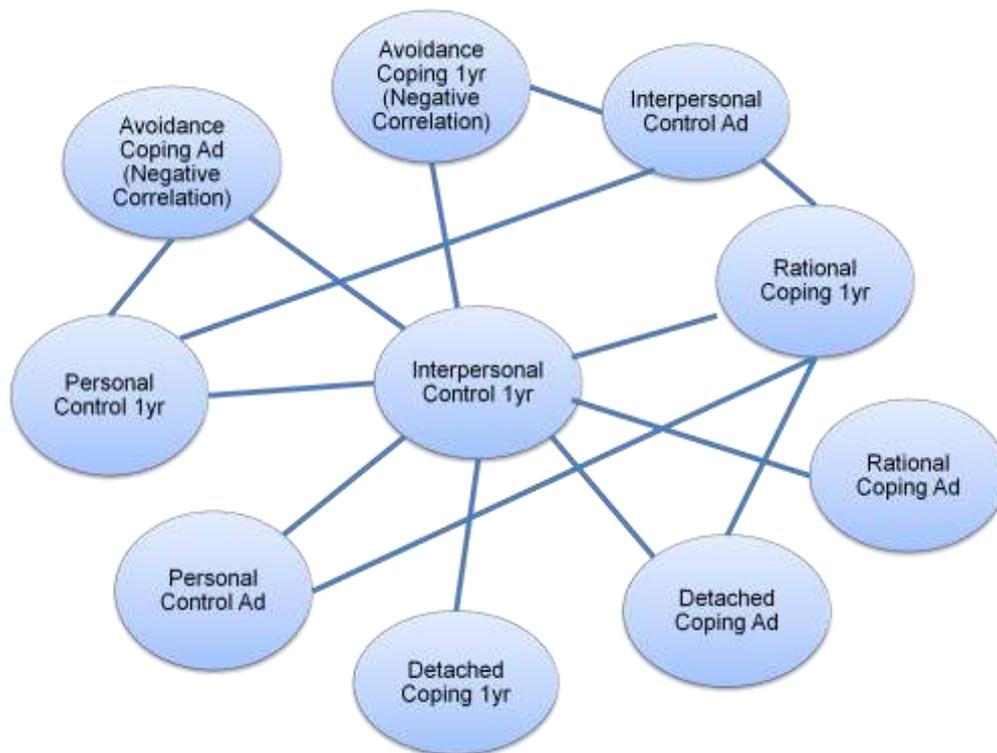
	Spheres of Control (SOCQ) 1yr			SOCQ Rating Difference (1 year – Admission Rating)		
	Personal Control	Interpersonal Control	SocioPolitical Control	Personal Control	Interpersonal Control	SocioPolitical Control
Mean	50.27 (CI 46.54 – 54.0)	50.3 (CI 46.3 – 54.3)	33.33 (CI 29.14 – 37.53)	-2.04 (CI -4.51-+0.44)	-0.46 (CI -2.81 -+1.88)	0.714 (CI -3.48 -+3.63)
Median	50.50 (IQR 11)	51.5 (IQR 15)	32.5 (IQR 15)	-2.5 (IQR 9.75)	0.5 (IQR 7.5)	-1.0 (IQR 8.25)
Std. Deviation	9.99	10.7	11.23	6.39	6.05	9.17
Mode	54	54	23	0	-9	0
Minimum	24	25	16	-9	-9	-1
Maximum	69	70	66	+12	+10	+21
Skewness (z)	-0.815 (-1.90)	-0.276 (-0.65)	0.957 (2.24)	0.531 (1.20)	-0.187 (-0.424)	0.756 (1.71)
Key:	IQR = Inter-quartile range CI = 95% Confidence Interval Items in italics are non-parametric data					

Table 7.3 Descriptive Statistics for Spheres of Control Questionnaire Rating During Admission and At One Year Post-Discharge

The group utilised more Rational, less Avoidance and less Emotional (and so more Detached) coping styles at one year post-discharge than during admission (Table 7.2), however these differences were not statistically significant (Appendix L, Table 7.6). Although the mean ratings in Table 7.3 suggest that there is shift toward a more external locus of both Personal and Interpersonal control and a more internal locus of SocioPolitical control these findings were also not statistically significant (Appendix L, Table 7.7). Changes in individual psychological measures as a distinct variable will not be examined further due to this lack of significance.

**7.3.2.1 Psychological Variable Interactions at One Year Post-Discharge**

All psychological variables during admission are highly correlated to the equivalent variable at one year post-discharge suggesting there is consistency in attributions and coping styles utilised, although none is a perfect correlation. Figure 7.2 is a graphical representation of the significant correlations for psychological measures at one year post-discharge as detailed in Table 7.1. Correlations that only relate to variables from the admission phase are not shown in this diagram as they have been detailed in Figure 7.1.



*Key: Ad=Admission, 1yr=one year post-discharge*

Figure 7.2 Significant Correlations between Psychological Variables

At one year post-discharge Rational coping is only significantly correlated to four variables, of which locus of Interpersonal control is the only one year post-discharge

variable. The descriptive statistics and t-test results reported in Table 7.2 and Appendix L, Table L.6 suggest this is not due to a significant reduction in use of Rational coping over time. SocioPolitical locus of control was not correlated to any of the other psychological factors either during admission or at one year post-discharge.

Subjects who had a more internal locus of Interpersonal control during their admission used significantly more Rational and less Avoidant coping styles at both time points (Table 7.9). They also had a greater sense of personal achievement and self efficacy as exhibited in a more internal locus of Personal control at both time periods. Subjects who had a more internal locus of Interpersonal control at one year post-discharge had a similar profile but also tended to use less Emotional (and therefore more Detached) coping styles at one year post-discharge than during admission. This suggests a trend towards an adaptive psychological profile in those who have a more internal locus of Interpersonal control. The findings also suggest that although significant changes were not detected between admission and one year post-discharge scores (Tables 7.5, 7.7 and 7.8), small changes may be occurring in the extent to which a coping style is employed or the perceived locus of control.

During admission a greater use of Rational coping styles and a lesser use of Avoidant coping were significantly related to a more internal locus of Personal locus of control and therefore higher perceptions of self-efficacy. These relationships were not sustained at one year post-discharge suggesting that a greater use of Rational coping styles and lesser use of Avoidant coping at one year post-discharge will not necessarily be related to greater perceptions of self efficacy (Table 7.9). However a perceived internal locus of Personal control during admission was significantly related to a greater use of rational coping at one year post-discharge.

The use of Detached coping styles during admission was not significantly related to the locus of Interpersonal control during admission however the utilisation of Detached coping styles at both time points was significantly related to perceived locus of Interpersonal control at one year post-discharge (Table 7.1.). A greater use of (maladaptive) Avoidant coping styles at both time points was related to a more external locus of Interpersonal control at both time points (Table 7.1 and Figure 7.2). This suggests that the use of adaptive Detached coping styles during admission may facilitate an increased perception of control in interpersonal situations, whereas the use of maladaptive Avoidance coping styles may facilitate a lesser feeling of control in interpersonal situations, however caution needs to be exercised when using correlations to attribute causality.

In summary the results obtained suggest that the use of Rational coping styles and an internal locus of Interpersonal control during admission indicate lower levels of psychological distress (as demonstrated in a lesser tendency to utilise the maladaptive emotional and avoidance coping styles) and a greater sense of self-efficacy (as demonstrated in an internal locus of Personal control) for some subjects during their admission. At one year post-discharge the role of Interpersonal control becomes more prominent in relationships with other psychological variables and an internal locus of Interpersonal control is significantly associated with higher levels of adaptive (Rational and Detached) coping styles and lower levels of maladaptive (Emotional and Avoidance) coping styles, as well as a greater sense of self efficacy. It appears that a more internal locus of Interpersonal control could be either a facilitator or a product of a greater perceived of self-efficacy and more adaptive coping styles during admission. Overall these relationships suggest better psychological outcomes for subjects with an internal locus of Interpersonal control.

The inter-relationships between the psychological variables have been identified above. In the following sections the relationships and associations with the rehabilitation and reintegration outcome measures examined in this research will be identified.

### 7.3.3 Quality Of Life

	Perceived Quality of Life – 1-10 Rating		
	Pre-Injury Rating	Current Rating	Change in QOL
Mean	9.22 <i>(CI 8.88 – 9.57)</i>	5.01 <i>(CI 4.37 – 5.65)</i>	-4.21 <i>(CI -4.92 - -3.50)</i>
Std. Deviation	1.18	2.17	2.41
Median	10 <i>(IQR 1)</i>	5 <i>(IQR 3.5)</i>	-4 <i>(IQR 4)</i>
Mode	10	4	-6
Minimum	6	1	-9
Maximum	10	9	1
Skewness (z)	-1.293 <i>(-3.72)</i>	-0.123 <i>(-0.35)</i>	-0.034 <i>(-0.098)</i>
Key:	IQR = Inter-quartile range CI = 95% Confidence Interval Items in italics are non-parametric data		

Table 7.4 Descriptive Statistics of Subject Ratings of QOL Ratings (1-10 scale)

47 subjects contributed information on their perception of their QOL pre- and post SCI. 95.74% of subjects rated their pre-injury QOL as highly significantly greater ( $t(df46)=11.979, p=0.000$ ) than their current QOL (Table 7.4). The change in QOL is a negative value for all but two subjects. The perceptions of current QOL and change in QOL are highly significantly related (Table 7.5). As change in QOL is a negative value

this suggests that those who have a lesser perceived change in QOL will have a higher current QOL, with rating of current QOL accounting for 76.2% of the variance in the perceived change in QOL. The rating of QOL pre-injury was not significantly related to either current QOL or to the perceived change in QOL. There is a non-significant trend for those who rate their pre-injury QOL as very high to perceive a greater change (reduction) in their QOL. The perceived pre-injury QOL was not significantly related to either of the other QOL measures but was significantly related to time since injury (Table 7.5). As the variables of main interest are current QOL and the perceived change in QOL, the variable of perceived pre-injury QOL will not be examined in further analyses.

	Time Since Injury	QOL Pre-SCI	Current QOL
QOL Pre-SCI (N=47)	$\tau=-0.237^*$ $p=0.038$		
Current QOL (N=47)	$\tau=-0.069$ $p=0.511$	$\tau=0.132$ $p=0.269$	
Change in QOL (N=47)	$\tau=-0.040$ $p=0.704$	$\tau=-0.222$ $p=0.064$	$r= 0.873^{**}$ $p=0.000, R^2=0.76.2$
Key: $\tau$ =Kendall's tau correlation $r$ =Pearson's correlation      Significant correlations are in bold. ** Correlation is significant at the 0.001 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed).			

Table 7.5 Correlations of QOL Ratings and Time since Injury

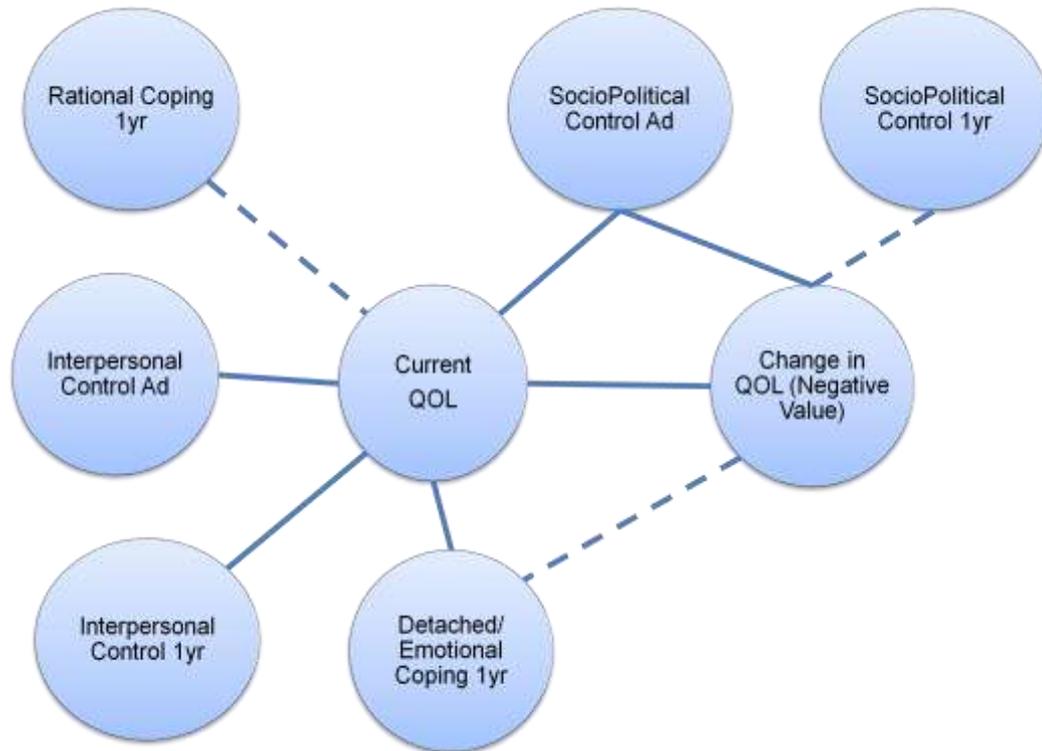
### 7.3.3.1 Psychological Variable (All Phases) and QOL Interactions

The research reviewed in Chapter 2 identified that QOL is suggested by researchers to be a measure of successful adjustment to SCI as well as an indicator of better psychological and health outcomes. This research aims to identify how the subjects view their QOL, how this may relate to other outcome measures and if contextual factors impact upon perceived QOL.

Due to the large number of analyses that can be performed only significant or non-significant relationships that are contrary to previously reported research will be discussed. Where possible the number of categories in variables will be reduced to two in order to reduce the potential for small group sizes to influence the ability to obtain a statistically significant result. Significant and near significant relationships are listed in Tables 7.6 and 7.7. These correlations are graphically represented in Figure 7.3.

A higher rating of current QOL was significantly correlated to a greater use of Detached coping styles at one year post-discharge (Table 7.6 and Figure 7.3). An internal locus of Interpersonal control is related to better outcomes as locus of Interpersonal Control at

both time points is significantly related to higher ratings of current QOL. Further relationships that approached significance between Current QOL and Rational coping at one year post-discharge and Perceived Change in QOL and Detached/Emotional coping styles at one year post were also identified (Figure 7.3 and Tables 7.6 and 7.7).



Key: Ad=Admission, 1yr=one year post-discharge  
 Dotted line indicates a correlation approaching significance

Figure 7.3 Significant and Near Significant Correlations between QOL and Psychological Variables

	Detached/ Emotional Coping Ad	Interpersonal Control Ad	Interpersonal Control 1yr	Rational Coping 1yr	Socio Political Control Ad
Current QOL	<b>r=0.367*</b> <b>p=0.046</b> <b>N=30</b>	<b>r=0.399*</b> <b>p=0.032,</b> <b>N=30</b>	<b>r=0.417*</b> <b>p=0.022</b> <b>N=29</b>	r=0.356, p=0.053, N=30	<b>τ=0.323*</b> <b>p=0.031,</b> <b>N=29</b>
Key	Ad=Admission, 1yr=one year post-discharge Significant correlations are bold τ=Kendall’s tau correlation r=Pearson’s correlation **. Correlation is significant at the 0.001 level (2-tailed). *. Correlation is significant at the 0.05 level (2-tailed).				

Table 7.6 Notable Correlations between Current QOL Ratings and Psychological Variables

Although locus of SocioPolitical control was not significantly correlated with any other the other psychological variables a significant correlation was identified between current QOL and SocioPolitical locus of control on admission (Table 7.6) and perceived change

in QOL (Table 7.7). Change in QOL is a negative value and so high values on SocioPolitical control is related to a small perceived reduction in QOL with a significant moderate effect during admission. Therefore subjects who perceive during their admission that they can influence policy and government during their admission will have a greater perceived current QOL and a smaller perceived reduction in QOL at one year post-discharge. An internal locus of SocioPolitical control at one year post-discharge does not significantly relate to Current QOL but does approach significance with Perceived Change in QOL (Table 7.7). This finding suggests that although locus of SocioPolitical control was not related to any psychological variables an internal locus of SocioPolitical control, certainly in the early stages post SCI, may be an important facilitator of a higher rating of current QOL and lesser perceived change in QOL.

	Detached/ Emotional Coping 1yr	Socio Political Control Ad	Socio Political Control 1yr
Perceived Change in QOL	r=0.352, p=0.056, N=30	<b>τ=0.323*</b> <b>p=0.019,</b> <b>N=29</b>	τ=0.260, p=0.055, N=30
Key	Ad=Admission, 1yr=one year post-discharge Significant correlations are bold τ=Kendall's tau correlation r=Pearson's correlation **. Correlation is significant at the 0.001 level (2-tailed). *. Correlation is significant at the 0.05 level (2-tailed).		

Table 7.7 Notable Correlations between Perceived Change in QOL and Psychological Variables

In summary a better current QOL is significantly related to: an internal locus of Interpersonal control at both time points, an internal locus of SocioPolitical control during admission, a greater use of Detached coping styles at one year post-discharge and a non-significantly greater use of Rational coping styles at one year post-discharge. A smaller change in perceived QOL is related to a significantly more internal locus of SocioPolitical control during admission and a greater use of Detached coping styles at one year post-discharge and an internal locus of SocioPolitical control at one year post-discharge (Figure 7.3). As locus of Interpersonal control and Rational coping are variables which are associated with an adaptive psychological profile further investigation in to these relationships may be beneficial in establishing if these outcomes are identified in a larger group and if there are ways in which improved psychological outcomes can be promoted in SCI individuals.

The following sections will aim to identify if the previously identified contextual factors can affect or be influenced by outcomes in addition to potentially being influenced by other contextual factors.

### 7.3.3.2 Variations in QOL and Psychological Variables in Relation to a Range of SCI, Demographic and Pathway Variables

There is a potential that some individual and SCI demographics or pathway variables may influence the psychological profile and perception of QOL of the individual. Analyses initially performed to investigate these issues during admission and are reported in Appendix L but yielded few significant results. The results will only be reported if the outcome of the analysis changed.

Although a significant difference in the use of Detached/Emotional coping styles was noted between males and females during admission (appendix L) this was not sustained at one year post-discharge ( $t(df28)=1.257, p=0.219, N=30$ ). However that females utilise notably more Emotional coping styles than males at one year post-discharge (Mean male=42.61, Mean female=37.57) echoes results reported elsewhere of a greater use of Detached coping styles amongst males (Lawrence, Ashford and Dent, 2006; Roger, Jarvis and Najarian, 1993). No significant difference was identified between males and on subject ratings of their current QOL ( $t=-0.751(df45) p=0.457, F=0.008, p=0.931, N=47$ ) or perceived change in QOL ( $t=-0.366(df45), p=0.716, F=3.141, p=0.083, N=47$ ).

None of the psychological or QOL variables varied significantly according to whether subjects had a delay in admission, delay in discharge or were paraplegic or tetraplegic (Appendix L, Table L.8) and no notable trends were identified.

Although during admission the use of Avoidance coping styles varied according to whether the SCI was sustained by traumatic or non-traumatic means (Appendix L) relationship was not sustained at one year post-discharge ( $H(df7)7.20, p=0.358, N=30$ ). However only four subjects in this group sustained NTSCI and this is likely to influence the ability to detect differences therefore further analyses using this variable at one year post-discharge will not be performed.

The significant difference in ratings of SocioPolitical locus of control during admission between those who did or did not have complications on admission to the SCIC (Appendix L) was also not sustained ( $U=78.0, z=0.748, p=0.476$ ) at one year post-discharge. However there is still a notable trend for those admitted with complications to have a more external locus of SocioPolitical control at one year post-discharge (median=28.0), compared to those admitted without complications (median=33.0). No significant difference was found on ratings of current QOL ( $t(df45)=0.411, p=0.683, (F=1.358, p=0.254) N=47$ ) between those who were admitted with complications (mean

current QOL=4.77) and those who were admitted without complications (mean current QOL=5.08).

In summary the results presented above suggest that there are no significant differences in either use of psychological variables or ratings of QOL between paraplegics and tetraplegics, demographic groups, or individuals who experienced differing pathways prior to and during their admission. However differing trends were noted in the use of Detached/Emotional coping in males and females and the perception of locus of SocioPolitical control in those who sustained sores on admission.

### 7.3.3.3 Variations in QOL and Psychological Variables in the Presence of Sequelae

As discussed in Chapters 1-3, research suggests that the sequelae of SCI may have the potential to influence psychological and QOL outcomes. Additionally the perception of the impact of sequelae may be influenced by the SCI individual's psychological profile. Analyses will be performed in this section to investigate these potential interactions and associations.

In Chapter 6, subjects were asked to state if they had 'frequently or persistently' experienced issues with the sequelae of SCI. In addition they were asked to rate: their level of pain and spasm 'today', the worst pain and spasm in the previous 24 hours and the amount that pain and spasm limited their abilities. This data was analysed with QoL and psychological measures data to establish if there were significant relationships or associations. A graphical representation of the relationships identified is given in Figure 7.4.

	Detached Emotional Coping Ad	Detached Emotional Coping 1yr
If Having Significant Issues with Pain N=30	$t(df28)=2.161$ , $p=0.039$ , $r=0.38$ $F=0.011$ , $p=0.915$	$t(df28)=2.188$ $p=0.037$ , $r=0.38$ , $F=0.531$ , $p=0.472$
Key	Ad = Admission 1yr = one year post-discharge	

Table 7.8 Analyses of Relationships between Pain Ratings and Psychological Variables

Subjects who reported persistent issues with pain at one year post-discharge favoured Emotional coping styles at both time points (mean without pain (N=13)=45.46, mean with pain (N=17) =38.35) with a moderate effect at both time points (Table 7.8 and Figure 7.4). Subjects who used more Emotional coping styles during admission also rated the worst pain they had in the last 24 hours as higher ( $r= -0.380$ ,  $p=0.038$ ,  $N=30$ ,  $R^2=0.14$ ) than those who utilised more Detached coping styles (Figure 7.4). Subjects who rated the amount that pain limited their abilities as high utilised the following at one

year post-discharge: more Emotional coping styles ( $r=-0.362$ ,  $p=0.050$ ,  $N=30$ ,  $R^2=0.13$ ), a greater amount of Avoidance coping styles ( $\tau=0.285$ ,  $p=0.040$ ,  $N=30$ ), they also reported a lower current QOL ( $r=-0.400$ ,  $p=0.005$ ,  $N=47$ ,  $R^2=0.16$ ) and a greater change in perceived QOL ( $r=-0.305$ ,  $p=0.037$ ,  $N=47$ ,  $R^2=0.09$ ). These findings suggest that higher ratings of the amount that pain limits abilities is associated lower perceived QOL, a greater reduction of QOL and greater use of maladaptive (Emotional and Avoidance) coping styles.

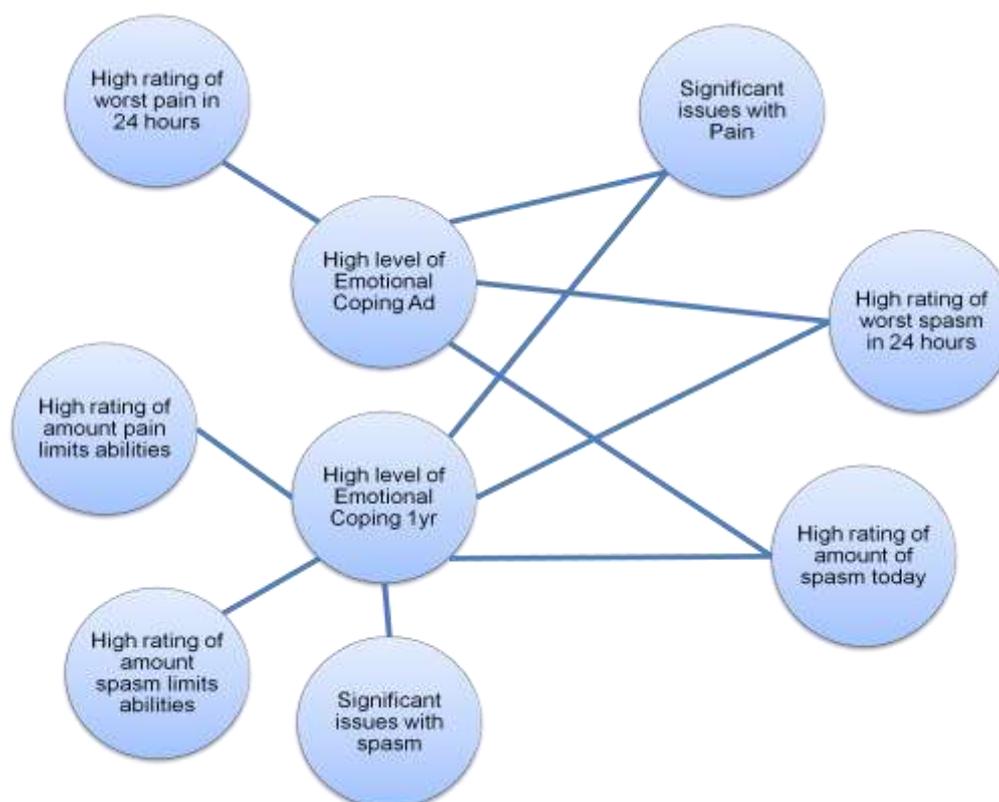


Figure 7.4 Significant Relationships Between Emotional Coping Styles And Subject Experience Of Pain And Spasm.

Subject reports of issues with spasms were more consistently associated with the use of Emotional coping styles both during admission (mean with spasms=35.5, mean no spasms=44.4) and at one year post-discharge ( $t(df28)=2.705$ ,  $p=0.012$ ,  $F=0.234$ ,  $p=0.633$ ,  $N=30$ ) with a moderate to strong effect ( $r=0.45$ ). A greater use of Emotional coping styles during admission was also significantly related to a higher rating of spasm today ( $r=-0.433$ ,  $p=0.017$ ,  $N=30$ ,  $R^2=0.19$ ) and a higher rating of the worst spasm in the previous 24 hours ( $r=-0.44$ ,  $p=0.015$ ,  $N=30$ ,  $R^2=0.19$ ) as shown in figure 7.4. The greater use of Emotional coping styles at one year post-discharge was significantly related to a higher rating of spasm today ( $\tau=-0.323$ ,  $p=0.019$ ,  $N=30$ ), a higher rating of the worst spasm in the previous 24 hours ( $r=-0.491$ ,  $p=0.006$ ,  $N=30$ ,  $R^2=0.24$ ) and a higher rating of the amount that spasm limited abilities ( $\tau=-0.403$ ,  $p=0.027$ ,  $N=30$ ).

Combined the above results suggest that the maladaptive coping styles are significantly related to reports of issues with the sequelae of pain and spasm (Figure 7.4), however the direction of causality cannot be confirmed in these analyses. Additionally the relationship between Emotional coping styles and pain is less clearly defined than the relationship with spasm as significant relationships are not consistent over both time periods. Higher levels of reported issues with pain are also significantly related to lower ratings of QOL and a greater perceived reduction in QOL.

	Current QOL	Perceived Change in QOL	Interpersonal Control 1yr post-discharge
If Having Significant Bowel Management Issues	t=2.847 ( <i>df</i> 45) p=0.007, r=0.39 F=0.265, p=0.609 N=47	t=2.260 ( <i>df</i> 45) p=0.029, r=0.32 F=0.868, p=0.357 N=47	t=2.202 ( <i>df</i> 28) p=0.036, r=0.38 F=0.587, p=0.450 N=30

Table 7.9 Analyses of Relationships between Bowel Issues and Psychological Variables

As identified in the literature reviews difficulties with maintaining a predictable and sustainable continence regime are also reported by individuals to be one of the more difficult aspects of SCI to adjust to and are suggested to impact upon QOL and psychological well-being.

Analyses identified that current QOL was rated as significantly lower by subjects who had experienced persistent bowel management problems over their first year of community reintegration (Mean Current QOL=4.19) than those who had not (Mean Current QOL=5.87) with a moderate effect. These subjects also perceived a much greater reduction in their QOL (Mean Change in QOL=-4.96) than those who had not experienced persistent bowel management issues (Mean Change in QOL=-3.43) with a moderate effect (Table 7.15). Additionally subjects who had experienced bowel management issues had a more external locus of Interpersonal control (Mean Interpersonal Control= 47.00) than subjects who had not experienced bowel management issues (Mean Interpersonal Control=55.25) during their first year of community reintegration (Table 7.9). Although caution needs to be exercised in attributing causality this finding suggests that issues with bowel management may impact significantly not only on QOL but also on the psychological variable that is suggested to be associated with superior psychological outcomes (Table 7.9 and Figure 7.2).

No significant difference was found in ratings of current QOL or change in QOL for those experiencing bladder management issues during the first year of community

reintegration (Appendix L, Table L.9), highlighting that although these are both continence management issues their impact upon psychological functioning is different.

The research reviewed suggested that sustaining pressure sores could impact upon psychological well-being and QOL. Analyses identified that the use of Avoidance coping strategies at one year post-discharge did vary significantly dependent on whether a subject had frequently and persistently experienced skin issues over their first year of community reintegration (Median=5) or not (Median=10) ( $U=51.5$ ,  $z=-2.290$ ,  $p=0.022$ ,  $N=30$ ,  $r=0.42$ ). This suggests a moderate effect for those who had not experienced skin issues during their first year of community reintegration to use a greater level of avoidant coping styles. However it cannot be discounted that other issues are influencing this relationship, such as the comparatively high percentage of subjects in this group (23.4%) who had experienced issues with pressure sores during the first year of community reintegration. It may also be that Avoidance coping styles are being utilised in response to other issues.

#### 7.3.3.4 Variations in QOL and Psychological Variable with Vocational Status

In order to investigate if the improved psychological functioning and QOL reported in research could be identified in this group of subjects, vocational status at one year post-discharge was examined in relation to psychological variables and QOL. As in Chapter 6 the group of subjects who were retired were excluded from these analyses, leaving two vocational groups in the analyses.

Vocational Status Group Interactions with:	Test statistic & <i>df</i>	<i>p</i>	Levene's Statistic	Mean
Rational Coping Admission N=17	$t=-2.266$ ( <i>df</i> 15)	0.039	$F=0.312$ , $p=0.585$	Mean Voc Active=19.78 Mean Voc Inactive=15.88
Current QOL N=26	$t=-2.880$ ( <i>df</i> 24)	0.008	$F=0.024$ , $p=0.879$	Mean Voc Active=5.93 Mean Voc Inactive=3.83

Table 7.10 Significant Differences in Coping and QOL Ratings between Vocationally Active and Vocationally Inactive Subjects

A strong significant effect ( $r=0.51$ ) was noted for those subjects who were vocationally active at one year post-discharge to utilise a significantly higher level of Rational coping styles during admission (Table 7.10). Ratings of current QOL were also significantly higher for those who were vocationally active (Table 7.10 and Figure 7.5).

In summary these results suggest that although QOL is better in the vocationally active group there were no significant differences in coping styles or attributions between the

two vocational status groups other than the greater use of Rational coping styles during admission by those who were vocationally active at one year post-discharge. Those who were vocationally inactive also had a greater but non-significant perceived reduction in QOL.

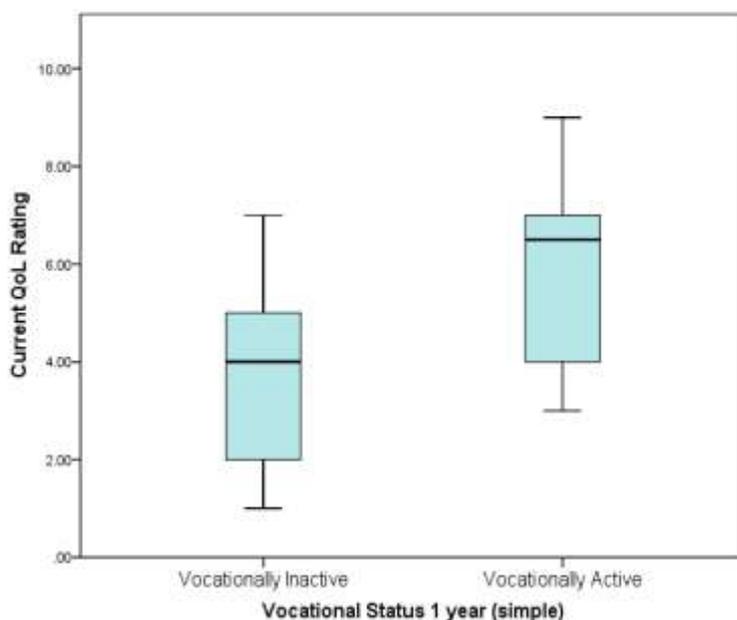


Figure 7.5 Boxplot Showing Mean Current QOL Rating According To Vocational Group at One Year Post-Discharge

### **7.3.3.5 Variations in QOL and Psychological Variable with Accommodation, Community Reintegration, Social Activity/Contact and Support**

This research aimed to identify if a variety of environmental contextual variables may influence or be influenced by a psychological variables or QOL. It was not possible to evaluate if differences in psychological or QOL variables were noted between subjects in differing forms of accommodation, if adaptations were outstanding at one year post-discharge or if subjects perceived they had control over how their care was provided due to unequal group sizes and small subject numbers (Appendix L).

Earlier a significant difference in the use of Avoidance coping styles at one year post-discharge was identified in those who experienced persistent skin issues during the first year of community reintegration. In order to investigate if this finding was the result of a relationship between the presence of skin issues and increased levels of care the use of Avoidance coping and levels of care were analysed. The number of care hours received per week was not significantly related to the use of Avoidance coping at either admission ( $\tau=0.052$ ,  $p= 0.711$ ,  $N=30$ ) or one year post-discharge ( $\tau=-0.086$ ,  $p= 0.540$ ,  $N=30$ ). At one year post-discharge this correlation became negative suggesting a change in the direction of the association meaning that a higher level of care was (non-

significantly) related to a low use of Avoidance coping styles, further implying that the difference in the use of Avoidance coping styles in those who had experienced persistent skin issues during the first year of community reintegration was unlikely to be influenced by the level of care the individual received.

Ratings of QOL and psychological variables did not vary significantly between subjects who left their home only weekly or less frequently (Mean Current QOL=4.39, Mean Change in QOL=-4.67) and those who left their home more frequently (Mean Current QOL=5.60 Mean Change in QOL=-3.77) however there was over 12% difference in rating of current QOL which did approach significance (Appendix L, Table L.10). Ratings of QOL and psychological variables also did not vary significantly regardless of whether or not the subject was able to access public transport, or owned their own car (Appendix L, Table L.10).

Prior to commencing this research, it was suggested that increased levels of social activity may influence QOL ratings and psychological variables. In this research, ratings of current and perceived change in QOL did not vary significantly (Appendix L, Table L.11) between subjects who had visits from friends only weekly or less frequently and those who received more frequent visits. Ratings of change in QOL also did not vary significantly between subjects who had visits from friends only weekly or less frequently. Additionally ratings of current and perceived change in QOL did not vary significantly (Appendix L, Table L.11) between subjects who had visits from their family only weekly or less frequently and those who received more frequent visits. As with visits from friends, those subjects who had visits from family members more often than once a week had a slightly (6.2%) higher current QOL and a 7.4% lesser perceived change in QOL.

However results of analyses did identify that subjects who had visits from friends more frequently than once a week utilised a Rational (adaptive) coping style (Mean=21.5) significantly more (Appendix L, Table L.11) than those subjects who had less frequent or no visits from friends (Mean=17.35). They also had a significantly more internal locus of Interpersonal control (Mean=55.83) than those subjects who had less frequent or no visits from friends (Mean=45.65). These findings suggest that those subjects who have friends visiting less frequently than once a week, or not at all, will utilise a less Rational coping style and have a more external locus of Interpersonal control, however causality in this relationship is not confirmed (Appendix L, Table L.11).

In summary, significant differences were not identified in ratings of QOL or psychological variables between subjects who had access to differing forms of transport, had differing forms of accommodation, left their homes more frequently or had more frequent contact from friends or family. However, higher levels of Rational coping styles were utilised by subjects who had more regular visits from friends.

#### **7.4 Discussion**

Prior to discussion of the results in relation to specific outcomes, it will be useful to view the relationships and variations in the personal contextual factors of locus of control and coping styles identified in this research.

Variations in the psychological measures mean scores identified in this population compared to the scores obtained in the general population. Although it may be expected that individuals in the exceptional situation of the early stages of SCI and community reintegration would vary in their psychological profile from a non-SCI population, it may also be that small subject numbers are influencing results. However, it is particularly worth noting that this group of subjects exhibited a notably more internal locus of Interpersonal control than has been reported elsewhere. A high score on this variable has been suggested by the scales' author to be associated with higher levels of social skills (Paulhus, 1983) which is a variable that Müller et al (Müller *et al.*, 2012) suggested may be an important factor in eliciting social support.

Subjects with a perceived internal locus of Personal control (and self efficacy) during admission, utilise greater levels of rational coping styles at one year post-discharge which in turn is associated with a (non-significantly) higher rating of current QOL. As the significant relationship between Rational coping styles and locus of Personal control was not sustained in the longer term, this suggests that a greater sense of self efficacy (as measured by locus of Personal control) in the early stages post injury may facilitate adaptive coping styles and through this, greater, perceived quality of life.

Although average scores on all of the psychological variables did not change significantly from the admission period to one year post-discharge, the relationships between variables did change, which suggests that discrete shifts were occurring in the application of coping styles and attributions of control. During admission by the locus of Interpersonal control and Rational coping were associated with adaptive coping styles and higher levels of perceived control but at one year post-discharge the number of variables that were significantly correlated with Rational coping had reduced. Whilst this may indicate a reduction in use of Rational coping over time, as found in other research

(Stougaard Nielsen, 2003), further research would be required to confirm this. By one year post-discharge locus of Interpersonal control is significantly associated with higher levels of adaptive (Rational and Detached) coping styles, lower levels of maladaptive (Emotional and Avoidance) coping styles, a greater sense of self efficacy and a higher rating of current QOL. Although the direction of causality cannot be confirmed these findings suggests that the importance of attribution of locus of Interpersonal control in facilitating superior psychological outcomes has increased as these subjects have progressed through their rehabilitation and reintegration. If, as suggested by Paulhus (Paulhus, 1983), this variable is an indicator of the subject's social skills. If, as suggested by Müller et al (Müller *et al.*, 2012), social skills are important in eliciting social support, this would suggest that individuals with a more internal locus of Interpersonal control are not only more likely to elicit and receive social support but they will also have a more adaptive psychological profile, exhibit less symptoms of psychological distress and have a better QOL. Subject numbers are small and therefore further research is required to confirm these findings, however they may indicate that the perception of the ability to influence other individuals and interpersonal situations could facilitate better outcomes in SCI individuals.

The significant relationship between a more Detached and less Emotional coping style at both time points and an internal locus of Interpersonal control at one year post-discharge but not admission lends support to suggestions in other research that the short term use of Emotional coping styles following a traumatic event such as sustaining an SCI may not be detrimental in the longer term (Ptacek and Pierce, 2003; Stougaard Nielsen, 2003; Cairns and Baker, 1993; Folkman and Lazarus, 1985). In other words, although a more Detached coping style during admission may be related to a more internal Interpersonal locus of control at one year post-discharge, the use of a less Detached (that is, more Emotional and maladaptive) style of coping during admission can be compensated for in the long run.

These findings suggest that although the scores for coping styles and attributions employed by subjects may not have changed significantly over the period examined, the extent to which these styles and attributions are employed and relate to each other has changed just as the situation that the subject experienced has changed (Kennedy *et al.*, 2012; Stougaard Nielsen, 2003; Lou, Dai and Catanzaro, 1997; Kennedy *et al.*, 1995; McColl and Skinner, 1995; Folkman and Lazarus, 1985). Some of these changes may facilitate superior psychological outcomes, whilst others will not. An unexpected result was that a measure of attribution of locus of control was highlighted as a variable associated more consistently with a more adaptive psychological profile and better QOL

outcomes than any measure of coping style. Potentially this data lends some power to the proposal put forward in Chapter 3 that locus of control is an attribution regarding the situation that the individual finds them self in whilst the use of coping styles demonstrates how the information gained from this attribution is processed and adapted to. Therefore, those subjects with a more internal locus of Interpersonal control perceive that they are able to influence others and draw on the resources of others to assist them in their current situation (Paulhus, 1983) which then facilitates them positively adapting and coping with their situation, perceiving a better quality of life and experiencing lower levels of distress (Kennedy, Evans and Sandhu, 2009; Stougaard Nielsen, 2003).

#### **7.4.1 Outcome Measures**

In the following sections the reintegration outcome measures proposed in Chapter 2 will be discussed in relation to the results obtained for the psychological variables (contextual factors) measured and potential reasons for variations discussed. Additionally, potential reasons for fluctuations in QOL in relation to variations in these outcomes will be explored. Finally the identified relationship and associations between the sequelae of SCI and the contextual factors of psychological variables will be discussed.

##### **7.4.1.1 Reintegration Outcome Measure: QOL**

Over 95% of subjects perceived their QOL to have significantly reduced since they sustained their SCI. The finding that a higher rating of current QOL was highly correlated to a lesser perceived change in QOL suggests that some subjects may not only be negatively appraising their current QOL but potentially also over-inflating their previous QOL and through this over-inflating the change in QOL. This appears to support findings on QOL in respect of negative appraisal and the impact of the inability to re-evaluate life-expectations reported elsewhere (Sakakibara *et al.*, 2012; Kennedy *et al.*, 2010b; Post and Noreau, 2005). The variable measuring perceived change in QOL could be asserted to reflect the perceived difference between the expected QOL and the current experience of QOL as discussed by Duggan and Dijkers (Duggan and Dijkers, 2001). As a measure of QOL was not taken during admission it is not possible to state definitively if any change in expectations or appraisal of QOL has occurred over this period. That neither current QOL, nor perceived change in QOL, were significantly related to the rating of pre-injury QOL highlights that this factor is isolated in relation to the subject's perceptions of current QOL. The significant reduction in the rating of pre-injury QOL (but not current QOL) noted with longer periods since injury suggests that subjects' appraisal of how their QOL was pre-injury (and therefore the perceived change in QOL) changes over time, as per Sakakibara *et al.* (Sakakibara *et al.*, 2012) and could indicate an

adjustment process. Further research may help to investigate if this is a sign of adjustment of appraisal or an anomalous finding as a result of the measure of QOL used or the small subject numbers.

A distinction is apparent in the relationships between the psychological measures and the variables current QOL and change in QOL. A high rating of current QOL is significantly related to an internal locus of Interpersonal control at both time points and adaptive coping styles. However, a low perceived change in QOL is associated with an internal locus of SocioPolitical control at both time points and a greater use of Detached (adaptive) coping styles at one year post-discharge. This suggests that although the locus of SocioPolitical control was not related to any psychological variables a more internal locus of SocioPolitical control, certainly in the early stages post SCI, is potentially a facilitator of a lesser perceived change in QOL and an important variable in the appraisal of the changing situation that the SCI individual finds themselves in. A further near significant relationship was identified for a smaller perceived change in QOL occurring with greater use of Detached coping styles at one year post-discharge (Table 7.7). Detached coping is an adaptive coping style and the use of this form of coping is suggested to result in lower levels of psychological distress and facilitate adjustment (Stougaard Nielsen, 2003; Roger, Jarvis and Najarian, 1993) and a lesser perceived reduction in QOL has been suggested to be the result of adjustment and changing appraisals (Sakakibara *et al.*, 2012; Kennedy *et al.*, 2010b; Post and Noreau, 2005). Therefore, an association may be expected between these variables. Several reasons could be proposed for why this relationship only approached significance. The obvious one is small subject numbers and it may be that, with a larger group, this relationship would be strengthened. Equally, relationships between variables have been noted in this research to change over time and as the process of adjustment continues over time this relationship may strengthen. Further research with a larger subject group could confirm if this is the case.

Contrary to findings elsewhere (Hammell, 2004; Manns and Chad, 2001; Chase, Cornille and English, 2000), there was a lack of significant difference in perception of locus of control, current QOL or perceived change in QOL between tetraplegic and paraplegic subjects. This may be due to either small subject numbers or the comparatively early stage post injury of these subjects compared to those in other research (Manns and Chad, 2001). Additionally, although subject groups were evenly balanced, the groups of paraplegic and tetraplegic incorporated subjects who had an AIS D grade injury, as well as those with more functionally complete SCI, which may have influenced the ability to detect trends in the data.

In summary, the reintegration outcome measure of a better perceived current QOL in this group of subjects appears to be facilitated by, or to facilitate, an internal locus of Interpersonal control and a greater use of adaptive coping styles at one year post-discharge. This finding supports similar findings in other research (van Leeuwen *et al.*, 2012; Kennedy *et al.*, 2010b; Mortenson, Noreau and Miller, 2010; Manns and Chad, 2001). This suggests that a greater perceived change in QOL is related to an external locus of SocioPolitical control and a greater use of maladaptive coping styles at one year post-discharge. This supports previous findings and theories that the longer term use of maladaptive perceptions and strategies are linked to higher levels of emotional distress and a negative appraisal of the situation the individual finds themselves in (Kennedy, Cox and Mariani, 2013; Sakakibara *et al.*, 2012; Kennedy *et al.*, 2010b; Mortenson, Noreau and Miller, 2010; Post and Noreau, 2005; Ptacek and Pierce, 2003; Stougaard Nielsen, 2003; Manns and Chad, 2001; Cairns and Baker, 1993; Folkman and Lazarus, 1985). The finding that longer periods of time since injury are significantly related to lower ratings of pre-injury QOL, may support assertions in other research that individuals will reappraise their perceptions of what QOL is and what influences it over time (Sakakibara *et al.*, 2012; Duggan and Dijkers, 2001). Particularly, that they will view their previous QOL less favourably as time since injury increases.

#### **7.4.1.2 Healthcare Systems Outcomes**

The healthcare systems outcome evaluated in this chapter were: delays to admission and discharge, particularly with the aim of identifying if these impacted upon personal contextual factors in the form of the psychological variable locus of control. Following the literature reviews it was suggested that subjects who experienced a lengthy delay to discharge or admission may perceive a greater degree of powerlessness and so a more external locus of SocioPolitical control than those who were not delayed. However, results suggest that neither delays in admission nor delays in discharge were significantly related to any of the psychological measures or QOL outcomes and no notable trends were detected. Potentially this could suggest that the impact of these issues is so transient as to not affect longer term psychological functioning or the small group size may be masking any potential trends. Equally, it may simply be that the assertion that delays in either admission or discharge would influence locus of SocioPolitical control was incorrect. There is no comparable research to assist in drawing further conclusions on the potential psychological impact, if any, of delays in admission and discharge.

#### **7.4.1.3 Reintegration Outcome Measure: Community Participation/Social interaction**

Assertions made elsewhere that the frequency of outings to the community may be important in the perception of current QOL (Kennedy *et al.*, 2010b; Mortenson, Noreau and Miller, 2010; Post and Noreau, 2005; Siosteen *et al.*, 1990) were not significantly supported. However, there was a notable trend and a difference of QOL ratings that approached significance. Although, contrary to other research, the ability to drive did not result in variations in current QOL (Siosteen *et al.*, 1990) and neither did the ability to access public transport. The variation in these last findings may be due to differing measures in QOL being utilised or due to the small group size resulting in an inability to detect differences in subject groups. Combined, these findings suggest that although participation in community activities and engaging in society (World Health Organisation, 2001) is an important facilitator of QOL, the means by which this participation is achieved is not important in relation to QOL, however, further research is required to confirm these findings.

The results from this research indicate that the frequency of visits from friends and family had a positive (although not statistically significant) impact on the two key psychological variables of Rational coping style and locus of Interpersonal control. This confirms suggestions elsewhere that this form of social interaction promotes psychological well-being (Müller *et al.*, 2012; Kennedy *et al.*, 2010b; Mortenson, Noreau and Miller, 2010; Raichle *et al.*, 2007; McColl and Skinner, 1995; Schulz and Decker, 1985). Additionally, that the higher levels of social skills demonstrated in a more internal locus of Interpersonal control result in significantly higher levels of visits (and therefore social support) from friends (Müller *et al.*, 2012). The direction of causality in these relationships is not confirmed, as reported levels of contact with friends may be a predictor variable for improved or impaired psychological functioning or equally the perception of level of contact may be influenced by the attitudes and behaviour of the SCI individual (Müller *et al.*, 2012; Mortenson, Noreau and Miller, 2010; Raichle *et al.*, 2007; Stougaard Nielsen, 2003; McColl and Skinner, 1995). However, the finding that the frequency of family visiting did not relate to any of the psychological variables or QOL is counter to suggestions elsewhere (Mortenson, Noreau and Miller, 2010; Chevalier, Kennedy and Sherlock, 2009). Although this may be due to a variety of reasons including the use of differing measures of psychological outcomes and QOL, the impact of small subject numbers or the number of subjects who lived with their family and therefore rarely had visits from family members. As the higher levels of Rational coping and an internal locus of Interpersonal control related to frequency of friends visiting have also been found to be associated with better outcomes in terms of QOL, vocational

activity and a lower impact of sequelae, the relationships between the level and forms of social contact that an SCI individual has and these psychological variables may benefit from further investigation.

#### **7.4.1.4 Reintegration Outcome Measure: Vocational status**

Although improved psychological functioning has been suggested to be related to vocational activity following SCI, only current QOL and the use of Rational coping styles during admission were significantly related to vocationally activity at one year post-discharge. It is unexpected that other positive psychological outcomes are not related to vocational status including locus of Interpersonal control which is a variable that is significantly related to a range of other positive psychological outcomes. However, a greater use of Rational coping styles during admission is significantly associated with a more internal locus of Interpersonal control at one year post-discharge and a range of other, superior, psychological outcomes including higher ratings of current QOL, therefore, it may be that vocational activity has an indirect impact, or is indirectly impacted upon by other psychological variables but this cannot be confirmed. Again, small subject numbers may be influencing the ability to obtain a significant result. Other research (to support or dispute these findings) is not available and this is an area that may benefit from further investigation. In summary, the findings from this research confirm the findings of other research that vocational activity is related to better QOL ratings (Sakakibara *et al.*, 2012; Noreau *et al.*, 2010) but also indicates that the adaptive, Rational coping style is also associated with better vocational outcomes.

#### **7.4.1.5 Reintegration Outcome Measure: Accommodation/Residential Situation**

It was not possible to evaluate if where the subject lived had an impact upon their perceived locus of control, as suggested elsewhere (Bergmark, Winograd and Koopman, 2008; Boschen, 1996), or to evaluate the impact of residential situation or outstanding adaptations on QOL (Heywood, 2004) due to small and uneven group sizes. Additionally, analyses may also have been influenced by the potential misinterpretation of the questions regarding outstanding adaptations by some subjects and therefore results obtained would have been questionable at best.

#### **7.4.1.6 The Potential Impact of Sequelae on QOL and Psychological Factors**

##### *Sequelae*

The results presented in this chapter confirm the ability of sequelae to impact upon QOL and psychological variables; however, they also indicate that differing sequelae have differing impacts even if the sequelae themselves are highly correlated. For example, as identified in other research (Anke, Stenehjem and Stanghelle, 1995), the presence of

pain was shown to significantly impact on perceived QOL. However, (and contrary to other research (Adams and Hicks, 2005)) those experiencing significant issues with spasms did not report a lower QOL. This highlights a difference in how the presence (or lack of) these two highly correlated sequelae impact on subject attitudes or perceptions. Additionally, although the presence of pain was correlated with the use of Emotional coping styles, the relationship between spasms and the use of Detached/Emotional coping was more consistent. This is both surprising and contrary to what might be expected (Raichle *et al.*, 2007; Wollaars *et al.*, 2007), although the impact of spasms on psychological functioning has been acknowledged to some extent (Adams and Hicks, 2005). Additionally, although the perception that pain limits abilities is significantly related to a higher level of Avoidance coping styles, there was no similar relationship with spasms emphasises these differences. In summary, these findings suggest that high ratings of spasms are consistently related to the maladaptive Emotional coping style, high ratings of pain has a wider impact psychologically (Raichle *et al.*, 2007). However, as noted previously, this may be an anomalous, incorrect finding and the potential impact of small group sizes on results obtained needs to be acknowledged. It is not appropriate to draw conclusions about causality from these findings as it is not possible to identify when the experience of pain or spasm began. Surprisingly, although the perception of control is suggested to result in better psychological and pain interference outcomes (Raichle *et al.*, 2007; Wollaars *et al.*, 2007), none of the locus of control scales were significantly related to the subject's reports of pain. This could be a reflection of the pain measure used or, equally indicate that, in this instance, a measure of Health related LOC may have been a more appropriate measure. In association with the previously reported findings of high levels of pain being related to low levels of community participation and vocational activity, these findings suggest that the impact of pain is wide ranging for the SCI individual and, consistent with previous research (Kennedy, Lude and Taylor, 2006), is often unresolved.

The results obtained indicate that, in addition to a significantly more external locus of Interpersonal control an attribution that will be negatively related to adaptive coping styles, individuals experiencing frequent bowel management issues will have a lower current QOL and a greater change in QOL since their injury. This confirms previous research (Akkoç *et al.*, 2013; Schurch *et al.*, 2007) and suggests a substantial psychological impact of the presence of bowel management issues. That there were also no significant differences on psychological measures between those who had, or had not, experienced significant issues with bladder management may highlight that different continence sequelae will impact on an SCI individual's life and psychological well-being in different ways but equally may be a reflection of small subject numbers.

A further unexpected finding was that subjects who had experienced significant skin issues over the first year of community reintegration used significantly less Avoidance coping styles at both time periods than those who had not experienced skin issues. This suggests that a greater use of Avoidance coping styles is associated with a lower incidence of skin issues during the first year of community reintegration. This is in opposition to the assertion that acceptance of the SCI and active participation in pressure sore prevention strategies is a key strategy for avoiding pressure sores (Regan *et al.*, 2012). As this trend is present with the measures taken at both time periods makes this less likely to be an anomalous finding. Another alternative explanation is that the Avoidance coping scale is measuring something else in these subjects other than avoidance in respect of skin issues. The scale's author has recently investigated the potential for avoidance to be a multidimensional concept incorporating general avoidance, emotional avoidance and conflict avoidance (Roger, 2013). This could suggest that a particular dimension of avoidance is being detected in this finding and this could be an issue that would benefit from further research.

In summary, it appears that different coping styles or attributions of control are associated with different sequelae. Although the direction of causality in these relationships is not established, subjects who utilise more detached and less avoidant coping styles are less likely to be experiencing issues with spasms, pain or pressure sores. Subjects who report a higher QOL are less likely to be experiencing issues with pain or bowel management. Subjects who perceive an internal locus of Interpersonal control are also less likely to be experiencing bowel management issues. This last relationship is of particular concern as it suggests that not only will those individuals who are experiencing bowel management issues perceive a lower QOL they may also perceive that they have a lesser ability to elicit assistance and support from others. However, in addition to a lack of clarity on the direction of causality in these relationships, there is the potential for small subject numbers to have influenced results. Although the ability to establish significant differences and interactions, or in many analyses, to identify trends has been significantly limited in this phase of the study, there are many notable findings in this study worthy of further investigation.

#### **7.4.2 Limitations**

Some limitations have been identified in the research process and the data collected in this research. The limitations will be discussed in relation to the issues they relate to.

##### *Subject issues*

- Although strategies have been taken to reduce the impact of small subject numbers by combining categories of subjects there was still an impact on the ability to perform some analyses. Additionally, the small group sizes may have impacted upon the ability to obtain statistically significant results.

#### *Measurement Issues*

- Psychological measures that have not generally been utilised in SCI research were used in this study. Although there were valid reasons for the selection of these measures rather than others more commonly used, this will have impacted upon the ability to draw comparisons between the findings in this and other studies.
- In the development of this research, a pragmatic decision was taken to use overt question of subjective perception of QOL in order to permit the individual to utilise their appraisal of how their life is compared to how they would expect it be (McKevitt *et al.*, 2003; Duggan and Dijkers, 2001). It could be suggested that, in addition to presenting difficulties with comparisons with other research, this question may have caused ambiguity resulting in the question measuring a range of differing variables that each individual classed as QOL. However, this is an accusation that could be levelled at the measurement of subjective QOL as a whole (Sakakibara *et al.*, 2012; Eng *et al.*, 2010c; Hill *et al.*, 2010). It is the subjective perception and variation between individuals in that perception that is being measured in subjective QOL (Sakakibara *et al.*, 2012; Post and Noreau, 2005; Duggan and Dijkers, 2001) and what this study was aiming to measure.
- One year post-discharge may have been too early a time point to perform a repeated measure to detect differences in the utilisation of attributions and coping styles. However, differences were noted in the relationships between variables, even at this early stage.

#### **7.5 Summary**

In summary, the findings from this phase of the study suggest that although the use of coping styles and perceptions of locus of control remains stable, overall between admission and one year post-discharge, the associations between psychological variables change from admission to one year post-discharge. This confirms the proposition that these variables, although not changing significantly, may shift as the individual adjusts to their new situation and their changing life and environment. These shifts indicate that the importance of some psychological variables will change over time for example; although the use of Emotional coping styles is generally associated with poor outcomes, if it was only used during the admission period, it did not automatically

result in poorer outcomes. Likewise, although an internal perception of SocioPolitical control during admission was significantly related to a more positive appraisal of the change in QOL this relationship only approached significance at one year post-discharge.

The subject's perception of an internal locus of Interpersonal control at both time periods has been identified in this research to be linked to better psychological, vocational and QOL outcomes.

The pertinent results identified in this chapter in relation to the identified outcome measure are:

#### *QOL*

The outcome measure of the subject's perception of current QOL is significantly lower than the rating given for pre-injury QOL. Over 95% of subjects perceived their QOL to have reduced since they sustained their SCI. Although the assertion that QOL may change as time since injury increased was not supported a significant change in the subject's rating of pre-injury QOL was identified.

It was not possible to examine the influence of modifiable variables such as accommodation or care provision on QOL due to subject numbers. However, the non-modifiable factor of whether a subject was a paraplegic or tetraplegic did not result in significant variations in QOL ratings.

#### *Healthcare Systems Outcomes*

Although delays in admission and discharge did not generally impact upon psychological measures, or QOL outcomes, a transitory impact by locus of SocioPolitical control was noted.

#### *Community Participation/Social interaction*

Although subjects who reported more frequent outings to the community rated their QOL more highly, this difference only approached significance and no difference in psychological variables was identified. QOL also did not vary significantly regardless of whether subject drove or were able to access public transport.

Subjects who had more regular visits from friends utilised greater levels of Rational coping styles but only had non-significantly higher ratings of QOL. Subjects who had more regular visits from family members did not have significantly higher ratings of QOL

but this may have been influenced by the numbers of subjects who lived with family members.

#### *Vocational status*

Subjects who are vocationally active at one year post-discharge did have a higher rating of current QOL as suggested in other research. They also utilised higher levels of Rational coping during their admission.

#### *Accommodation/Residential Situation*

Analyses could not be performed due to small subject numbers and uneven group sizes.

#### *Sequelae*

The sequelae of SCI are related to coping styles and attributions of control in distinctly different ways:

- The use of Detached or Emotional coping styles is related to the presence of absence of pain and (particularly) spasms but in different ways.
- Bowel management issues are related to an external locus of Interpersonal control.
- Pain impacts negatively on the perception of current QOL as do bowel management issues but spasms do not.
- Low levels of Avoidance coping at both time periods were related to the experience of significant and persistent skin issues at one year post-discharge.

Although small subject numbers have limited the ability to perform some analyses and, potentially, to obtain significant results in others there are many notable findings in this study that would benefit from further investigation. In the next chapter these findings will be discussed in relation to the findings from the two previous chapters. The results obtained will be evaluated in the context of the research hypotheses and the areas for investigation that were proposed in Chapters 2 and 3.

## **CHAPTER 8: Summary and Conclusions**

### **Overview**

This chapter will discuss the results presented in the three preceding chapters in the context of current research and the ICF model of disability. The research project will be evaluated and the strengths and limitations of the project discussed. Potential implications for SCIC, acute hospital and community services as well as service planners will be discussed in addition to recommendations for further research.

## **8.1 Introduction**

The aim of SCI rehabilitation is for the individual to reintegrate in to their society at the end of their rehabilitation and to be an active participant in this society, to work, and have relationships as they would have done if they had not sustained an SCI. Through a critical review of existing literature this thesis identified potential outcomes following spinal cord injury (SCI) which are commonly viewed as measures of successful rehabilitation and reintegration. However there is little UK-based research identifying whether SCI individuals actually manage to achieve these outcomes and if contextual factors limit or facilitate their ability to achieve these outcomes. This research project was devised to investigate the potential for SCI individual to achieve these outcomes as well as to explore the factors which may facilitate or limit these outcomes. An additional aim was to address some of the issues with lack of clarity in the definitions used to describe milestones in the patient pathway present in research investigating lengths of rehabilitation stay which often result in difficulties in drawing comparisons between research results. This research aimed to clearly define milestones and transition points in the subjects' injury and rehabilitation pathway. These issues have led to a novel research study which contributes substantially to knowledge in this field. Additionally a notable amount of novel demographic information has been produced which gives further depth to the information provided by this research than has previously been available.

This research mapped longitudinal outcomes in a group of newly injured SCI individuals and comprised of two phases. Additionally, relationships with psychological variables were investigated in a cohort of subjects. While the results of each phase and form of the research have been discussed in the three previous chapters, this chapter will summarise the knowledge that arises from these results. A significant number of findings have been identified in this research some support previous research whilst others present alternative, many have no equivalent research to assist in drawing conclusions and therefore will be discussed as novel findings. The implications of this knowledge for our understanding of issues which may impact upon the successful rehabilitation and reintegration of people following spinal cord injury will be discussed and important avenues for further research identified.

## **8.2 Summary of Findings:**

In the following sections results from this research will be discussed in relation to the proposed rehabilitation outcome measures of Community Reintegration and Participation, Vocational Status, Quality Of Life and Accommodation/Residential

Situation. Additionally the healthcare systems outcome measures of functional improvement, lengths of stay (including discharge delays) and readmissions.

Discussions regarding the results for sequelae of SCI, QOL and personal contextual factors of locus of control and coping styles in addition to the environmental contextual factors of provision of resources including equipment and care will be presented first as these factors have bearing on the results presented for the established outcome measures.

### **8.2.1 Outcome Measure: QOL**

Higher ratings of current QOL were associated with a smaller perceived difference in the quality of life echoing other reports of the importance of reappraisal of life expectation following SCI (Sakakibara *et al.*, 2012). However the mean reduction in QOL of 4 (approximately 46%) suggests that the outcome measure of good rating of QOL (Sakakibara *et al.*, 2012; Kennedy *et al.*, 2010b; Post and Noreau, 2005; Duggan and Dijkers, 2001; Sprangers and Schwartz, 1999) has not been achieved in these subjects.

Previous research has suggested that perceptions and appraisals of QOL will change over time (Sakakibara *et al.*, 2012; Duggan and Dijkers, 2001). This research did not identify any significant change in the rating of current QOL with increasing time since injury but did identify a significant decrease in the perception of pre-injury QOL with increasing time since injury. This, perhaps, indicates the adjustment to SCI that has been suggested in other research (Sakakibara *et al.*, 2012; Post and Noreau, 2005; Sprangers and Schwartz, 1999). Further research in to this issue is required to confirm these findings and to identify if changes to current QOL occur with greater time since injury (Sakakibara *et al.*, 2012).

As with findings elsewhere this research suggests that higher levels of QOL were related to vocational activity (Duggan and Dijkers, 2001; Manns and Chad, 2001) and lower ratings of pain (Ataoglu *et al.*, 2012; Anke, Stenehjem and Stanghelle, 1995). The lack of significant relationship between QOL and the level of injury is not surprising considering the conflicting findings reported elsewhere (Post and van Leeuwen, 2012; Hammell, 2004).

### **8.2.2 Personal Contextual Factors: Locus of Control and Coping Styles**

Overall ratings on both coping and the spheres of control scales were within the range of mean scores reported elsewhere (Borrill *et al.*, 2009; Spittal *et al.*, 2002) except subjects

had more internal ratings of Interpersonal control than the previously reported mean scores (Spittal *et al.*, 2002).

Although ratings on the scales themselves did not change significantly over the first year of community reintegration the relationships between variables on the scale did change significantly, supporting the assertion that it is not changes on individual scales that are important, rather the identification of underlying trends, relationships and mechanisms (Dunn and Elliott, 2008). Trends were seen in this research that indicate although adaptive coping styles are associated with better outcomes and maladaptive coping with poor outcomes locus of Interpersonal control is was significantly associated with a greater range of psychological variables. There is little research into the role of the perception of locus of control (LOC) and appraisal of control in SCI research, and much that is available has focused on health related LOC and so many findings discussed here have comparable research. Additionally as Spheres of Control scale utilised in this study has not been used in the SCI population before, any relationships identified are novel findings.

Higher ratings of current QOL were significantly related to a more internal locus of Interpersonal control and greater use of adaptive coping styles (and so lower levels of psychological distress). As well as being associated with a better psychological profile at one year post-discharge subjects who had a more internal locus of interpersonal control during admission were also significantly more likely to have a better psychological profile at one year post-discharge. This profile consisted of lower levels of psychological distress, greater use of adaptive coping strategies and a higher rating of current QOL, suggesting that locus of Interpersonal control may be both predictive and facilitative of better psychological outcomes in this group of subjects. An internal locus of Interpersonal control has been suggested to be associated with higher levels of social skills (Paulhus, 1983) which have been suggested to facilitate the SCI individual eliciting social support (Müller *et al.*, 2012). The potential impact of locus of Interpersonal control will be discussed in relation to the levels of social contact in a later section.

### **8.2.3 Environmental Contextual Factors: Provision of Care and Equipment**

Over 80% of subjects were in receipt of some form of care support on discharge with approximately a quarter of subjects receiving 24 hour care and over 30% receiving informal support from a family member or friend on discharge. That the level of care received on discharge and at one year post-discharge varied according to the injury group is unsurprising and reflects research and guidance elsewhere (Cohen *et al.*, 2012;

DeVivo *et al.*, 2011), however little information regarding levels of support or costs have been identified in the UK before.

Although the level of care (and cost of care) received at one year post-discharge had reduced, although not significantly, the proportion of subjects receiving care had increased despite an increase in the proportion of (potentially more functionally independent) paraplegic and Tetraplegic (AIS D) subjects had increased. These groups also had an increase in the median number of care hours received. This potentially reflects the increase in the amount of informal care was being provided to subjects at one year post-discharge which, for some subjects was a substantial amount of their care package. When viewed in association with research identifying the impact of the caregiver role on the relative or loved one providing the care (Boucher, Ballantyne and Boschen, 2012) along with the potential loss of autonomy and deteriorating relationships for the SCI individual (Bergmark, Winograd and Koopman, 2008) this is a concern, but further investigation of this would be required to identify what level of support is required and with which tasks.

In addition to the numbers of individuals privately funding their care there was an increase in the number of subjects who were funded by NHS Continuing Healthcare Funding. A corresponding reduction was seen in the numbers of subjects funded by Social Services Departments indicating a shift towards individuals either privately funding their care/using informal care or having NHS funded (free at source) care. This is novel information which assists in compiling a clearer picture to the requirements of the SCI population but is of little research value.

Issues were noted in this research with the provision of equipment (a contextual environmental factor). Many subjects were discharged without their permanent wheelchair and two without provision of any form of wheelchair from local teams and at one year post-discharge over 8% of subjects had still not received their permanent wheelchair. These subjects are likely to have experienced the limitations in activity reported elsewhere (Harvey *et al.*, 2012; Hastings *et al.*, 2011; Wilson *et al.*, 2008; Chaves *et al.*, 2004; Rose and Ferguson-Pell, 2002) particularly the 80% of Tetraplegic (AIS A-C) subjects discharged without a powered chair, however the subject numbers are were too small to be able perform any analyses. This is evidence of the increasing trend for delays in the state funded provision of powered wheelchairs in the UK (Rose and Ferguson-Pell, 2002) and may have a significant impact on the psychological well-being of the subject concerned due to their need for assistance to mobilise for any distance.

Although the lack of standing equipment at one year post-discharge was not significantly related to increased this may be due to no measurement of frequency of use of the standing frame being taken as to small group size, or different forms of spasm, as suggested in the contradictory research findings that have been elsewhere on this issue (Adams and Hicks, 2005).

No significant relationships were identified between the contextual factor of provision of care or equipment and any of the measures of participation other than vocational activity. The relationship between care and vocational activity will be discussed in the relevant section.

#### **8.2.4 Environmental Contextual Factors: Alternative sources of funding**

As discussed in Chapter 3 there is the potential for payments from either compensation or personal insurance policies to be used to pay for resources which may take longer to be provided through UK state funding (IUA/ABI, 2007). As no investigation of this kind has been performed before in the UK all findings for this issue are novel. Only a small percentage of subjects were in receipt of interim payments prior to discharge. These payments were used to pay for a variety of resources including temporary accommodation or adaptation works to an existing property. In some cases the provision of an interim payment from a compensation claim may not occur for a substantial period of time following discharge or may never occur and therefore there may have been an undefined number of additional subjects who may have been able to benefit from provision of an interim payment.

Additionally small number of subjects were able to access relatively small payments from a personal or employer's insurance policy identify that in addition to easing financial distress during the lengthy hospitalisation occurring following SCI, they potentially may have assisted the individual in purchasing equipment or paying for some adaptations to assist their transition in to the Community. As public sector budgets are being increasingly cut and resources becoming harder to secure the potential for offering SCI individuals another means of accessing funds may yield benefits but further investigation is needed to confirm this.

#### **8.2.5 Sequelae**

This research identified that the majority of subjects identified issues with sequelae at one year post-discharge, however the relationships between these sequelae and the

outcome measures (as well as psychological variables) differed reflecting the differing impact that these issues will have on the SCI individual.

Issues with spasms were consistently and significantly related to Emotional, maladaptive coping styles, and through this psychological distress but not to impaired activities or reduced QOL. Whereas issues with pain, although highly correlated with reports of spasm were not as consistently related to Emotional coping styles but (as has been reported elsewhere (Ataoğlu *et al.*, 2012; Noreau *et al.*, 2010; Raichle *et al.*, 2007; Jensen, Hoffman and Cardenas, 2005; Donnelly and Eng, 2005; Anke, Stenehjelm and Stanghelle, 1995)) did have a more wide ranging affect in that they also impacted upon function, community and social activities, low levels of vocational activity, lower ratings of QOL, and were also associated with higher levels of Avoidance (maladaptive) coping. Additionally although levels of social support were still present and accepted, subjects with high levels of pain were less likely to leave their home to seek out social support (Donnelly and Eng, 2005; Jensen, Hoffman and Cardenas, 2005) and so are passive in this situation.

Bladder management issues were not significantly related to any of the outcome measures or psychological measures. However bowel management issues were significantly related to lower ratings of QOL and greater perceived change in QOL reflecting findings from other research (Krassioukov, Eng and Venables, 2012; Coggrave, Norton and Wilson-Barnett, 2009) as well as a more external locus of control, which suggests impaired ability to elicit social support. This hints at a deep and wide ranging impact of issues with bowel management in addition to those previously reported (Krassioukov, Eng and Venables, 2012; Coggrave, Norton and Wilson-Barnett, 2009; Hitzig *et al.*, 2008). It also suggests that there is not only a need to address why subjects are experiencing these issues but also to ameliorate the psychological and social impact of these issues. However this is a novel finding with a measure that has not been utilised in the SCI population before and therefore needs to be verified in further research.

Issues with frequent skin issues/pressure sores were significantly related to low levels of avoidance coping at both time periods and the presence of significant and persistent skin issues at one year post-discharge. This is contrary to suggestions that individuals with maladaptive psychological styles are at higher risk of developing pressure sores (Regan *et al.*, 2012) and the lack of relationship between Avoidance coping and the level of care received indicates that this is unlikely to be an indication that subjects with higher levels of care have passed on responsibility for their skin management to their

carer, and therefore are not having to avoid what they do not acknowledge. Alternatively the Avoidance coping scale may be measuring something in these subjects other than avoidance in respect of skin issues. The scale's author has been undertaking work on a multidimensional concept of avoidance incorporating general avoidance, emotional avoidance and conflict avoidance (Roger, 2013) and there is a potential that this multi-dimensional aspect of Avoidance coping is what is being demonstrated in this result but subject numbers are too small to be able to investigate this further. This may be an issue that would benefit from further research to identify if facilitating different forms of coping may assist in the prevention of sores.

Additionally, individuals who sustained sores prior to admission demonstrated a clinically significant trend for frequent issues with sores during their first year of community reintegration and this impacted (non-significantly) on levels community. Although this is a novel finding it supports previous research regarding the impact of pressure sores and potential for recurrence (Regan *et al.*, 2012). Pressure sores are widely acknowledged to be avoidable and if sustained in the acute phase, are generally viewed as the result of inappropriate or inadequate care (Regan *et al.*, 2012; Somers, 2010; Grundy and Swain, 2002; Harrison, 2000). The link between pressure sores on admission and frequent issues with skin issues at one year post-discharge highlights the long standing impact for the SCI individual and across a range of hospital and community services of avoidable skin issues sustained in the early stages of SCI.

In summary the issues identified with sequelae highlights the varying forms of impact that these issues may have not only on levels of participation but also the personal contextual factor of psychological well-being.

#### **8.2.6 Outcome Measure: Functional improvement**

Neurological and functional improvement is an outcome that benefits both the individual, through increased abilities and the UK state through reduced requirements. In this research neurological changes were noted over the period of the admission to the SCIC although not to the extent noted in other research (Wolfe, Hsieh and Mehta, 2012). This is likely to be due to the protracted delay in admission for some subjects which will have resulted in them having already had their most significant period of neurological recovery prior to their admission to the SCIC (Wing, 2008; Scivoletto *et al.*, 2006).

Although the expected level of functional improvement was achieved in the majority of cases (Wolfe, Hsieh and Mehta, 2012; Somers, 2010; South of England Spinal Cord Injury Board, 2010; Grundy and Swain, 2002) this was affected factors which could be

temporary, such as limitations due to an orthosis (Young *et al.*, 2006) or long term. Long term issues were either pre-existing medical conditions or the diagnosis of a new condition. Subjects diagnosed with a new condition during admission generally achieved their goals but with a longer LOS. Although subjects with a pre-existing condition did not require a longer LOS they did not achieve all of their rehabilitation goals (DeVivo, 2012; Wolfe *et al.*, 2012; Aito *et al.*, 2007; Cifu *et al.*, 1999). Whether, as suggested elsewhere (Cifu *et al.*, 1999), an adjustment in LOS would have assisted these subjects achieve the expected level of improvement requires further investigation. It is also an issue that is particularly important as the demographics of the SCI population changes to reflect an older newly injured population with a range of pre-existing conditions (DeVivo, 2012; Wyndaele and Wyndaele, 2006) as although a longer LOS may impact upon SCIC resources in the short term it may reap functional benefits for the individual that reduces care or equipment requirements in the long term. There is a need for further research in this area.

### **8.2.7 Healthcare System Outcome Measures: Length of Stay and Discharge Delays**

These outcomes aimed to identify if there was an optimal treatment and rehabilitation pathway for the SCI individual, as well as issues that may arise if this pathway is not achieved. Additionally the reported increase in the SCI incidence of SCI and changing demographics (DeVivo, 2012; Wyndaele and Wyndaele, 2006) suggests that it may be beneficial to have an awareness of the requirements of the SCI individual and pressures on the SCIC service that may affect service delivery. This research aimed to clarify these requirements for a cohort of SCI individuals, define the key milestones in their pathway and identify internal and external pressures on the SCIC services. Many of the results obtained are novel, particularly in the UK, and therefore contribute significantly to our knowledge of the requirements of the SCI individual and SCIC services.

*Injury to Mobilisation Period* Contrary to previous UK based research (Barr and Spinal Injuries Association, 2009; Amin *et al.*, 2005), the majority of delays in admission were due to a delays in referral. Over 50% of subjects not referred to the SCIC for over 10 days post injury, higher proportions than have previously been noted (Barr and Spinal Injuries Association, 2009). The results from this research indicate that this delay does not just result in a delay in the awareness of SCIC staff that the individual has sustained an SCI, or just to a delay in the acute hospital team receiving advice and support in the management of the acute SCI individual (National Specialised Commissioning Group, 2010; Wing, 2008) but also to a significantly increased incidence of avoidable complications, particularly pressure sores.

A further novel finding was that a delay in referral often results additional delays in admission for that SCI patient, compared to one who was referred earlier and with this an increased risk of avoidable complications (NHS England, 2013a; Wing, 2008). This information is particularly important for referring hospitals to know.

A further novel finding was that delays in admission actually resulted in a shorter pre-mobilisation LOS in those admitted without complications or with some forms of complications. This research also identified that different forms of avoidable complications on admission have differing effects on the subject's pre-mobilisation LOS, with the longest pre-mobilisation LOS occurring in those admitted with pressure sores. This underlines the importance of ensuring that the SCI individual is 'rehabilitation ready' when transferred to the SCIC in order to prevent lengthy extensions to LOS. It also underlines the importance of ensuring that if SCI individual has to be cared for in a non-SCIC facility, for whatever length of time, that they are cared for *well* and that the referring hospital seek and receive advice and support from the SCIC team.

*Rehabilitation LOS Period* This research clearly identified the points at which the different phases of admission started and finished in an attempt to give clarity to research investigating LOS. Potential variations in these definitions reported elsewhere (Wolfe, Hsieh and Mehta, 2012) may, at least in part, explain some of the differences identified in the relationships with rehabilitation LOS identified in this research compared to those in other studies (DeVivo, 2012; Wolfe, Hsieh and Mehta, 2012; Aito *et al.*, 2007; Cifu *et al.*, 1999). Variations in the order of LOS (Tooth, McKenna and Geraghty, 2003) for those with AIS D injuries may be due to small numbers in the AIS D paraplegia injury group. That LOS in this research did not vary with age may be due to the use of age as a continuous variable in this study, as well as the potential impact of differing definitions of rehabilitation LOS.

This research identified a highly significant and novel finding that pressure sores sustained prior to admission impact upon the rehabilitation LOS, in addition to the pre-mobilisation, LOS with mean overall LOS for these patients being almost twice as long as for those admitted without sores. This impact was still experienced at one year post-discharge as subjects admitted to the SCIC with pressure sores had a clinically significant trend to have experienced frequent and persistent skin issues during their first year of community reintegration. This clearly highlights that not only will treatment plans and expectations of LOS need to be reviewed accordingly for these SCI individuals but also that pressure sores will have a wide ranging impact on the potential of SCI

individuals in both their rehabilitation and reintegration. The impact of other complications was limited to the pre-mobilisation phase.

A further novel finding was shorter LOS was not related to a delay in discharge. Although this suggests that community teams were able to arrange for the necessary resources to be in place in time for discharge for these subjects, further investigation of this may identify that some individuals, either due to neurological profile or discharge situation were less likely to have a delayed discharge regardless of LOS. The sample size of this group was too small to support this analysis and therefore further research would be of benefit.

*Discharge Delays* Consistent with other research (Barr and Spinal Injuries Association, 2009; Anzai *et al.*, 2006; Forrest and Gombas, 1995) accommodation issues were the most frequent cause of discharge delays, however a novel finding was that issues with funding of care or placements were the cause of significantly more delay days than any other cause of discharge delay. An additional novel finding was that subjects who were discharged to their own property had significantly fewer discharge delay days.

Other issues significantly pre-disposing a subject to discharge delays or lengthier discharge delays were being an A-C tetraplegic, being funded by Social Services and being discharged to a nursing home. As those with AIS A-C tetraplegia are more likely to require funding for a substantial care package or placement these associations are likely to be a reflection of the funding application processes in the UK and therefore reflects funding constraints and issues currently occurring in community NHS and social services rather, than an issue related to the injury group specifically.

The novel finding that approximately 11% of specialist SCIC beds were unavailable for new admissions for the entire period of the research due to discharge delays is of specific concern and has significant implications for the ability of the SCIC service to admit newly injured patients. This results in delays in admission for another SCI individual and the potential increased risk of sustaining avoidable complications (NHS England, 2013a; Wing, 2008).

Neither delays in admission nor discharge had any impact upon outcomes for these subjects at one year post-discharge.

### 8.2.8 Outcome Measure: Vocational Status

Vocational activity has been identified as desired outcome of rehabilitation following SCI since Guttmann (Schultke, 2001) established the first SCIC in the UK. However less than half of the subjects who were in employment at the point of injury were employed on discharge, with rates of vocational activity in the low end of the range reported in European studies (Kennedy *et al.*, 2010a). Although this had increased by one year post-discharge to 50% this is likely to be, in part, due to the exclusion of those who are retired from calculations. As noted elsewhere, those over the age of 45 are less likely to be vocationally active following SCI (Noreau *et al.*, 2010; Krause, 2001) and bearing in mind the trend for an accelerated aging process following SCI, along with the potential for long term issues due to complications (Hitzig *et al.*, 2011; Coll, 2007) potentially there is a need to consider whether employment should be viewed as a desired outcome in SCI individuals who are in their late 40's or older. This impact of aging with an SCI or sustaining an SCI at a greater age need to be acknowledged when vocational activity is being examined and this research aimed to present figures for vocational status in light of this.

Although previous findings that vocational status at the point of injury predicts vocational status post-SCI (Noreau *et al.*, 2010; Schonherr *et al.*, 2004; Fiedler *et al.*, 2002) are supported in this research, a variety of other suggested facilitators of vocational activity were not related to vocational status at one year post-discharge. These non-significant contextual person and environmental factors include the pre-SCI level of education, levels of social support, marital status, whether the individual could drive, injury group and whether the subject was a paraplegic or tetraplegic, in contrast to findings elsewhere (Noreau *et al.*, 2010; Fiedler *et al.*, 2002). Overall, the number of non-significant relationships identified suggests that, as concluded elsewhere (Noreau *et al.*, 2010) a combination of factors are important in facilitating vocational activity rather than one particular variable, although the potential for differing classifications of vocational activity to affect these results must be acknowledged. Additionally there was a clinically significant trend for subjects who were vocationally active at one year post-discharge to report lower levels of pain, in line with findings elsewhere (Noreau *et al.*, 2010; Engel *et al.*, 1998).

The novel finding that if a subject was discharged to a physically enabling environment they were significantly more likely to be vocationally active both on discharge and at one year post-discharge echoes historical findings that a physically restrictive home environment will curtail vocational activities (Oliver *et al.*, 1988) but also highlights that it

is not only necessary to provide suitable accommodation but to provide it at the time that it is required, in other words *on discharge*.

A large number of subjects who were vocationally active at one year post-discharge worked from home, however it is uncertain if this is due to the issues with access to work environments reported elsewhere (Noreau *et al.*, 2010; Schonherr *et al.*, 2004) and so may be demonstrating flexibility on the part of the employer to facilitate return to work. The greater tendency for subjects to be working from home also may explain why, contrary to other research (Noreau *et al.*, 2010) the lack of relationship between being able to drive and being vocationally active. It also highlights the potential for some subjects to have reduced levels of the social interactions and activities in the community that would normally occur as a consequence of going to work. This is a novel finding and although the small subject numbers involved would generally only be of worth as descriptive information it may also indicate that the increased trend for home working to occur in the UK generally may assist those with SCI to gain or retain employment in the future.

Vocational activity was also significantly related to the subject having privately funded care with a non-significant trend for fewer care hours received. The non-significant relationships between vocational status and level of injury/functional ability suggest that the lower levels of care are due to lower levels of physical dependence. The relationship with the source of care funding is more difficult to explain. Potentially it may identify that the greater flexibility associated with care that is purchase and organised directly by the subject is a significant facilitator of vocational activity (Boucher, Ballantyne and Boschen, 2012) however this is an issue that would benefit from further investigation.

In this research those who were vocationally active at one year post-discharge had a more internal locus of Interpersonal control (which itself if related to better psychological outcomes), lower ratings of pain and higher ratings of quality of life (QOL). Additionally, the benefits of return to work have been widely discussed in terms of improved health and reduced risk of mortality (Krause, Saunders and Acuna, 2012) as well as better psychological functioning and perceived QOL (Duggan *et al.*, 2002; Manns and Chad, 2001; Duggan and Dijkers, 2001) and improved social integration (Noreau *et al.*, 2010) and so it is a concern that very few subjects appeared to receive support from a Department of Employment adviser to assist in investigating options for vocational activity. This low emphasis on vocational support and rehabilitation post-discharge is surprising when evidence links this support with higher rates of vocational activity (Noreau *et al.*, 2010; Schonherr *et al.*, 2004) and is recommended in Dept of Health

Guidance (Great Britain. Department of Health Long Term Conditions NSF Team., 2005, QR 6.).

In summary the results of this research indicate that the outcome measure of vocational activity was not achieved by a significant proportion of subjects. Although a range of personal and environmental contextual factors may impact upon the ability to achieve this outcome none independently significantly increased the chance of this outcome being achieved with the exception of pre-SCI employment status and being discharged to an accessible environment. Therefore as suggested in the ICF (World Health Organisation, 2013) these relationships highlight the dynamic and multi-dimensional interaction of disability, and a range of contextual factors but overwhelmingly the home environment itself in promoting participation, in the form of vocational activity,

### **8.2.9 Outcome Measure: Accommodation**

Over 78% of subjects in this research were able to be discharged to the community, in line with other UK based findings (Barr and Spinal Injuries Association, 2009; Aspire, 2009), however, only 36.5% were able to return to their previous home. Delays in the provision of adaptations or accommodation lead to a notable proportion of subjects remaining in hospital longer than they required (Barr and Spinal Injuries Association, 2009; Post *et al.*, 1997; Forrest and Gombas, 1995) or being discharged to an environment that did not meet their needs and so, ultimately, may impact upon their ability to reintegrate into their community.

This research confirmed subjects with a high level tetraplegia were significantly more likely to be discharged to a nursing home (Anzai *et al.*, 2006; DeVivo, 1999). Although this relationship was not significant at one year post-discharge, all subjects still in a nursing home at this point were high level tetraplegics (Duggan *et al.*, 2002; van Asbeck, Raadsen and van de Loo, 1994; Boschen, 1988; Oliver *et al.*, 1988).

Adaptations to the home were outstanding on discharge for over 38% of subjects, mainly awaiting public funds to assist with costs. Issues with delays in adaptations were still highlighted at one year post-discharge. However it appears that some subjects who were discharged to an accessible property perceived that they required adaptations at one year post-discharge. This suggests that not only may some subjects have experienced issues with inadequate or poorly done adaptations, as have been reported elsewhere (Heywood, 2004) but also potentially that as an SCI individual lives in an environment they become aware of the restrictions placed on them by that environment

in a way that the able-bodied assessors of that environment cannot (Heywood, 2004; World Health Organisation, 2002; Manns and Chad, 2001).

Although delays in the provision of adaptations or accommodation are suggested to lead to many who could be independent in the community being limited by their environment (Heywood, 2004; Oliver *et al.*, 1988) and so, ultimately, unable to participate and reintegrate into their community (World Health Organisation, 2002), none of the relationships between accommodation and community participation were significant at one year post-discharge. As some subjects may have been provided with their accommodation or adaptations later than others, potentially not long before the completion of the one year post-discharge survey this may have impacted upon their levels of community participation and affected the ability of this research to identify significant trends. However, clinically significant positive trends were identified for more frequent social or general outings in the community in those subjects who were discharged to a physically enabling environment.

#### **8.2.10 Outcome Measure: Participation, Social and Community Activity**

Despite consistent ratings that community activities, from going grocery shopping to having a social outing were highly important, over 48% of subjects reported that they only left their home weekly or less often, with approximately 32% stating that they only had a social outing monthly or did not have one at all. These low levels of community activity, of participation, and difficulties with access are of particular concern but these are not novel findings (Smith and Spinal Injuries Association., 1999). Also, although many subjects considered visits from friends and family to be highly important (and despite over 39% living alone), low levels of visits in the home from family and friends were noted. Additionally many of the subjects who were vocationally active at one year post-discharge worked from home and therefore will have reduced community activities compared to those who worked in their employer's premises. Combined these findings suggest that many subjects were at risk of social isolation at one year post-discharge in line with other UK based findings (Smith and Spinal Injuries Association., 1999). Social isolation is suggested to affect the psychological and physical well-being of individuals (Marmot, 2010). However other forms of social contact were possible such as online chat-rooms, video links via the internet that were not identified in this survey and may have assisted to reduce any perceptions of isolation. Further research investigating these issues would be of benefit.

A further novel finding in this research was that although car ownership and the ability to access public transport resulted in higher levels of community activity, the ability to drive

did not. Additionally a non-significant and novel trend was identified for higher levels of community outings and social outings in those who were discharged to a physically enabling environment, further underlining the importance of accessible accommodation being provided at the time required. This suggests that the environment in the form of accommodation, but particularly the contextual environmental factor of delays in provision of suitable accommodation/adaptations (World Health Organisation, 2013) impact on the subject's participation in the community as well as significantly impacting upon their vocational status.

Although a near significant relationship was identified between the frequency of community activity and current QOL this was not as strong as reported elsewhere (Kennedy *et al.*, 2010b; Mortenson, Noreau and Miller, 2010). However this is only one form of community activity and as previously discussed vocational activity was related to higher ratings of QOL. Potentially a range of activities need to be undertaken to influence QOL, therefore measuring just one is inadequate.

More regular visits from friends was significantly related to a more optimal psychological profile in the form of an internal perception of locus on Interpersonal control and a greater use of Rational coping style and a higher rating of current QOL. If, as suggested by Müller *et al.* (Müller *et al.*, 2012), social skills are important in eliciting social support this result would suggest that individuals with a more internal locus of Interpersonal control are not only more likely to elicit and receive social support but they will also have a more adaptive psychological profile, exhibit less symptoms of psychological distress and have a better QOL. That the opposite occurs with less frequent than weekly visits from friends suggests that those who are potentially socially isolated are experiencing some psychological impact in line with other research findings (Müller *et al.*, 2012; Mortenson, Noreau and Miller, 2010; Chevalier, Kennedy and Sherlock, 2009; Stougaard Nielsen, 2003) and that potentially the absence of social contact is as important as the presence of it.

However the direction of causality in the relationship is not clear, as the psychological profile of the individual may be promoting the level of social contact or the *perception* of the level of social contact as much as the level of social contact is promoting the psychological profile. That lack of relationship with the frequency of family visits is surprising but may be an undetected influence of those subjects who were living with family members at one year post-discharge. However these were superficial measures of social contact and support and when findings elsewhere are also considered (Müller *et al.*, 2012; Kennedy *et al.*, 2010b; Mortenson, Noreau and Miller, 2010; Chevalier,

Kennedy and Sherlock, 2009; Raichle *et al.*, 2007; Stougaard Nielsen, 2003; McColl and Skinner, 1995; Schulz and Decker, 1985), the need for more detailed investigation is highlighted.

The impact of pain and sores on community participation have already been discussed but should be acknowledged as combined with the findings above they also indicate that participation in the community and society for SCI individuals is influenced by a range of health, disability and environmental and personal contextual factors. However two factors are consistently highlighted as important, these are environmental issues in the form of early provision of accessible accommodation and an internal locus of interpersonal control. These factors permit engagement in the community and inclusion of the SCI individual in a social group in which they are able to elicit support.

### **8.2.11 Outcome Measure: Readmissions**

Although over 40% of subjects were readmitted in their first year of community reintegration for a variety of issues, without information clarifying if the readmission was planned, unavoidable or avoidable, the data on the number of readmissions is of only superficial value. Likewise information on the number of readmission bed days during the first year of community reintegration is only an estimate due to some patients having multiple admissions but information only being collected on the longest LOS. However, it is notable that over 15% of readmissions were due to skin issues which are, generally, avoidable complications. It is also worth noting that the number of readmission days per subject (4.6 days) noted in this research, approximate those reported in another UK based research (Savic *et al.*, 2000).

## **8.3. Appraisal of the Research Study**

### **8.3.1 Strengths**

Although subject numbers were significantly smaller than was planned for, the depth of data collected has allowed new information to be obtained regarding many issues prior to, during and post admission. Through this it has been possible to identify relationships that previously had not been explored or revealed and in many cases this has resulted in novel findings.

These novel findings are:

- Delays in referral resulted in longer periods to admission in many cases.
- Delays in admission did not significantly impact upon a range of outcomes on discharge or at one year post-discharge.

- Those who are admitted with pressure sores will have a prolonged rehabilitation LOS, in addition to a longer pre-mobilisation LOS.
- Subjects who experienced a delay in admission but did not have avoidable complications on admission had a shorter pre-mobilisation LOS.
- Individuals who are admitted with pressure sores are more likely to experience frequent skin issues during their first year of community reintegration and this will have some impact on their participation in community activities at one year post-discharge.
- Injury group is significantly related to discharge destination, level of care provided and the cost of care (novel findings in the UK).
- The provision of interim payments from a compensation claim may speed up provision of required resources and facilitate individuals being discharged to accessible property.
- Delays in discharge did not significantly impact upon a range of outcomes at one year post-discharge.
- Paraplegic SCI individuals are more likely to have a delay to discharge due to accommodation issues. Tetraplegic SCI individual are more likely to experience a delay to discharge due to funding issues and their discharge delay will be longer than for other injury groups.
- The majority of subjects did not have contact with a Department of Employment Adviser on discharge or at one year post-discharge, despite low levels of employment on discharge.
- Individuals who are discharged to a physically enabling environment are more likely to be vocationally active on discharge and at one year post-discharge.
- Individuals who are discharged to a physically enabling environment will have more regular outings to the community for both social and general reasons at one year post-discharge.
- SCI individuals who are vocationally active at one year post-discharge have higher ratings of QOL and employ greater levels of adaptive (Rational) coping styles.
- The perception of an internal locus of Interpersonal control appears to be an important facilitator of psychological well-being and is linked to greater levels of social contact.
- The frequency with which an individual leaves their home at one year post-discharge is significantly related to their ability to access public transport or if they own a vehicle but not to their ability to drive.

In addition to the novel findings and depth of data considered in this research a further strength is that there were clear and replicable definitions of many of the significant milestones considered. For example, a clear definition of when rehabilitation was deemed to have commenced. These definitions will permit any further research in these areas to be able to make clear comparisons of outcomes.

The range of data collected over the period of this research, whilst presenting difficulties for the researcher in terms of sheer number of analyses performed, has permitted a great deal of detail and insight to be obtained on outcomes and influencing factors following discharge. Additionally avoiding focusing on just one area of interest has permitted relationships to be identified that may not have been identified otherwise, such as the subjects who were delayed in their referral were more likely to have pressure sores on admission and to experience frequent issues with sores during their first year of community reintegration. That data was collected on a longitudinal basis and has also permitted clearer identification of the impact of some contextual factors.

As this research was performed at one site, it was possible to control for potential confounding variables. These confounding variables may take the form of differing treatment and management regimes, differing admission and discharge and LOS pathways and variations in the way in which rehabilitation was provided. Remaining as a single site study permitted far more between subject comparisons than could have been facilitated otherwise.

### **8.3.2 Weaknesses or Limitations**

In addition to the strength of this research there are some weaknesses and limitations which, in some cases, may have influenced statistical outcomes and in others have resulted in difficulties when drawing comparisons with other identified research findings. The identified weaknesses in this research are:

#### *Subject issues*

Small subject numbers This has limited the ability to perform some analyses and to establish significant differences and interactions in others. Where possible, strategies have been taken to reduce the impact of small subject numbers by combining categories of subjects but on occasion this resulted in highly uneven group sizes. Unfortunately, many of the analyses investigating outcomes following delays in provision were unable to be performed due to these small subject numbers.

The three years over which the inpatient phase was conducted had a smaller than anticipated number of admissions and contained a larger proportion of 'excluded' patients than was expected. Although a potential solution would have been to have recruited subjects over a longer period of time than the three years of this research, 2010, the year in which data collection for the inpatient phase ceased, was the year in which a new government was elected. A strong point of this research is that it was conducted during one government term and so was less susceptible to political changes in service provision. Additionally, the research ended when impacts of the 'austerity measures' implemented by the previous government were only beginning to manifest in community service structures and provision.

Potentially, if the research protocol had been adjusted to reflect the changes in outpatient follow-up procedure, a larger sample of patients contributing data in the second phase of the research may have been achieved but it is unclear if this would have contributed enough additional subjects to affect the results. However, in hindsight, and considering some subjects did not send back their questionnaires until 15-16 months post discharge, perhaps a 6 month shift in the protocol would not have influenced results detrimentally.

Missing data This was mainly an issue in the one year post-discharge phase of the research and some of this missing data may have been obtained if a copy of the questionnaire had been returned to the subject to request completion. This was not considered during the period of the research and the potential for benefit from this can only be evaluated in retrospect.

Change in Injury Group Proportions There was a high percentage of subjects with AIS D grade SCI particularly at one year post-discharge (37.5%), although this does not appear to have skewed results toward greatly improved outcomes. However, the proportional increase of AIS D grad SCI in the group of 48 subjects who contributed data at one year post-discharge was the same as in the larger group of 74 subjects at discharge. An increasing number of incomplete tetraplegics are being noted as age at the time of injury is increasing (DeVivo, 2012; Couris *et al.*, 2010; van den Berg *et al.*, 2010; O'Connor and Murray, 2006; Wyndaele and Wyndaele, 2006; McKinley, Seel and Hardman, 1999; Schonherr *et al.*, 1996), the median age of those contributing data at one year post-discharge was significantly higher than those who did not contribute data, and more than 72% of those with AIS D injuries were tetraplegic. Therefore, although the proportion of subjects with an AIS D grades SCI may appear large, it is likely to be

reflecting the changing age and injury demographic of the newly injured SCI population generally and particularly in the group contributing data at one year post-discharge.

Effect of Complications on Admission - 30% of subjects contributing psychological data at one year post-discharge were admitted with complications (16% due to skin issues). As only 27% of subjects were admitted with complications in the larger group of subjects, this is worth noting. Potentially factors around increased length of acute stay, prolonged periods of bed rest or the impact of the complication experienced may have influenced the results of psychological measures for these subjects.

#### *Measurement Issues*

Time of Measurement - As the first year of community reintegration will be a time of flux as provisions of outstanding equipment and adaptations are made and the subject attempts to re-establish themselves in the community and their society, this may have been too early a point to measure reintegration outcomes. There is the potential that some subjects will have only recently returned to work or been able to move in to their home, whereas others will have achieved these goals 11 months earlier. This issue could result in a variation in outcomes and may have influenced the potential for differences to be visible between groups.

Vocational Status Categories - The inclusion students, voluntary workers and full-time care-givers in to the vocational active category may present difficulties when drawing comparisons between other studies which only consider paid employment. However, non-paid vocational activities have been suggested to be as psychologically beneficial as paid employment (Duggan *et al.*, 2002; Duggan and Dijkers, 2001) and therefore this was felt to be an important inclusion. Additionally, if an SCI individual needs to retrain following SCI this should be considered as a vocational activity. Also, if an individual was a full-time care-giver prior to sustaining their SCI, then their returning to this role is an indication of rehabilitation success (Noreau *et al.*, 2010). Due to small subject numbers it was not possible to perform analyses with these sub-groups but information on them is included in Appendix K.

Age Cut-off - The creation of a cut-off point at 47 years, above which an individual would not be expected to actively pursue employment, reflected employment trends reported in other research (Noreau *et al.*, 2010; Krause, 2001) but may have restricted the ability to compare results from this study with other research. However, a significant amount of research does not discuss the age of the subject when classifying them as retired and if this category was applied by the subject or the researcher (Noreau *et al.*, 2010).

Frequently individuals aged over 65 have been included in simple categories of 'employed' or 'unemployed' in other studies which may also have skewed results. This is particularly important when comparing studies from different countries in which conventions regarding retirement age will vary. Therefore, issues with the comparison of results from other studies is an issue that is unlikely to be limited to just this research.

Misinterpretation of Questions - Some subjects misinterpreted the question 'Are adaptations to your home still outstanding?' as asking if they as individuals felt that adaptations to their home were required. The question was intended to query if all adaptations assessed as required had been performed. It is not possible to establish how many subjects misinterpreted this question in this or other ways and so the validity of this specific data item is questionable. Obviously this has an impact on the relevance and validity of the results regarding the impact of ongoing delays in provision of adaptations at one year post-discharge, therefore only simple analyses were performed with this data and caution used their interpretation. However, this finding does highlight the need to explore the satisfaction of the SCI individual with their home environment as well as to involve them in discussions regarding works to their home as reported elsewhere (Manns and Chad, 2001; Post *et al.*, 1997; Siosteen *et al.*, 1990). As the subject's perception and experience of their ability to access the inside and outside of their home is an important determiner of residential satisfaction (Boucher, Ballantyne and Boschen, 2012; Manns and Chad, 2001; Boschen, 1996), perhaps more appropriate questions would have investigated the subject's perception of access within their home, for example: 'Can you access all areas of your home that you need to?' or 'Have adaptations been performed to the level you feel are required?'

Participation and social activity were only measured in terms of physical presence. During the time of the development and running of this research technological advances resulted in an increasing ability for individuals to communicate with each other via web cams and chat rooms. Arguably, this may have meant that even subjects who rarely left their homes, or rarely had visitors, may still have had regular social contact with friends or family. Potentially, future research investigating social connectedness and the potential for social isolation will, in future, need to attend to alternative forms of contact in their analyses.

#### *Additional Information Required*

Although a wide range of information was collected from subjects during this research project, analyses of the results has identified that there are some pieces of information

which, if they had been collected, may have given greater clarity to findings or permitted meaningful analyses.

Reasons for vocational inactivity - Simply asking individuals to state what they felt was the main reason or reasons for why they were or were not vocationally active may potentially have identified common issues or facilitators of vocational activity.

Reason why the subject works from home - Although subjects were asked if they worked from home they were not asked why they work from home or if they do this for all or only part of their working week. In some cases the subject may have always worked from home. In other cases, it may be that their employer has made adjustments to allow them to work from home for all or part of the week as a means of facilitating their return to work due to poor access in the work environment. Having this information would permit a clearer picture of factors which may facilitate vocational activity.

When outstanding resources were provided - Differences in the timing of provision of outstanding resources may have impacted on the outcomes measured but cannot be controlled for in analyses if the information is not available. For example, an individual who was only provided with an accessible property at 11 months post-discharge will have experienced different barriers to participation than those who were discharged to an accessible property. The high number of non-significant relationships between the identified outcome measures and the contextual factor of resources provision may be a reflection of this issue. Further investigation in to the timing of provision of resources such as accommodation, adaptations and equipment would potentially be of benefit.

Pre-Discharge Community Participation - Information was not obtained on the actual number of independent outings and overnight stays performed by the subject prior to their discharge. Regular overnight leave prior to discharge will have provided more opportunities to practice skills acquired during rehabilitation and troubleshoot problems prior to discharge. This could have been a measure of the subject's 'discharge preparedness' and may have impacted on their outcomes pre- and post discharge. Those who have had regular day outings with friends and family will have also been able to do this to a lesser degree. This could potentially have had an impact on the speed and success of their reintegration post discharge.

Reasons for Readmissions and LOS - No distinction was made in this research between subjects having a planned or unplanned admission. Readmissions in the first year of community reintegration may occur for a variety of reasons (Wolfe, Hsieh and Mehta, 2012) and without specific information; the data on the number of readmissions is only

of superficial value. Similarly, the information on the number of readmission bed days is only an estimate due to only having information on the longest LOS. For these reasons, this information was only used in limited analyses. Future research should ensure these issues are corrected.

### **8.3.3 Implications for clinical services.**

Many findings have been identified in this research with implications for SCIC, acute or community services. A few have implications for all services. These implications will be discussed in relation to the service they impact upon.

#### *SCIC Services*

The changes in neurology and additional conditions identified over the period of admission confirms suggestions elsewhere (Wolfe, Hsieh and Mehta, 2012) that attention needs to be paid to these issues over the course of rehabilitation with the proposed LOS and treatment plan reviewed accordingly. In addition to this, the incidence of newly diagnosed conditions occurring during admission to the SCIC indicates a need for treating teams to be prepared to adjust treatment plans and LOS accordingly. Additionally, although increased LOS is not associated with pre-existing medical conditions but impaired goal achievement is, it may be that with a prolonged LOS the improved goal achievement noted elsewhere may be achieved (Cifu *et al.*, 1999).

It is unclear from this research if vocational activity promotes better psychological profiles, less pain and higher ratings of quality of life or if low levels of pain, a greater perceived QOL and a more internal locus of Interpersonal control facilitates vocational activity. However, the variable of locus of Interpersonal control is suggested to predict and facilitate better outcomes across a range of measures of participation, psychological variables and perceptions. Therefore, it may be that the perceived locus of Interpersonal control is a psychological variable which is worthy of further investigation and that efforts could be put in to promoting this in SCI individuals during rehabilitation.

The potential levels of isolation noted in this research coupled with the low levels of community activity suggest that a greater focus needs to be placed in rehabilitation on promoting community access and activities. This research identified that although car ownership and the ability to access public transport resulted in higher levels of community activity (and from this a higher rating of QOL), the ability to drive did not. This suggests that during rehabilitation there is a need to emphasise ability to access public

transport (where feasible) as much as driving or car ownership as a means of accessing the community.

The improved outcomes reported here in those who are provided with suitable accommodation on discharge highlights the need to ensure that this provision is made wherever possible and if alternative sources of provision are available, that these are pursued where state provision is lacking. The potential for other insurance policy payments, however small, should also not be ignored as not only a means of easing financial distress but also potentially assisting the individual in their transition in to the Community.

#### *Acute Services*

As identified in this research, delays in referral to an SCIC lead to longer periods to admission following this. There is no research to compare this finding to and therefore it is not possible to confirm that this reflects findings elsewhere or whether this is purely a reflection of the admission processes in this SCIC. However, referring institutions would do well to attend to this as it suggests that an initial delay in referral on their part has significant implications for their ability to transfer an SCI patient onwards.

That these delays in referral were also associated with the occurrence of avoidable complications is a concern. This highlights the importance of early liaison between the acute hospital and the SCIC team and for appropriate management to be implemented from an early stage (NHS England, 2013a; South of England Spinal Cord Injury Board, 2010) to ensure that avoidable complications do not occur. This is a highly significant finding, that delays in implementation of appropriate management early in the patient pathway can have long standing and costly effects.

#### *Community Services*

The finding that higher levels of community participation and vocational activity at one year post-discharge (and the resulting higher ratings of QOL) were associated with the provision of suitable accommodation on discharge and suggests that protracted processes and delays in provision of adaptations or accommodation to SCI individuals do result in poor outcomes. If we wish improved outcomes to occur and SCI individuals to potentially have a greater level of financial independence, as may be expected if they are working, then resources and assistance needs to be given to facilitate SCI individuals being discharged to suitable accommodation.

Additionally, a greater emphasis needs to be placed on supporting SCI individuals to explore options for vocational activity prior to and on discharge. This will require an increased level of support to be made available by the Department of Employment.

#### *All Services*

The impact of avoidable sores sustained prior to admission will not just be experienced at the SCIC it can also be experienced at the acute hospital in which another SCI individual is staying whilst awaiting an SCIC bed. The acute hospital will need to effectively treat these SCI individuals until a bed is available at the SCIC (which may be occupied by another SCI individual who was admitted with pressure sores), for however long or short that time is. The fact that those admitted with avoidable pressure sores will, on average have an 8.5 times longer pre-mobilisation LOS once admitted to the SCIC. An average of 26.9 days over the target LOS and an average 1.9 times overall LOS suggests that the issue of avoidable pressure sores on admission with or without delays in referral is an issue that will not only impact upon that SCI individual or the SCIC service but also on the services who are attempting to have their patients admitted to the SCIC. In addition to this, there is the increased likelihood that those who are admitted with sores will experience persistent skin issues when in the community. This will not only impact on the SCI individual's ability to reintegrate in to the community but also on their requirement for provision of community services and potentially readmission (Regan *et al.*, 2012).

There is also a significant chance that the transfer of the SCI individual at an acute hospital will be delayed due to the 11% of SCIC beds occupied by SCI individuals experiencing either a delayed discharge or their being treated for the occurrence and potential recurrence of pressure sores. Whilst community services are facing increased demands on their increasingly restricted budgets (Lungu-Mulenga *et al.*, 2013; Samuel, 2011; Samuel, 2009; Brangwyn, 2007), the NHS is currently facing significant acute hospital bed shortages. The potential then for delays in any part of the SCI individual's pathway to be prevented and through this the throughput of patients in SCIC beds to be maximised will be of benefit to both the SCIC and acute hospital services as well as an obvious benefit to the SCI individual on that pathway.

Much of the above suggests that prolonged LOS in an SCIC may be a regular occurrence for SCI individuals either due to pre-existing conditions, new conditions, avoidable complications or delays to discharge. If these findings are correct and further changes to the demographics of newly injured SCI individuals are occurring as being noted (DeVivo, 2012), then an increase in provision of SCIC services, and with this

increased funding levels, are likely to be required. This may be the case in some situations but the novel findings that those who arrive in the SCIC fit and able to commence rehabilitation have shorter LOS suggests that there is a need to ensure that as many individuals as possible are able to do this.

#### **8.3.4 Recommendations for further research**

Many novel findings were identified in this research and they are all worthy of more research which will hopefully be investigated further. There are also additional issues that require investigation, as well as standards for research which may assist with future cross study comparisons.

Although the definitions and benchmarks utilised in this research may not be universally adopted, difficulties were experienced in comparisons with other research findings due to lack of definitions of benchmarks or categories. An example of this is a lack of clarity on the point at which the SCI individual is deemed able to commence rehabilitation or of what constitutes vocational activity. Consistency and clarity of measurement is required across research studies to permit cross study comparisons and development of a solid knowledge base in SCI research and management. Some of this will come about through the use of the International Spinal Cord Injury Core Data Set (Cripps *et al.*, 2011; DeVivo *et al.*, 2006) and expanded data sets but this will not address all areas of SCI research. Therefore individual researchers will need to identify in their areas of research where a lack of clarity in definitions and measurement are present and try to build this clarity in to their research.

There is little research into the role of the perception of locus of control (LOC) and appraisal of control following SCI and much research that is available has tended to focus on health related LOC. This research has identified that perception of locus of control; particularly the locus of Interpersonal control is related to and potentially facilitates better psychological outcomes including higher ratings of QOL and this would merit further investigation. Additionally, that the differing dimensions of locus of control were impacted by or impacted upon by different factors both internal and external to the individual suggests that a multi-dimensional measure of locus of control is a useful tool for identifying potential issues which may influence the ability of the SCI individual to physically, socially and psychologically function at their optimal level.

Although the link between emotional coping (and the associated psychological distress) and perceptions of pain have previously been investigated it may be beneficial for research to focus at the opposite end of the Detached and Emotional coping continuum

to establish if optimal outcomes can be achieved in relation to the management of the impact and perception of pain.

Although the range and depth of data available has been useful when drawing conclusions on how a variety of apparently disparate factors may relate to each other; it has also become abundantly clear that it is necessary to concentrate on smaller focussed studies utilising large numbers of subjects if significant and meaningful results are to be obtained. Perhaps with clear definitions of variables and rehabilitation pathways and structures, the multi-site studies necessary to ensure large subject group numbers could be performed.

A notable finding in this research was that those who were privately funding care had reduced their care input over the first year of community reintegration, tended to have friends or family caring for them but were significantly more likely to be vocationally active. Whether this is simply a reflection of those who are working, privately funding care or privately funded care facilitating vocational activity would bear further investigation. The potential impact of the care giver role on the family and friends of the SCI individual as well as the potential impact on the SCI individual themselves would also bear further investigation.

This research identified that provision of suitable accommodation on discharge resulted in better outcomes (vocational activity and community participation) not only on discharge but also at one year post-discharge. Further research should seek to build on this and also investigate if other participation outcomes are improved for individuals discharged to a physically enabling environment. Although better outcomes were related to the provision of suitable accommodation improved outcomes with the provision of equipment on discharge were unable to be detected this may be due to small subject numbers and further investigation of this is required.

The question of which issues facilitate or hinder SCI individuals in vocational activity has been researched extensively; however, there is little consistency in the measures taken or definitions used in this area of research. This includes clarity regarding the age at which an individual can be considered to be retired. This is particularly important when investigating vocational outcomes in the initial years post injury as the SCI individual may need to retrain and pursue a new career, in other words to consider if it is realistic to expect the individual to undergo retraining when they may be close to retirement.

#### 8.4 Summary & Conclusions

A significant number of findings have been identified in this research. Some support previous research, whilst others present alternatives. Some have no equivalent research to assist in drawing conclusions. Although, as has been noted there are some issues with this study in terms of some of the measures used and small subject numbers limiting some of the analyses that could be performed; this is a novel research project with many novel findings. Some of the findings contribute significantly to our knowledge in the field of rehabilitation and reintegration following SCI and have significant implications for clinical and community services if the ability of the SCI individual to achieve their optimal outcomes are not to be curtailed or limited.

Delays in referral and admission occurred to the majority of subjects with an associated high risk of complications which then significantly impacted upon the whole length of stay of the individual and outcomes following discharge. However, those who were admitted without complications generally progressed through the rehabilitation in the expected length of time or less. These findings have significant implications for SCIC and acute hospital services and suggest a need for acute services to commence liaison with SCIC services at an early stage.

Unfortunately, due to small subject numbers, the proposed investigation of whether delays in provision of resources influenced outcomes was not able to be fully investigated. Significant numbers of delays to discharge were noted to occur due to delays in provision of resources which had a significant impact on the SCIC service. Therefore, the overall null hypothesis for this research of '*Timely provision of accommodation, care and equipment does not make a difference to the speed of discharge once rehabilitation is completed, or on reintegration outcomes once discharged.*' has only been partially disproved by these findings as discharge was delayed due to the provision of both accommodation and care. The short-term impact on the SCI individual in terms of delays in being able to participate in the community and their society is a given, however, the long term impacts of these delays were unable to be detected.

Delays to discharge due to accommodation tended to occur for paraplegics and were comparatively short; however, a large proportion of discharge delay days occurred to tetraplegics who were awaiting funding of a care package or placement. That 11% of the SCIC beds were essentially closed to admissions over the period of this research due to delays in discharge will have lead to a significant proportion of newly injured SCI individuals remaining in acute hospitals for difficulties for a significant period of time.

When viewed in combination with the prolonged lengths of overall stay in the 18.9% of subjects who were admitted with pressure sores this indicates that ability of the SCIC services to meet the needs to the newly injured SCI population is being detrimentally affected by external issues that impact throughout the service pathway. These external issues present as delays due to some 'receiving' organisations (such as Social Services and the NHS) becoming involved in protracted discussions regarding responsibility for funding and the level of funding provision. These are in addition to issues with some referring institutions delaying the referral and liaison with specialist SCIC team which may then result in the SCI individual developing a complication which will prolong their eventual admission in the SCIC.

Community participation is a goal that has eluded many of the subjects in this research as, although community activity was facilitated by accessible accommodation being provided on discharge and the subject owning a car or being able to access public transport, a high proportion left their home infrequently and reported many difficulties with access. A high number of subjects also reported that they had infrequent visits at home from friends or family, suggesting a high risk of social isolation in these individuals.

Although the majority of subjects were able to be discharged to the community, many experienced issues due to a lack of access in the home and delays in performing adaptations due to funding issues. Many subjects reported that they were still awaiting adaptations at one year post-discharge or had other issues with accommodation. Notably those who were discharged to accessible accommodation had higher levels of community and vocational activity at one year post-discharge, emphasising the importance of this provision being made at the time that it is required.

The identified outcome measure of vocational activity (of all forms) was achieved for 55% of those who were classed as being of working age, with many of these subjects working from home. Those who were vocationally active reported higher levels of QOL and lower reports of pain. They had been vocationally active at the time of injury and tended to be privately funding their care. A low level of Employment Services support in investigating vocational activities was noted on discharge and at one year post-discharge which may have also had an impact on vocational outcomes.

Similarly, QOL of life at one year post-discharge is rated as significantly lower than pre-SCI however, some factors were found to facilitate a better QOL such as vocational and community activity, low levels of pain and regular visits from friends. The psychological

variables of an internal locus of interpersonal control and a greater use of both Detached and Rational (adaptive) coping styles were also related to higher ratings in QOL and appear to be important facilitators of improved psychological outcomes. However, as noted above, many subjects reported infrequent community activities, infrequent visits, were vocationally inactive and reported low levels of QOL.

In the 1940's Guttman (Guttman, 1979) proposed that individuals with SCI would, on completion of their rehabilitation, be able to return to their community, be fully able to participate in society, be vocationally active and lead fulfilling and enriching lives. It appears that some subjects in this study are falling short of these targets. However, this research has identified that some subjects have been able to achieve at least some of these outcomes. However the differences between the varying levels of achievement appear to be at least partially contributed to by contextual factors of delays in provision of some resources, particularly accessible accommodation, and potentially some personal contextual factors. However, the number of non-significant relationships suggests that it may be that a combination of many factors influences outcomes following reintegration, rather than individual factors as indicated in the ICF Model of Disability (World Health Organisation, 2013). Further research of these issues and the patient pathway through UK based services is required. Several novel findings have been identified in this research, many of which are worthy of further investigation.

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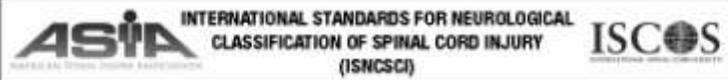
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## **Appendices**

# Appendix A: ISNCSCI Documents

Fig 1: The ASIA/ISCSO Spinal Cord Injury Classification



**INTERNATIONAL STANDARDS FOR NEUROLOGICAL CLASSIFICATION OF SPINAL CORD INJURY (ISNCSCI)**

Patient Name: \_\_\_\_\_ Date/Time of Exam: \_\_\_\_\_

Examiner Name: \_\_\_\_\_ Signature: \_\_\_\_\_

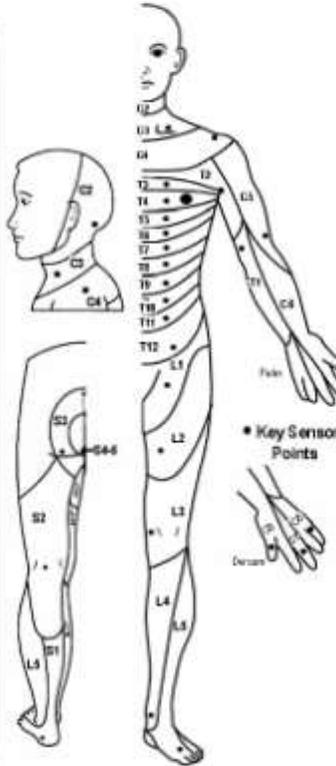
  

**RIGHT**

	MOTOR KEY MUSCLES		SENSORY KEY SENSORY POINTS	
	Light Touch (LT)	Pin Prick (PP)	Light Touch (LT)	Pin Prick (PP)
C2				
C3				
C4				
C5	Elbow flexors			
C6	Wrist extensors			
C7	Elbow extensors			
C8	Finger flexors			
T1	Finger abductors (5th finger)			
T2				
T3				
T4				
T5				
T6				
T7				
T8				
T9				
T10				
T11				
T12				
L1				
L2	Hip flexors			
L3	Knee extensors			
L4	Ankle dorsiflexors			
L5	Long toe extensors			
S1	Ankle plantar flexors			
S2				
S3				
S4-5				
<b>RIGHT TOTALS (MAXIMUM)</b>				

(UER) Upper Extremity Right (LER) Lower Extremity Right

(VAC) Voluntary anal contraction (Yes/No)



• Key Sensory Points

**LEFT**

	SENSORY KEY SENSORY POINTS		MOTOR KEY MUSCLES	
	Light Touch (LT)	Pin Prick (PP)	Light Touch (LT)	Pin Prick (PP)
C2				
C3				
C4				
C5			Elbow flexors	
C6			Wrist extensors	
C7			Elbow extensors	
C8			Finger flexors	
T1			Finger abductors (5th finger)	
T2				
T3				
T4				
T5				
T6				
T7				
T8				
T9				
T10				
T11				
T12				
L1				
L2			Hip flexors	
L3			Knee extensors	
L4			Ankle dorsiflexors	
L5			Long toe extensors	
S1			Ankle plantar flexors	
S2				
S3				
S4-5				
<b>LEFT TOTALS (MAXIMUM)</b>				

(UEL) Upper Extremity Left (LEL) Lower Extremity Left

(DAP) Deep anal pressure (Yes/No)

**MOTOR SUBSCORES**

UER  + UEL  = UEMS TOTAL  (MAX (25) (25) (50))

LER  + LEL  = LEMS TOTAL  (MAX (25) (25) (50))

**SENSORY SUBSCORES**

RLT  + LLT  = LT TOTAL  (MAX (56) (56) (112))

RPP  + LPP  = PP TOTAL  (MAX (56) (56) (112))

**NEUROLOGICAL LEVELS** (Steps 1-5 for classification as of reverse)

1. SENSORY	R <input type="text"/>	L <input type="text"/>
2. MOTOR	R <input type="text"/>	L <input type="text"/>

3. NEUROLOGICAL LEVEL OF INJURY (NL)

4. COMPLETE OR INCOMPLETE?  (Incomplete = Any sensory or motor function in S4-5)

5. ASIA IMPAIRMENT SCALE (AIS)

(R = complete lesion only) **ZONE OF PARTIAL PRESERVATION** (Must occur first with any impairment)

SENSORY	R <input type="text"/>	L <input type="text"/>
MOTOR	R <input type="text"/>	L <input type="text"/>

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## Muscle Function Grading

- 0** = total paralysis
- 1** = palpable or visible contraction
- 2** = active movement, full range of motion (ROM) with gravity eliminated
- 3** = active movement, full ROM against gravity
- 4** = active movement, full ROM against gravity and moderate resistance in a muscle specific position
- 5** = (normal) active movement, full ROM against gravity and full resistance in a functional muscle position expected from an otherwise unimpaired person
- 5\*** = (normal) active movement, full ROM against gravity and sufficient resistance to be considered normal if identified inhibiting factors (i.e. pain, disease) were not present
- NT** = not testable (i.e. due to immobilization, severe pain such that the patient cannot be graded, amputation of limb, or contracture of > 50% of the normal range of motion)

## Sensory Grading

- 0** = Absent
- 1** = Altered, either decreased/impaired sensation or hypersensitivity
- 2** = Normal
- NT** = Not testable

## Non Key Muscle Functions (optional)

May be used to assign a motor level to differentiate AIS B vs. C

Movement	Root level
<b>Shoulder:</b> Flexion, extension, abduction, adduction, internal and external rotation.	<b>C5</b>
<b>Elbow:</b> Supination	
<b>Elbow:</b> Pronation	<b>C6</b>
<b>Wrist:</b> Flexion	
<b>Finger:</b> Flexion at proximal joint, extension.	<b>C7</b>
<b>Thumb:</b> Flexion, extension and abduction in plane of thumb	
<b>Finger:</b> Flexion at MCP joint	<b>C8</b>
<b>Thumb:</b> Opposition, adduction and abduction perpendicular to palm	
<b>Finger:</b> Abduction of the index finger	<b>T1</b>
<b>Hip:</b> Adduction	<b>L2</b>
<b>Hip:</b> External rotation	<b>L3</b>
<b>Hip:</b> Extension, abduction, internal rotation	<b>L4</b>
<b>Knee:</b> Flexion	
<b>Ankle:</b> Inversion and eversion	
<b>Toe:</b> MP and P extension	
<b>Hallux and Toe:</b> DIP and PIP flexion and abduction	<b>L5</b>
<b>Hallux:</b> Adduction	<b>S1</b>

## ASIA Impairment Scale (AIS)

**A = Complete** No sensory or motor function is preserved in the sacral segments S4-5

**B = Sensory Incomplete** Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-5 (light touch or pin prick at S4-5 or deep anal pressure) AND no motor function is preserved more than three levels below the motor level on either side of the body

**C = Motor Incomplete** Motor function is preserved below the neurological level<sup>\*\*</sup>, and more than half of key muscle functions below the neurological level of injury (NLI) have a muscle grade less than 3 (Grades 0-2)

**D = Motor Incomplete** Motor function is preserved below the neurological level<sup>\*\*</sup>, and at least half (half or more) of key muscle functions below the NLI have a muscle grade  $\geq 3$

**E = Normal** If sensation and motor function as tested with the ISNCISQ are graded as normal in all segments, and the patient had prior deficits, then the AIS grade is E. Someone without an initial SCI does not receive an AIS grade

<sup>\*\*</sup> For an individual to receive a grade of C or D, i.e. motor incomplete status, they must have either (1) voluntary anal sphincter contraction or (2) sacral sensory sparing with sparing of motor function more than three levels below the motor level for that side of the body. The International Standards at this time allows even non-key muscle function more than 3 levels below the motor level to be used in determining motor incomplete status (AIS B versus C)

NOTE: When assessing the extent of motor sparing below the level for distinguishing between AIS B and C, the motor level on each side is used, whereas to differentiate between AIS C and D (based on proportion of key muscle functions with strength grade 3 or greater) the neurological level of injury is used.



## Steps in Classification

The following order is recommended for determining the classification of individuals with SCI

### 1. Determine sensory levels for right and left sides.

The sensory level is the most caudal, intact dermatome for both pin prick and light touch sensation

### 2. Determine motor levels for right and left sides.

Defined by the lowest key muscle function that has a grade of at least 3 (on supine testing), providing the key muscle functions represented by segments above that level are judged to be intact (graded as a 5)

Note: In regions where there is no myotome to test, the motor level is presumed to be the same as the sensory level, if testable motor function above that level is also normal

### 3. Determine the neurological level of injury (NLI)

This refers to the most caudal segment of the cord with intact sensation and anti-gravity (3 or more) muscle function strength, provided that there is normal (intact) sensory and motor function rostrally respectively

The NLI is the most cephalad of the sensory and motor levels determined in steps 1 and 2

### 4. Determine whether the injury is Complete or Incomplete.

(i.e. absence or presence of sacral sparing)

If voluntary anal contraction = **No** AND all S4-5 sensory scores = **0** AND deep anal pressure = **No**, then injury is **Complete**  
Otherwise, injury is **Incomplete**

### 5. Determine ASIA Impairment Scale (AIS) Grade:

Is injury **Complete**? IF YES, AIS=A and can record ZPP (lowest dermatome or myotome on each side with some preservation)

NO ↓

Is injury **Motor Complete**? IF YES, AIS=B

NO ↓

(No=voluntary anal contraction OR motor function more than three levels below the motor level on a given side, if the patient has sensory incomplete classification)

Are at least half (half or more) of the key muscles below the neurological level of injury graded 3 or better?

NO ↓

AIS=C

YES ↓

AIS=D

If sensation and motor function is normal in all segments, AIS=E

Note: AIS E is used in follow-up testing when an individual with a documented SCI has recovered normal function. If at initial testing no deficits are found, the individual is neurologically intact, the ASIA Impairment Scale does not apply

# Appendix B: Spinal Cord Independence Measure

Figure B.1. Spinal Cord Independence Measure



## LOEWENSTEIN HOSPITAL REHABILITATION CENTER

Affiliated with the Sackler Faculty of Medicine, Tel-Aviv University

Department IV, Medical Director: Dr. Amiram Catz Tel: 972-8-7709090 Fax: 972-8-7709986 e-mail: amiram@ciaiit.org.il

Patient Name: \_\_\_\_\_ ID: \_\_\_\_\_ Examiner Name: \_\_\_\_\_

(Enter the score for each function in the adjacent square, below the date. The form may be used for up to 6 examinations.)

### SCIM-SPINAL CORD INDEPENDENCE MEASURE

Version III, Sept 14, 2002

#### Self-Care

DATE

Exam 1 2 3 4 5 6

1. **Feeding** (cutting, opening containers, pouring, bringing food to mouth, holding cup with fluid)      
  0. Needs parenteral, gastrostomy, or fully assisted oral feeding
  1. Needs partial assistance for eating and/or drinking, or for wearing adaptive devices
  2. Eats independently; needs adaptive devices or assistance only for cutting food and/or pouring and/or opening containers
  3. Eats and drinks independently; does not require assistance or adaptive devices
2. **Bathing** (soaping, washing, drying body and head, manipulating water tap). **A-upper body; B-lower body**
  - A. 0. Requires total assistance
  1. Requires partial assistance
  2. Washes independently with adaptive devices or in a specific setting (e.g., bars, chair)
  3. Washes independently; does not require adaptive devices or specific setting (not customary for healthy people) (adss)
  - B. 0. Requires total assistance
  1. Requires partial assistance
  2. Washes independently with adaptive devices or in a specific setting (adss)
  3. Washes independently; does not require adaptive devices (adss) or specific setting
3. **Dressing** (clothes, shoes, permanent orthoses: dressing, wearing, undressing). **A-upper body; B-lower body**
  - A. 0. Requires total assistance
  1. Requires partial assistance with clothes without buttons, zippers or laces (cwobzl)
  2. Independent with cwobzl; requires adaptive devices and/or specific settings (adss)
  3. Independent with cwobzl; does not require adss; needs assistance or adss only for bzl
  4. Dresses (any cloth) independently; does not require adaptive devices or specific setting
  - B. 0. Requires total assistance
  1. Requires partial assistance with clothes without buttons, zips or laces (cwobzl)
  2. Independent with cwobzl; requires adaptive devices and/or specific settings (adss)
  3. Independent with cwobzl without adss; needs assistance or adss only for bzl
  4. Dresses (any cloth) independently; does not require adaptive devices or specific setting
4. **Grooming** (washing hands and face, brushing teeth, combing hair, shaving, applying makeup)      
  0. Requires total assistance
  1. Requires partial assistance
  2. Grooms independently with adaptive devices
  3. Grooms independently without adaptive devices

SUBTOTAL (0-20)

#### Respiration and Sphincter Management

##### 5. Respiration

0. Requires tracheal tube (TT) and permanent or intermittent assisted ventilation (IAV)
2. Breathes independently with TT; requires oxygen, much assistance in coughing or TT management
4. Breathes independently with TT; requires little assistance in coughing or TT management
6. Breathes independently without TT; requires oxygen, much assistance in coughing, a mask (e.g., peep) or IAV (bipap)
8. Breathes independently without TT; requires little assistance or stimulation for coughing
10. Breathes independently without assistance or device

##### 6. Sphincter Management - Bladder

0. Indwelling catheter
3. Residual urine volume (RUV) > 100cc; no regular catheterization or assisted intermittent catheterization
6. RUV < 100cc or intermittent self-catheterization; needs assistance for applying drainage instrument
9. Intermittent self-catheterization; uses external drainage instrument; does not need assistance for applying
11. Intermittent self-catheterization; continent between catheterizations; does not use external drainage instrument
13. RUV < 100cc; needs only external urine drainage; no assistance is required for drainage
15. RUV < 100cc; continent; does not use external drainage instrument

##### 7. Sphincter Management - Bowel

0. Irregular timing or very low frequency (less than once in 3 days) of bowel movements
5. Regular timing, but requires assistance (e.g., for applying suppository); rare accidents (less than twice a month)
8. Regular bowel movements, without assistance; rare accidents (less than twice a month)
10. Regular bowel movements, without assistance; no accidents

##### 8. Use of Toilet (perineal hygiene, adjustment of clothes before/after, use of napkins or diapers).

0. Requires total assistance
1. Requires partial assistance; does not clean self
2. Requires partial assistance; cleans self independently
4. Uses toilet independently in all tasks but needs adaptive devices or special setting (e.g., bars)
5. Uses toilet independently; does not require adaptive devices or special setting)

SUBTOTAL (0-40)

Mobility (room and toilet)

DATE

1 1 1 1 1 1 1  
[ ][ ][ ][ ][ ][ ][ ]

9. Mobility in Bed and Action to Prevent Pressure Sores

- 0. Needs assistance in all activities: turning upper body in bed, turning lower body in bed, sitting up in bed, doing push-ups in wheelchair, with or without adaptive devices, but not with electric aids
- 2. Performs one of the activities without assistance
- 4. Performs two or three of the activities without assistance
- 6. Performs all the bed mobility and pressure release activities independently

[ ][ ][ ][ ][ ][ ][ ]

10. Transfers: bed-wheelchair (locking wheelchair, lifting footrests, removing and adjusting arm rests, transferring, lifting feet).

- 0. Requires total assistance
- 1. Needs partial assistance and/or supervision, and/or adaptive devices (e.g., sliding board)
- 2. Independent (or does not require wheelchair)

[ ][ ][ ][ ][ ][ ][ ]

11. Transfers: wheelchair-toilet-tub (if uses toilet wheelchair: transfers to and from; if uses regular wheelchair: locking wheelchair, lifting footrests, removing and adjusting armrests, transferring, lifting feet)

- 0. Requires total assistance
- 1. Needs partial assistance and/or supervision, and/or adaptive devices (e.g., grab-bars)
- 2. Independent (or does not require wheelchair)

[ ][ ][ ][ ][ ][ ][ ]

Mobility (indoors and outdoors, on even surface)

12. Mobility Indoors

- 0. Requires total assistance
- 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
- 2. Moves independently in manual wheelchair
- 3. Requires supervision while walking (with or without devices)
- 4. Walks with a walking frame or crutches (swing)
- 5. Walks with crutches or two canes (reciprocal walking)
- 6. Walks with one cane
- 7. Needs leg orthosis only
- 8. Walks without walking aids

[ ][ ][ ][ ][ ][ ][ ]

13. Mobility for Moderate Distances (10-100 meters)

- 0. Requires total assistance
- 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
- 2. Moves independently in manual wheelchair
- 3. Requires supervision while walking (with or without devices)
- 4. Walks with a walking frame or crutches (swing)
- 5. Walks with crutches or two canes (reciprocal walking)
- 6. Walks with one cane
- 7. Needs leg orthosis only
- 8. Walks without walking aids

[ ][ ][ ][ ][ ][ ][ ]

14. Mobility Outdoors (more than 100 meters)

- 0. Requires total assistance
- 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
- 2. Moves independently in manual wheelchair
- 3. Requires supervision while walking (with or without devices)
- 4. Walks with a walking frame or crutches (swing)
- 5. Walks with crutches or two canes (reciprocal walking)
- 6. Walks with one cane
- 7. Needs leg orthosis only
- 8. Walks without walking aids

[ ][ ][ ][ ][ ][ ][ ]

15. Stair Management

- 0. Unable to ascend or descend stairs
- 1. Ascends and descends at least 3 steps with support or supervision of another person
- 2. Ascends and descends at least 3 steps with support of handrail and/or crutch or cane
- 3. Ascends and descends at least 3 steps without any support or supervision

[ ][ ][ ][ ][ ][ ][ ]

16. Transfers: wheelchair-car (approaching car, locking wheelchair, removing arm- and footrests, transferring to and from car, bringing wheelchair into and out of car)

- 0. Requires total assistance
- 1. Needs partial assistance and/or supervision and/or adaptive devices
- 2. Transfers independent; does not require adaptive devices (or does not require wheelchair)

[ ][ ][ ][ ][ ][ ][ ]

17. Transfers: ground-wheelchair

- 0. Requires assistance
- 1. Transfers independent with or without adaptive devices (or does not require wheelchair)

[ ][ ][ ][ ][ ][ ][ ]

SUBTOTAL (0-40)

TOTAL SCIM SCORE (0-100)

[ ][ ][ ][ ][ ][ ][ ]

## **Appendix C: Ethics Committee Applications and Approval**

Ethics approval for the project, data collected and questionnaires used was sought and obtained from both the local NHS ethics committee and the Brunel University ethics committee in December 2003 and May 2004 respectively.

Revisions were submitted to the NHS ethics committee on the following dates:

### **September 06 – Substantial amendment.**

1. Finalisation of data collection periods and data collection tools to be used.
2. Inclusion of a pilot phase.
3. Inclusion of 2 quality of life questions and free text boxes for subjects to state: what they feel improves or detracts from their quality of life and if there were additional things that they feel could have been done/offered to them during their rehabilitation and since their discharge that could have had a significant positive impact for them.
4. Change of primary investigator's name on consent forms and patient information following marriage.

### **May 08- Minor amendment.**

1. Changes to details of 2 supervisors on Patient Information Sheet and Consent form following retirement of one and change in post for another.
2. Changes to structure/phrasing of data questions at all 3 stages to aid meaningful data collection and analysis..

Both amendments received a favourable response and details of amendment and response were forwarded through to Brunel University ethics committee for information.



**RNOHT/IOMS RESEARCH ETHICS COMMITTEE**

Research and Development Office/CDRI  
Royal National Orthopaedic Hospital  
Brockley Hill  
Stanmore  
HA7 4LP

Tel: 020 8909 5752  
Fax: 020 8385 7151

11 December 2003

Miss Janine Lockwood-Johnson  
Reintegration Manager  
RNOHT.

Dear Miss Lockwood-Johnson

**31/2003 – Impact of time of discharge and provision of resources on  
successful community reintegration of patients with spinal cord injury**

Thank you for attending the Ethics Committee meeting on 4<sup>th</sup> December 2003. I am happy to confirm that your project was given ethical approval at that meeting. However I would advise that you consider other types of data analyses as suggested at the meeting.

Additionally, please let the Committee have a report on your project in one year's time or when the project is finished, whichever is sooner.

With best wishes

Yours sincerely

Dr Jonathan Berman  
Chairman, JREC



**Brunel University**  
**Faculty of Life Sciences**  
**Department of Health and Social Care**

*Departmental Research Ethics Committee*

7 June 2004

**Proposer:** Janine Lockwood-Johnson  
**Title:** Impact of time of discharge and provision of resources on successful community reintegration of patients with spinal cord injury

The Departmental Research Ethics Committee has reviewed the above proposal and would wish to make the following comments:

- *We note that LREC permission was granted by RNOHT/IOMS Research Ethics Committee by letter dated 11<sup>th</sup> December 2003. We would, however, seek clarification with regard to the following matters:*
  - *Q.A.30(+ Part B Section 7: Declaration): Please clarify the relationship between UCL and Brunel University and identify the Supervisor*
  - *Q.B.4: "...or any other person that investigators deem to be unsuitable to take part in this study shall be excluded." Bearing in mind the ethical value of equity and fairness, please clarify.*
  - *Q.B.4: Please state how the initial approach to patients/participants will be made.*
  
- *With regard to the Participant Information Sheet, and on the assumption that the sheet provided is the revised Information Sheet considered by the LREC at its meeting on 4<sup>th</sup> March 2004:*
  - *Brunel University headed paper should be used* E 2004
  - *Line 1: Please clarify "we"*
  - *There should be a statement re. why the individual qualifies for the sample and how they have been identified.*
  - *"Initially we will ask you...". Please clarify when and how this will occur.*
  - *"It is not compulsory to take part in this study" should read "participation is entirely voluntary". This should also be added to the Consent Form.*

**David Anderson-Ford**  
**Chair, Departmental Research Ethics Committee**



19<sup>th</sup> July 2004

David Anderson-Ford  
Dept of Health and Social Care  
Faculty of Life Sciences  
Brunel University

Firstly, apologies for my delay in responding to your queries.

*For the sake of clarity I will address each issue raised in turn.*

1. *Q.A.30 (+ Part B Section 7: Declaration): Please clarify the relationship between UCL and Brunel University and identify the supervisor.'*

Prof DeSouza (Brunel University) and Prof Ferguson-Pell (UCL) are both supervisors for this project.

2. *Q.B.4: '.....or any other person that investigators deem to be unsuitable to take part in this study shall be excluded.' Bearing in mind the ethical value of equity and fairness, please clarify.*

This statement was formulated to cover for any 'unforeseen situations' where the treating teams may deem that it was in the patients' best interests not to be approached/included in this project. Possible examples of this may be: if a patient is in significant psychological distress but has not been diagnosed with a 'mental illness' in the strictest terms and performing a 'battery' of psychological questionnaires may possibly exacerbate their distress. Another possibility is that a patient is 'borderline' for a diagnosis of dementing illness, or, for a variety of possible reasons, a diagnosis cannot be made (this has happened recently). Certain factors such as patient clarity on/acceptance of diagnosis may also affect timings for/possibility of approaching possible participants. This is not an attempt to exclude certain groups or skew results, merely an attempt on my part to ensure that the best interests of the patient are always paramount in considerations of whether to recruit them or not.

3. *Q.B.4: Please state how the initial approach to patients/participants will be made.*

Following notification of patient admission and stabilisation I will check with the treating teams that they have no concerns about inclusion (see above) or recommend that approach is delayed. I will then approach the patient to arrange an appointment to discuss the project and their possible consent to

be included. The Patient Information Sheet will be given to them at this point. The details and aims of the project will be discussed with them in more depth at the pre-consent appointment. Any questions they may have regarding the project will be answered. At the conclusion of the interview an appointment will be made in approximately 7 days time at which the patient may ask any further questions they have and then decide whether they wish to give their consent or not. If consent is given psychological questionnaires will be completed at this time, unless the patients' timetable or requirements dictate otherwise, in which case a further appointment will be made for this.

*4. With regard to the Participant Information Sheet and on the assumption that the sheet provided is the revised Information Sheet considered by the LREC at its meeting on 4<sup>th</sup> March 2004.*

The Information Sheet entitled 'The effects of provision of resources on reintegration outcomes in spinal cord injury' refers to this project and was approved at the LREC meeting in December 2003. The reference to the revised Information Sheet refers to a separate project looking in to the number of SCI patients who may have recourse to funds via a compensation claims. Information on this project was included for your information as the LREC applications refer to each other, I apologise if this caused confusion. As the issues raised apply to both Information Sheets I will respond to them all from the perspective of the Information Sheet that refers to the project concerned.

*5. Brunel University headed paper should be used.*

As the patients approached are all patients of RNOH I have been advised that RNOH headed paper must be used. I understand your wish for Brunel headed paper to be used and although it should be possible to use RNOH headed paper with a Brunel logo displayed in a prominent position I would then also have to use the logo for UCL. This is not an ideal solution and could then cause confusion on the part of participants. A possible alternative solution is that a statement is put at the end of the information sheet stating: 'This research project has been approved by RNOH and Brunel University ethics committees.

Academic supervision is via Prof L DeSouza, Centre for Rehabilitation Research, Brunel University and Prof M Ferguson-Pell, ASPIRE Chair in Disability & Technology, UCL.

Clinical supervision is via Dr FRI Middleton, Clinical Director, Spinal Injuries Unit, RNOH.....

.....If you have any queries regarding this research that can't not be resolved by the lead researcher they can be addressed to one of the supervisors listed.' Providing, of course, that this solution is acceptable to yourselves and the RNOH LREC.

I have amended the Patient Information Sheet to include these changes and enclose a copy for your approval. I will also approach RNOH LREC for their approval of these amendments.

*6. Line 1: Please clarify 'we'.*

This term was used to recognise that I have collaborators on this project, as referred to in Q.A.4 and the Patient Information Sheet.

7. *There should be statement re. why the individual qualifies for the sample and how they have been identified.*

I have amended the Information Sheet to include your suggestion and enclose a copy of this for your approval. I will also approach RNOH LREC for their approval of this amendment.

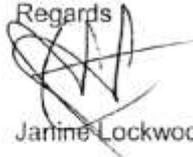
8. *'Initially we will ask you....' Please clarify when and how this will occur.* Please refer to point 4.

9. *'it is not compulsory to take part in this study' should read 'participation is entirely voluntary'. This should also be added to the Consent Form.*

I have amended the both documents to include your suggestions and enclose a copy of these for your approval. I will also approach RNOH LREC for their approval of these amendments.

Please do not hesitate to contact me if you have any further queries or comments. I would be happy to attend one of your meetings if this would assist the process.

Regards



Janine Lockwood



**BRUNEL UNIVERSITY  
SCHOOL OF HEALTH SCIENCES AND SOCIAL CARE**

*School Research Ethics Committee*

4 August 2004

**Proposer: Janine Lockwood-Johnson**  
**Title: Impact of time of discharge and provision of resources on  
successful community reintegration of patients with spinal cord  
injury**

The Chair of the Departmental Research Ethics Advisory Committee has considered the amendments submitted in your letter dated 19<sup>th</sup> July 2004 in response to the Committee's earlier review of the above application.

The Chair, acting under delegated authority, is satisfied that the amendments accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- In relation to the headed paper issue (your reply Item 5), the Committee accepts your proposal for an alternative solution in the form that you have presented it for inclusion at the end of the Information Sheet, provided that contact details re. Professors De Souza and Fergusson-Pell are included.
- The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.
- (*Where relevant*) if projects are approved before funding is received, the Committee must see, and approve, any major changes required by the funding body.

**David Anderson-Ford**  
**Chair, School Research Ethics Committee**  
**School of Health Sciences and Social Care**

## **Appendix D: LOS for SCI Injury Groups and Process Definitions**

Table D.1: ICP Proposed Rehabilitation LOS 2008

<b>Patient Group</b>	<b>Target Length of Rehabilitation Stay (Weeks)</b>
Paraplegic (AIS A-C)	12
Incomplete UMN Paraplegic (AIS D)	16
Ambulant Cauda Equina	6
Ventilator Dependent Tetraplegic (AIS A-C)	12
C3-C5 Tetraplegic (AIS A-C)	12
C6-C8 Tetraplegic (AIS A-C)	15
Incomplete Tetraplegic (AIS D)	16

## **Stages during the Injury to Discharge Process**

*Injury to Admission:* This is the period of time from the individual sustaining their spinal cord injury until they are admitted to the SCIC. During this period initial management of the SCI and any accompanying injuries, in the case of polytrauma, will occur and this time period may be lengthy or short, therefore it is appropriate to record differences in these periods and so dates of injury, referral and admission will be recorded.

*Pre-mobilisation Length of Stay (LOS):* This is the period of time in between the SCI individual being admitted to the SCIC and commencing mobilisation and is calculated from these two dates. A long pre-mobilisation LOS may occur if they were medically unwell when admitted (for example if they sustained polytrauma at the time of injury) or if they had a skin issue that prevented mobilisation. During this phase some elements of rehabilitation will occur (education in the effects of injury, establishing ranging and splinting regimes, training the individual in directing their care) but rehabilitation will not be 'active' as they will be on bed rest and will not be expected to attend the therapy gym and attempt physical activities such as transfers or mobilisation and wheelchair propulsion. Some individuals will have a very short pre-mobilisation LOS if they were ready to commence mobilisation on admission, therefore it is important to record the length of time of this period of the inpatient stay to ensure that this period is distinguished from the formal rehabilitation period.

*Date of Mobilisation:* In the London SCIC mobilisation indicates the formal commencement of 'active' rehabilitation and is recorded as when the SCI individual is fit and able to mobilise (in a wheelchair or otherwise), for approximately 4 hours although the length of time may vary slightly. It is important to note that mobilisation may occur prior to admission to the SCIC, particularly if the delay in admission is lengthy, in which case date of mobilisation will be taken as the date the SCI individual is admitted to the SCIC.

*Target Rehabilitation LOS* for each subject is derived from a predefined formula established from the average length of stay for an SCI individual with the same injury level and AIS grade. These estimated LOS commences at the point of mobilisation and could be amended as required by the individual's condition. This Target Rehabilitation LOS is confirmed or changed at a formal discharge planning meeting midway through rehabilitation, but may be further extended if required or if the neurological profile of the individual has changed to the extent that their original Target LOS no longer applies.

*Actual Rehabilitation LOS* For the purposes of this study this is taken as the length of time from the date of mobilisation to the point at which the subject has completed all rehabilitation goals that require continuing inpatient rehabilitation.

*Overall LOS* is the period from admission to the point of discharge, including any discharge delay days.

*Length of Discharge Delay:* If a subject was medically fit for discharge but external objectives are not met by the proposed discharge date a discharge delay may occur. The length of discharge delay is calculated as the number of days past the completion of rehabilitation goals that the subject remains on the SCIC due to community based safe discharge objectives not being achieved.

## **Appendix E: Pilot Project Paperwork**



### ***Patient Information Sheet***

#### **THE EFFECTS OF PROVISION OF RESOURCES ON REINTEGRATION OUTCOMES IN SPINAL CORD INJURY – PILOT STUDY**

We would like to invite you to take part in a research study that is currently being undertaken in the hospital. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully and discuss it with anyone you feel you need to. If you have any questions or would like to receive more information then the lead researcher will be happy to talk to you before you make your decision. (Details of how the lead researcher can be contacted are at the end of this sheet). The purpose of this information sheet is to explain to you what information will be collected if you agree to participate.

#### **What is the purpose of this research project?**

This research is part of a long term study looking at how patients progress through their rehabilitation and eventual return to their home and life. You are being asked to take part in a pilot study that is being performed to establish if the information that is being collected is valid and useful.

It has been suggested that delays in providing services such as housing, care, equipment, etc. can affect the ability of a person with spinal cord injury to resume their life in the community. It can potentially lead to higher costs, for both the individual and the state, in terms of increased number of complications, increased need for care, lower levels of independence to name but a few. Through this study we would hope to be able to demonstrate how and when services should be provided to people who have sustained a spinal cord injury for them to be able to get the best out of their lives. From that we hope to be able to lobby to make sure that services are provided effectively.

#### **What is this study about?**

This study will look at how the services that people with spinal cord injury receive or do not receive may affect their ability to resume their life.

#### **Why have I been approached to take part in this study?**

You have been approached because you have sustained a spinal cord injury and so are one of a unique group of people who may be able to contribute to this study. You are important as an individual because it is only by obtaining information from individuals that we can hope to compile enough information to show general trends and so make possible recommendations and suggestions.

#### **What will happen to me if I take part?**

You will be allocated to one of 3 groups depending on whether you are just starting or ending your rehabilitation or if you have been discharged.

Two types of information will be collected. **1)** Information regarding your injury, rehabilitation or discharge. This information will vary depending on which group you are allocated to so see the specific details for each group for more information.

**2)** The answers given on 2 brief psychological questionnaires.

#### ***Group One***

Appendix E: Pilot Project Paperwork

Participants in this group will be just starting their rehabilitation. We will ask you to complete the 2 brief psychological questionnaires. No further active input will be required from you. We will collect information from your hospital records for this research study. This will include details focussing on your demographics, i.e. your situation prior to injury (where you lived, if you had a significant medical condition, etc), your injury and how it happened. A full list of the information we will gather throughout this research project is available if you wish to have it. After a couple of weeks we may approach you to complete one of the psychological questionnaires again. This is to ensure that the questionnaire is 'robust' enough to reliably show the same results over a short period of time.

### ***Group Two***

Participants in this group will be close to discharge. We will ask you to complete the 2 brief psychological questionnaires. On your discharge from hospital we will record details of your independence levels, support needed, type of discharge accommodation, and how the care and equipment you require are provided. We will also make a note of any of your needs that still have to be met. If your discharge was delayed, we will establish how long this was for and why it happened. We will also include information on how your rehabilitation progressed and any issues that limited the scope of your rehabilitation, e.g. complications, service issues, etc. Once again we will not require your direct participation at this stage. All of this information is normally recorded as part of your discharge process but we would ask for your permission to also use it as part of this research study. Again we may ask you to complete one of the psychological questionnaires again so that we can confirm its reliability.

### ***Group Three***

Participants in this group will have been discharged for approximately 1 year. You will be seen when you attend for Outpatient review. We will ask you to complete the 2 brief psychological questionnaires. In one further questionnaire will ask you to rate how able you feel to access the environment inside and outside your home and whether your housing meets your needs, as well as how you feel this impacts on your ability to live your life. We will ask what vocational activities you undertake, e.g. work, further education or job training, hobbies or family responsibilities, and how important you rate some activities to be to you. We will also ask for details of the support you require, whether you feel that the support you have received meets your needs and any issues that have arisen because your needs have not been met..

### **Do I have to take part?**

It is up to you whether you take part or not. If you feel that you need more information to make that decision one of the researchers will be happy to talk to you and provide you with specific details of the information that will be collected if you require. You will be asked to sign a consent form, if you decide to take part. Your original consent form and a copy of this information sheet will be given to you to keep.

### **What if I do not want to take part?**

Participation in this study is entirely voluntary and your decision either way will not affect the care you will receive from this hospital. Just advise the researcher of your decision when they approach you. We are grateful for your time in considering this study.

You are welcome to withdraw from this study at any time without giving a reason.

### **What are the possible disadvantages, side effects and risks of taking part?**

We do not anticipate any disadvantages, side effects or risks from taking part in this study.

### **What are the possible benefits of taking part?**

This is part of a long-term study that will be carried out over the next 3 years. Although participation in this study is unlikely have a direct effect on the services you receive. We hope that the results from this study will change services for spinal cord injured people to their advantage both during their rehabilitation and in the community. By taking part in this pilot study you are helping us to ensure that we are collecting the right information before we start the main study.

### **Will my taking part in this study be kept confidential?**

No one other than the researchers will know that you are taking part in this study. The Spinal Injuries Unit Team have been informed of this study and instructed to presume that either all patients are taking part or none are taking part.

The researchers are required to ensure that all information is kept confidential and in accordance with the both Data Protection Act and Research Governance requirements. If you agree to take part in this study you will be given a subject identification number, whilst we are collecting your data we will also hold your hospital number in order that we can make sure that data is linked to the right subject. Once we have collected all of the data we need any information that may be able to identify you (e.g. your hospital number, your date of injury and admission) will be removed and your data will be completely anonymous. When results are published only information for the groups of subjects and the group as a whole will be available.

### **Contact for further information**

This research project has been approved by RNOH and Brunel University ethics committees. It is being funded through an RNOH Research & Development Committee Grant.

Lead Researcher      Janine Khare  
Contact details:      020 8909 5582 (internal ext: 5582)  
Email: [janine.khare@rnoh.nhs.uk](mailto:janine.khare@rnoh.nhs.uk)

Please feel free to contact the Lead Researcher if you have any queries or would like to discuss this research study. If you have any queries regarding this research that can not be resolved by the lead researcher they can be addressed to one of the supervisors listed below.

Academic supervision is via Professor L DeSouza, Centre for Rehabilitation Research, Brunel University (Tel: 020 8891 0121) and Professor M Ferguson-Pell, ASPIRE Chair in Disability & Technology, UCL (Internal ext.5447).

Clinical supervision is via Dr FRI Middleton, Clinical Director, Spinal Cord Injury Centre, RNOH (Internal ext: 5596).

Thank you for your time and consideration.



**CONSENT TO PARTICPATE  
IN RESEARCH STUDY**

**The effects of provision of resources on reintegration outcomes in spinal  
cord injury**

Investigators: Janine Khare, Case Manager  
Prof L DeSouza, Centre for Rehabilitation Research, Brunel  
University  
Prof. M Ferguson-Pell, ASPIRE Chair in Disability &  
Technology, UCL  
Dr FRI Middleton, Clinical Director, Spinal Cord Injuries Centre,  
RNOH

- 1 I have read the information sheet and I understand what will be required of me if I take part in this study.
- 2 My concerns regarding this study have been answered by.....
- 3 I understand that at any time I may withdraw from this study without giving a reason and without affecting my normal care and management.
- 4 I understand that information from this study may be published in scientific journals, but that I will not be identified.
- 5 I understand that participation in this study is entirely voluntary.
- 6 Please delete one of the following as appropriate:
  - a I agree to take part in this study.
  - b I agree to take part in this study but do not wish to complete the psychological questionnaires.

Patient's signature or independent witness .....

Name in BLOCK LETTERS .....

Date .....

Investigator's signature .....

Name in BLOCK LETTERS .....

Date .....

## **Psychological measures and covering note (pilot use)**

### ***Psychological Questionnaires Information***

In this following section we need you to give answers to questions on 2 brief psychological questionnaires. These are the CSQ - Coping Styles Questionnaire (Roger 1996) and the SOCQ – Spheres of Control Questionnaire (Paulhus 1981 & 1990). The Coping Styles Questionnaire, as the name suggests measures how you normally deal with stressful situations. As you can imagine your way of coping with situations will vary greatly from the time of your admission, to discharge and then to one year post-discharge. We want to try and track these changes and show if they are affected by how support and services are provided or not provided.

The Spheres of Control Questionnaire examines where you feel that the control is in your life for example you may feel that you have no control at all and others (be it your family or government) control what you do and when you do it. Alternatively you may feel that you are responsible for absolutely everything in your life. As you can appreciate neither of these situations is ideal and we want to measure if certain situations may push a people to perceive control one way or the other and how this may then affect their ability to live their lives.

Both of these questionnaires have been validated for use in the general population and have been extensively researched. The Coping Styles Questionnaire has also been validated for use in Spinal Cord Injured Persons. The Spheres of Control Questionnaire has not but measures elements that the researchers feel will be of high importance to Spinal Cord Injured People and so part of this research project will be validation of this questionnaire for use in this group.

We need to stress at this point that we will be looking at *trends* in the data that is collected i.e. how the *group* of subjects as a whole generally respond to the questions, not individual responses. By the time your questionnaires are scored you will be an anonymous 'number' and so not identifiable. However, if you wish to know your 'scores' on these questionnaires please ask when you are submitting them and the lead researcher can arrange to score the questionnaire with you and go through what the results suggest with you.

**CSQ(3)**

Name:

Age:

Gender:

**Instructions:** Although people may react in different ways to different situations, we all tend to have a characteristic way of dealing with things which upset us. How would you describe the way you typically react to stress? Circle **Always (A)**, **Often (O)**, **Sometimes (S)**, or **Never (N)** for each item below:

- |    |  |   |   |   |   |
|----|--|---|---|---|---|
| 1  | Feel overpowered and at the mercy of the situation.                    | A | O | S | N |
| 2  | Work out a plan for dealing with what has happened.                    | A | O | S | N |
| 3  | See the situation for what it actually is and nothing more.            | A | O | S | N |
| 4  | Become miserable or depressed.   | A | O | S | N |
| 5  | Feel that no-one understands.  | A | O | S | N |
| 6  | Do not see the problem or situation as a threat.                       | A | O | S | N |
| 7  | Feel that you are lonely or isolated.                                  | A | O | S | N |
| 8  | Take action to change things.  | A | O | S | N |
| 9  | Feel helpless - there's nothing you can do about it.                   | A | O | S | N |
| 10 | Try to find out more information to help make a decision about things. | A | O | S | N |
| 11 | Keep things to myself and not let others know how bad things are.      | A | O | S | N |
| 12 | Feel independent of the circumstances.                                 | A | O | S | N |
| 13 | Sit tight and hope it all goes away.                                   | A | O | S | N |
| 14 | Take my frustrations out on the people closest to me.                  | A | O | S | N |
| 15 | Resolve the issue by not becoming identified with it.                  | A | O | S | N |
| 16 | Respond neutrally to the problem.                                      | A | O | S | N |
| 17 | Pretend there's nothing the matter, even if people ask.                | A | O | S | N |
| 18 | Get things into proportion - nothing is really that important.         | A | O | S | N |
| 19 | Believe that time will somehow sort things out.                        | A | O | S | N |
| 20 | Feel completely clear-headed about the whole thing.                    | A | O | S | N |
| 21 | Try to keep a sense of humour – laugh at myself or the situation.      | A | O | S | N |
| 22 | Keep thinking it over in the hope that it will go away.                | A | O | S | N |
| 23 | Believe that I can cope with most things with the minimum of fuss.     | A | O | S | N |
| 24 | Daydream about things getting better in future.                        | A | O | S | N |
| 25 | Try to find a logical way of explaining the problem.                   | A | O | S | N |
| 26 | Decide it's useless to get upset and just get on with things.          | A | O | S | N |
| 27 | Feel worthless and unimportant.  | A | O | S | N |

28	Trust in fate - that things will somehow work out for the best.	A	O	S	N
29	Use my past experience to try to deal with the situation.	A	O	S	N
30	Try to forget the whole thing has happened.	A	O	S	N
31	Become irritable or angry.	A	O	S	N
32	Just give the situation my full attention.	A	O	S	N
33	Just take on one thing at a time.	A	O	S	N
34	Criticise or blame myself.	A	O	S	N
35	Pray that things will just change.	A	O	S	N
36	Think or talk about the problem as if it did not belong to me.	A	O	S	N
37	Talk about it as little as possible.	A	O	S	N
38	Prepare myself for the worst possible outcome.	A	O	S	N
39	Look for sympathy from people.	A	O	S	N
40	See the thing as a challenge that must be met.	A	O	S	N
41	Be realistic in my approach to the situation.	A	O	S	N

©: D.Roger (1996)

Paulhus Spheres of Control Scale  
(Version 1 and 3 Composite)

Please circle or cross a number to indicate how much you agree with each statement.

	Disagree		Neutral			Agree	
1. I can usually achieve what I want if I work hard for it.	1	2	3	4	5	6	7
2. -Even when I'm feeling confident about most things, I still seem to lack the ability to control interpersonal situations.	1	2	3	4	5	6	7
3. By taking an active part in political and social affairs we, the people can control world events.	1	2	3	4	5	6	7
4. Once I make plans, I am almost certain to make them work.	1	2	3	4	5	6	7
5. I have no trouble making and keeping friends.	1	2	3	4	5	6	7
6. The average citizen can have an influence on government decisions.	1	2	3	4	5	6	7
7. -I prefer games involving some luck over games requiring pure skill.	1	2	3	4	5	6	7
8. -I'm not good at guiding the course of a conversation with several others.	1	2	3	4	5	6	7
9. -It is difficult for people to have much control over the things politicians do in office.	1	2	3	4	5	6	7
10. I can learn almost anything if I set my mind to it.	1	2	3	4	5	6	7
11. I can usually establish a close personal relationship with someone I find sexually attractive.	1	2	3	4	5	6	7
12. -This world is run by the few people in power and there is not much the little guy can do about it.	1	2	3	4	5	6	7
13. My major accomplishments are entirely due to my hard work and ability.	1	2	3	4	5	6	7
14. When being interviewed I can usually steer the interviewer toward the topics I want to talk about and away from those I wish to avoid.	1	2	3	4	5	6	7
15. With enough effort we can wipe out political corruption.	1	2	3	4	5	6	7
16. -I usually do not set goals because I have a hard time following through on them.	1	2	3	4	5	6	7
17. -If I need help in carrying out a plan of mine it is usually difficult to get others to help.	1	2	3	4	5	6	7
18. One of the major reasons we have wars is because people don't take enough interest in politics.	1	2	3	4	5	6	7
19. -Bad luck has sometimes prevented me from achieving things.	1	2	3	4	5	6	7

	Disagree			Neutral			Agree		
20. If there's someone I want to meet, I can usually arrange it.	1	2	3	4	5	6	7		
21. -There is very little we, as consumers, can do to keep the cost of living from going higher.	1	2	3	4	5	6	7		
22. Almost anything is possible for me if I really want it.	1	2	3	4	5	6	7		
23. -I often find it hard to get my point of view across to others.	1	2	3	4	5	6	7		
24. -When I look at it carefully I realise it is impossible to have any really important influence over what politicians do.	1	2	3	4	5	6	7		
25. -Most of what happens in my career is beyond my control.	1	2	3	4	5	6	7		
26. -In attempting to smooth over a disagreement, I usually make it worse.	1	2	3	4	5	6	7		
27. -I prefer to concentrate my energy on other things rather than on solving the world's problems.	1	2	3	4	5	6	7		
28. -I find it pointless to keep working on something that's too difficult for me.	1	2	3	4	5	6	7		
29. I find it easy to play an important part in most group situations.	1	2	3	4	5	6	7		
30. In the long run, we the voters are responsible for bad government on a national as well as a local level.	1	2	3	4	5	6	7		

**For completion by researcher**

**CSQ score: RatCop \_\_\_\_ Det/EmCop \_\_\_\_\_ AvCop \_\_\_\_\_**

**SOCQ score: PE \_\_\_\_\_ IPC \_\_\_\_\_ SPC \_\_\_\_\_**

<b>ASIA level (if changed)</b>		<b>Classification</b>	
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**Admission Data Collection Tool (Pilot use)**

**Reintegration Outcomes following Spinal Cord Injury**

**Admission data - Staff form**

**1.0**

**Patient MPI**

**D/O/B**

**Sex**

Male

Female

**ASIA level (post surgery)**

Date:

**ASIA Classification/Grade**

Date:

**1.1. Mode of injury:**

- Fall  Industrial Accident  Self Harm  
 Violence/Assault  Medical accident  Medical condition  
 RTA (Passenger/Pedestrian)  RTA (driver)  
 Sporting/leisure activity  Other (specify) \_\_\_\_\_.

**1.2. Additional injuries sustained at the time of injury:** \_\_\_\_\_  
\_\_\_\_\_

**1.3.**

Date of injury

Date of referral

Date of admission

Date of outreach (if performed)

**2.0 Reason for delayed admission (if over 72 hours):**

- Delay in referral  Patient health  Surgical delay  
 Non-acute admission  Bed availability (incl. ITU/isolation bed)  
 Further information required (blood gases, outreach, etc.)  
 Other (specify) \_\_\_\_\_

**2.1. If delayed admission please indicate type of complications on admission that could have been avoided if admitted within 72 hours:**

- Skin  Contractures  
 Unresolved fractures  Other (specify) \_\_\_\_\_

**3.0**

**1<sup>st</sup> documented GCS after injury**

**GCS on transfer to RNOH**

**4.0 Give details of any significant PMH**  
\_\_\_\_\_

**5.0 History of significant drug abuse?**  Yes  No

**6.0 History of significant alcohol abuse?**  Yes  No

**7.0 Cultural/Ethnic origin:** \_\_\_\_\_

Is the patient a first generation immigrant to the UK?

- Yes  No  N/A

**8.0 Please state patients reported religious group:** \_\_\_\_\_

**9.0 Employment status on injury:**

- Employed  Self-Employed  Retired  
 Student  Unemployed  Full time care giver  
 Unpaid/voluntary work

If working/volunteering/student please state no of hours/week \_\_\_\_\_

Please state job title of current/last job \_\_\_\_\_

**10.0 Educational status:**

- Basic state level (up to age 16)  Full high school education  
(A levels etc.)  
 Graduate (including primary professional qualification – diploma etc)  Post graduate

**11.0 Social situation at the time of injury:**

- Single (including divorced)  Widowed  Married/cohab  
 In relationship but not cohabiting

**12.0 Who did patient live with at the time of injury?**

- Family (parents and siblings)  Family (Spouse &/or children)  
 Friends  Partner  
 Alone (incl. with carer)/Shared accommodation

**13.0 Accommodation type**

- House  Flat  Bedsit  Room

**13.1. Tenancy/ownership**

- Owner/ occupier  Rented –private  Rented - HA/LA  
 Rented – sublet  Tied accommodation  
 Family Home – please state who owns it: \_\_\_\_\_

**13.2. Is the property occupied to its capacity – including an ‘office room’ if necessary?**

- Yes  No

**14.0 Social support network reported by patient:**

- Family only  Family and small network of friends  
 Family & wide network of friends  Friends only  
 Socially isolated

**For completion by researcher**

CSQ score: RatCop \_\_\_\_\_ Det/EmCop \_\_\_\_\_ AvCop \_\_\_\_\_  
SOCQ Score: PE \_\_\_\_\_ IPC \_\_\_\_\_ SPC \_\_\_\_\_

**Discharge Data Collection Tool (Pilot use)**  
**Reintegration Outcomes following Spinal Cord Injury**  
**Discharge - Staff form**

**1.0 Neurology and demographics**

**Discharge ASIA level**

**Classification**

1.1. Social situation at time of discharge:

- |   |   |
|---|---|
| <input type="checkbox"/> Single (including divorced)                    | <input type="checkbox"/> Widowed  |
| <input type="checkbox"/> In relationship but not cohabiting<br>cohab as | <input type="checkbox"/> Married/cohab (including not<br>going to Nursing Home) |

1.2. If the patient is not being discharged to a Nursing Home please indicate who they will be living with.

- |   |  |
|---|--|
| <input type="checkbox"/> Family (parents and siblings)            | <input type="checkbox"/> Family (Spouse &/or children) |
| <input type="checkbox"/> Partner <input type="checkbox"/> Friends | <input type="checkbox"/> Alone/Shared accommodation    |

1.3. Vocational activities:

- |   |  |
|---|--|
| <input type="checkbox"/> Returning to previous job/studies within 2 months/plan for return in place |  |
| <input type="checkbox"/> Returning to previous job/studies but no date for return yet               |  |
| <input type="checkbox"/> Retraining/actively job hunting  | <input type="checkbox"/> Retraining being considered |
| <input type="checkbox"/> Retraining declined at present   |  |
| <input type="checkbox"/> Previously retired   | <input type="checkbox"/> Full time caregiver         |

**2.0 Length of stay, rehabilitation and delaying factors**

2.1. Discharge date:    \_\_\_\_ / \_\_\_\_ / \_\_\_\_

2.2. If discharge was delayed please specify number of days    \_\_\_\_\_

2.2.1. Please specify reason for delayed discharge:

- |  |  |
|--|--|
| <input type="checkbox"/> Accommodation-adaptations required – Approx cost of work to be done    £_____ |  |
| <input type="checkbox"/> Accommodation – no housing available  | <input type="checkbox"/> Funding of care package |
| <input type="checkbox"/> 'Home starter' funds required   | <input type="checkbox"/> Patient/family refusal  |
| <input type="checkbox"/> Carer recruitment/training  | <input type="checkbox"/> Other (specify) _____   |

2.3. Was the patient diagnosed with any other condition during their stay (e.g. memory deficits, heart condition, etc.)? If yes please specify. \_\_\_\_\_

2.3.1. Does this impact on their functional abilities?    Yes        No   

2.4. Were any goals outstanding on discharge?    Yes        No   

2.4.1. If yes then indicate type/s:

- |                                    |                                     |   |
|------------------------------------|-------------------------------------|---|
| <input type="checkbox"/> Mobility  | <input type="checkbox"/> Continence | <input type="checkbox"/> Self-care        |
| <input type="checkbox"/> Education | <input type="checkbox"/> Vocational | <input type="checkbox"/> Medical/surgical |

2.4.2. Reason for outstanding goals:

- |  |  |   |
|--|--|---|
| <input type="checkbox"/> Patient choice  | <input type="checkbox"/> Patient stamina | <input type="checkbox"/> Patient cognitive/psych issues |
| <input type="checkbox"/> medical (further investigation/treatment time required) |  |   |
| <input type="checkbox"/> medical (specialist intervention required - PMH)        |  |   |
| <input type="checkbox"/> medical (specialist intervention required - SCI)        |  |   |
| <input type="checkbox"/> other (specify) _____                                   |  |   |

**Compensation Issues – If not applicable please state n/a**

2.5. Date legal audit performed (state n/a if not done) \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

2.6. Frequency of liaison with solicitor (if applicable).

Regular  Attended meetings only  One-off contact  None

2.6.1. If no involvement state reason for this:

Patient choice  Solicitor choice  Not known

2.7. Frequency of liaison with insurance company

Regular  Attended meetings only  One-off contact  None

2.7.1. If no involvement state reason for this:

Patient choice  Insurance co choice  Not known

2.8. Has an interim payment been made? Yes  No

**3.0 Care Package - If discharged to a nursing home please go to qu 5**

No of paid care hours received per week Tick box if 24/7

No of informal care hours given per week Tick box if 24/7

No of hours/week that 2 carers are required Tick box if 24/7

Does an informal carer act as second carer? Yes  No

Approx cost of care package (obtain from Care Manager)

3.1. Please indicate the areas of activity that care is required and the reason

<b>Area of need</b>	<b>Reason</b>		
Personal care	Physical restrictions	Cognitive issues	Psychological issues
Mobility	Physical restrictions	Cognitive issues	Psychological issues
Domestic care	Physical restrictions	Cognitive issues	Psychological issues
Social activities	Physical restrictions	Cognitive issues	Psychological issues
Employment activities	Physical restrictions	Cognitive issues	Psychological issues
Child care	Physical restrictions	Cognitive issues	Psychological issues

3.2. Please indicate source of funding for care package: *Note: Private Provision includes only any contribution above the statutory minimum contribution made by all.*

Public – SSD  Public – NHS  Public – SSD & NHS  
 Public & private  Private only – individual  Private only – interim payment

3.3. No. of care hours due to home/outside environment being inaccessible ....

3.4. Is the Care Agency a Specialist SCI Agency? Yes  No

3.5. Is care provision at a higher or lower level than advised? Yes  No

3.5.1. If Yes then please specify which: Higher  Lower

3.5.2. Also please specify the reason for this:

Patient request  Transitional support  Community team decision

**4.0 Accommodation and Environment:**

4.1. Discharge destination. Tick all applicable  
**Previous home with:**  adaptations performed  awaiting LT adaptations   
 no/minimal adaptations required and done

**Nursing/residential home as:**  Permanent accommodation  
 Interim – permanent accommodation identified – no adapts required  
 Interim – permanent accommodation identified – adapts required  
 Interim - no accommodation identified

**Private rental:**  Long term  Short term  ASPIRE  
 property

Privately purchased accommodation  Long term public sector housing  
 Temporary public sector accommodation inc. B+B/hostel  
 NHS transfer

5.0 Is patient able to access the following? Please answer yes if assistance to do this  
 is required due to the level of injury rather than environment.  
Yes No

The whole of the inside of their home  
 The outside of their home  
 GP surgery

**6.0 Mobility and equipment**

Please specify the nature of equipment provision on discharge:

<b>Wheelchair:</b>	Temporary wheelchair provided	Powered	Manual
	Recommended wheelchair provided – state provision		
	Recommended wheelchair provided – private provision (including joint purchase through voucher scheme)		
<b>Moving and Handling:</b>	Temporary equipment provided		
	Recommended equipment provided – state provision		
	Recommended equipment provided – private provision		
<b>Other recommended equipment provided and type</b>	State provision	Mobility	Self care
	Private provision	Mobility	Self care
	State and private provision	Mobility	Self care

6.1. Does patient have their own vehicle that they can access? Yes  No

6.2. Do they drive/intend to drive when car available? Yes  No

**7.0 Social support and Community activities:**

Number of times over the past month patient reports that they have:

Not at all    1-5 times    5-10 times    10 or more

Had Family visiting:  
 Had Friend visiting  
 Had a social outing from the  
 unit (incl weekend leave)

**8.0 Community Support:**

**8.1. Please indicate if they will have ongoing contact with any of the following  
Community professionals**

- Social Services Care Manager
- Dept of Employment Advisor
- District Nurse
- Physio
- Community OT
- Support/link worker
- External Case Manager
- Intermediate care/community rehab team

**8.2. If they will receive outpatient therapy input please indicate the reason:**

- Standing
- Brief intervention due to issues/complications
- Ongoing functional/neuro improvement
- Carer training

**For completion by researcher**

**SOCQ Score: PE   . IPC           . SPC           .**

**CSQ score: RatCop        DetCop        EmCop**

**AvCop**

**Post-Discharge Phase Booklet Form (Pilot use)**  
**Reintegration Outcomes Following Spinal Cord Injury Study**

**Post Discharge Phase**

*Now that you have been discharged from the SCIC for one year we need to ask you some questions about where you live, the support you are receiving, what problems you have had and how you have managed over the past year. We also need to ask you to complete the 2 brief psychological questionnaires again.*

*At this stage in the study we are not only looking at how the equipment, care, medical issues, etc you have can affect what you can do but also how it can affect your perceptions. Once again we are trying to observe the 'trends', both good and bad that will only become apparent from many peoples answers. However, your answers as an individual are extremely important to us because if individuals do not answer these questions then we have no means of obtaining information about the group as a whole.*

*Please read the instructions at the beginning of each questionnaire carefully before completing it. Once you have finished please go back through your answers and make sure that you have responded to each item. You may find that some of the questionnaires appear to ask similar questions, we would be grateful, however, if you could answer all the questions. Leaving a few questions unanswered in any scale will limit the usefulness of the rest of the information in this scale and in others.*

*Please note that all of the information obtained from participants will be kept confidential. Only researchers working on the project will have access to this information.*

*Thank you for your continued support of this research project. We would be grateful if you could take the time to complete the following questionnaires and bring them with you to your clinic appointment. If you require assistance to complete the questionnaires then please contact the primary researcher on 020 8909 5582 (or text your phone number to 07843 056054) at least 48 hours before your appointment or ask when you see the doctor and support will be arranged for you.*

## 1.0 Your accommodation & environment:

**Where do you live?** Tick all of the boxes that are applicable

In temporary accommodation		In permanent accommodation	
On your own (including a live-in carer)		With partner and/or children	
With parents or other close relative		In a nursing/residential home	

1.1. Are adaptations to your home still outstanding?

Yes                       No                       No accommodation identified yet

1.2. Do you have an environmental control unit yet?

Yes                       No    If yes when was it provided? \_\_\_\_\_

1.3. Are you able to access the following places? *Please tick 'Yes' if assistance to do this is required due to the level of your injury rather than the environment you are in.*

	Yes	No	Not known /never visited
The whole of the inside of where you live			N/A
The outside of where you live			N/A
GP surgery			
Dentist			
Local shops/food store			
Chemist			
Leisure shopping facilities			
Accessible public transport system			
Accessible leisure facilities (cinema, sports centre, etc.)			
Your place of work or study			

1.4. Please let us know here if there is anything significant happening in your physical environment at the moment. For example: the council are digging up the road outside your home, the outside temperature is very hot or very cold, you are having building work done at home, etc. \_\_\_\_\_

## 2.0 Care or assistance required (If you live in a Nursing Home please go straight to question 3.)

How many hours per week do you receive care or assistance?

(Tick this box if you have a carer 24 hours a day ) \_\_\_\_\_Hours/week

2.1. Who provides this care? Tick as many boxes as are applicable

Paid Carer                       District Nurse                       Family member or friend

2.2. Not counting the standard contribution from your DLA/benefits, who funds your care package? Tick as many boxes as are applicable.

Social Services (including direct payments)                       Health services  
 Private (e.g. your own funds or money from an interim payment)  
 Not known

2.3. Please indicate the areas of activity that you need assistance with:

Tick as many boxes as are applicable.

- Personal care       Child care       Domestic care  
 Social activities     Employment activities     Mobility

2.4. Changes in your care package since discharge

	Yes	No	Not applicable
Has your care package been reduced since you left the Unit?			
Has your care package been increased since you left the Unit?			
Has the amount of care/assistance you need on a day to day basis changed since you left the unit?			
Has your care package been reduced against your wishes?			
Do you feel that you have sufficient control over how and when your care is provided?			

**3.0 Activities & Social Support: Could you please indicate on average how often you participate in the following activities and what importance you feel this has to you:**

	Not at all	Daily/ every few days	Once a week	Once a month	Level of importance this activity has to you
Go to work or college/training course					High Med Low
Go shopping for daily needs (food, etc.)					High Med Low
Have family visitors at home					High Med Low
Have friends visiting you at home					High Med Low
Are seen by professionals in your home (not counting a live-in carer)					High Med Low
Leave your home for social reasons, e.g. an outing, visiting friends or family, etc.					High Med Low

3.1. If you leave your home only once a week or less please specify why this is, for example: no transport, no assistance available, you do not wish to leave house more frequently, etc. \_\_\_\_\_



**7.0 Complications:** Have you frequently or persistently experienced any of the following complications since your discharge? Tick as many as are applicable

Unmanageable Spasms		Skin Issues	
Frequent breakdown of care package		Urinary tract/bladder infection	
Bowel management problems		Autonomic Dysreflexia	
Bladder management problems		Reduction of function	
Pain		Other significant issue (please specify)	

7.1. Have you been admitted to hospital since your discharge because of any of the above issues?  Yes  No - Go to question 8

7.2. Please indicate how many times you have had to go to an hospital because of these problems since discharge and if you were admitted to hospital:

Issue	No of times	Were you admitted? (yes/no)	No of admissions	Length of longest admission (days)
Unmanageable Spasms				
Skin Issues				
Breakdown of care package				
Urinary tract/bladder infection				
Bowel management problems				
Autonomic Dysreflexia				
Bladder management problems				
Reduction of function				
Pain				
Other significant issue				

**8.0 Pain.** Please place a cross on the lines below at the point that you feel shows how severe you feel your pain is generally and today.

8.1. How would you rate your level of pain today?

None	Moderate to severe	Extremely bad

8.2. Please rate the worst pain that you have experienced in the last 24 hours

None	Moderate to severe	Extremely bad

8.3. How much do you feel that your pain limits your ability to do things?

No limitation	Occasionally limits abilities	Extremely limits abilities

**9.0 Spasms/spasticity.** Please place a cross on the lines below at the point that shows how severe you feel your spasms are and rating of your worst spasm in last 24 hours.

9.1. How would you rate the level of your spasms today?

None	Moderate to severe	Extremely bad

9.2. Please rate the worst spasm that you have experienced in the last 24 hours

None	Moderate to severe	Extremely bad

9.3. How much do you feel that your spasm limits your ability to do things?

No limitation	Occasionally limits abilities	Extremely limits abilities

**10.0 Quality of Life:**

10.1. On the scale below please rate the level that you feel your general quality of life was before your injury

1	2	3	4	5	6	7	8	9	10
Very poor									Extremely good

10.2. On the scale below please rate the level that you feel your general quality of life is now

1	2	3	4	5	6	7	8	9	10
Very poor									Extremely good

10.3. What do you think could have been done differently during your inpatient stay that would have made a significant improvement to how you are now?

10.4. What do you think could have been done differently since your discharge that would have made a significant improvement to how you are now?'

10.5. Please list below the things that you feel add to your quality of life and the things that you feel make your quality of life worse

Things that add to my quality of life	Things that make my quality of life worse

**11.0 Have any significant events happened in your life since your discharge? For example: the birth of your child, getting married, the death of someone close to you?**

No  Yes

**If yes then please state what this was \_\_\_\_\_**

**12.0 Would you be willing for us to continue collecting this information from you in the future?**

Yes  No

If you would be willing to contribute the above data to this research project on a yearly/two yearly basis, then please sign below or ask a witness to sign below to indicate your consent and tick the appropriate box to indicate what you are consenting for. *Please note: As before, you can withdraw your consent at a later date if you wish to.*

I would like to continue to contribute all data to this research project

I would like to only contribute the above information to this research project – not the psychological questionnaires data.

*Signed:* \_\_\_\_\_

**The Psychological Questionnaires were included at this point**

## **Appendix F: Data Management and Analyses**

### **F.1. Data Management**

A great deal of data was collected over the period of this research. In order to ensure that meaningful analyses were performed and accurate results presented steps needed to be taken to ensure that correct and consistent data was held and appropriate analyses are performed. The following sections will discuss the management and handling of data collected, along with the strategies adopted when data is missing. The methods of evaluation and analyses of data will also be discussed along with the methods of reporting of results of analyses. Many of the methods of analyses performed and missing data strategies utilised were selected and adopted in response to form that the data, both missing and present, took.

#### **F.1.1. Data validation and cleaning**

Data collected were checked and confirmed prior to data analysis being performed. This included the lengthy process of confirming data collected through Case Management notes being cross checked with medical notes and therapy or nursing notes as appropriate.

Once data was entered in to the SPSS data file the data was viewed to ensure any potential inconsistencies and entry errors were identified. All analyses were performed using SPSS/PASW Statistics18. Statistical support was obtained via the University College London visiting statistical service at RNOH and Brunel University.

#### **F.1.2. Types Of Data Collected**

Both continuous and categorical data was collected on a longitudinal basis. Some data items were repeated measures, therefore within subject analyses will be performed with these data items where appropriate. The majority of data items will be utilised in between subject analyses to significant differences between groups or to identify if particular variables are associated.

If categorical variables contained categories with only one subject similar category groups were combined, wherever viable, to permit meaningful data analyses.

## **F.2. Dealing with Missing data**

### **F.2.1 Missing Categorical Data**

Even whilst subjects were inpatients it was not possible to ensure that all data was collected. Generally, this is because data was not available in the subject's medical or case management notes or the subject was not available to confirm information. This missing data needs to be handled appropriately in order that results obtained from analyses accurately reflect the characteristics of the groups being studied.

The majority of missing data falls in to the category of missing completely at random (MCAR) in that the 'missingness' of the data did not relate to any observed values. Generally only one or two data items are missing which is below the 5-10% margin deemed acceptable in these situations (White, 2011; Graham, 2009). Where data is missing a note will be made of this when analyses are presented. Due to relatively small numbers in missing data and the need to ensure that the potential for bias is reduced listwise deletion of data was applied, unless discussed otherwise (Graham, 2009; Rubin, 1976).

Due to the nature of a postal survey it was not possible to ensure that all data was collected at one year post-discharge. The potential data set at one year post-discharge for each subject consisted of 158 data items. Omitted data were often answers to sub-questions in a particular section. For example the question in the Post Discharge Booklet

"4.2. How often, on average, do you go shopping for daily needs (food, etc.)?"

Not at all    Daily or every few days    Once a week    Once a month or less"

may have been answered, but the sub-question

"4.2.1. What level of importance do you give this activity?"

High importance    Medium importance    Low importance"

was not. In these cases subjects were deemed to have overlooked a question if all other similar questions in that particular section were answered. In cases where this was the situation and only one or two subjects had omitted to answer questions (less than 5-10% of the data for each question) then data was treated as missing completely at random (White, 2011; Graham, 2009; Rubin, 1976). The majority of data items that are missing fall in to this category. Where data were missing a note will be made of this when analyses are discussed. Due to relatively small numbers of missing data (and so the small impact on statistical power) as well as need to ensure that the potential for bias that may be produced by using other methods is reduced; listwise deletion of data was applied, unless discussed otherwise.

One set of data that is not deemed to be MCAR relates to question 4.1.2 in the Post Discharge Booklet which related to the level of importance the subject ascribed to going to work or college. 14 subjects failed to answer this question. Analyses of the demographics of the non-responders suggested that the group had distinct features and therefore it could not be assumed that the data was MCAR. Analysis of the missing data would require assumptions to be made about the missing data which could be inaccurate and result in biased and inaccurate results (White, 2011). Equally analysing the data without acknowledging the potential influence of the data that were missing could also lead to bias (White, 2011; Graham, 2009; Rubin, 1976). Performing listwise deletion of this data would reduce subject numbers to 34 which would be too small a group for meaningful analysis, but pair wise deletion could bias results (Graham, 2009). For this reason a description of the data available will be presented along with a brief discussion of the profile of non-responders. Further analysis of this data will be restricted to a small number of simple analyses.

### **F.2.2. Missing Continuous Data**

An example of missing continuous data is the date that the SCI individual was referred to the SCIC team, this information was not available for 9 patients either because it was not recorded on the referral form or was could not be found in the medical notes. This is in excess of the 5-10% missing data which can generally be treated as MCAR and has a potential to result in loss of power and potential bias of results. However all patients will have been referred to the SCIC date in order to be admitted. The availability of the date of referral would not impact on either treatment or outcomes. However not using the available data would result in many meaningful analyses being unable to be performed. In order to ensure that there were no distinguishing factors in either group which may explain the 'missingness' of the data. comparison of demographics of these subjects and the remaining 65 that details were available for found no differences between the two groups in terms of demographics or time to admission. Therefore this data was treated as missing completely at random and a complete case analysis performed using listwise deletion of data (White, 2011; Graham, 2009).

### **F.2.3. Psychological Questionnaires Missing Data**

One respondent did not complete both questionnaires during their admission. The first psychological questionnaire was fully completed and in subsequent stages of the research the individual gave full and complete data. Listwise deletion of data was performed when analysis of data involving the SOCQ during admission was performed. When correlations were computed comparing SOCQ data during admission and at one year post-discharge pair wise deletion of data was performed. When difference scores

Appendix F: Data Management and Analysis Methods

were calculated to evaluate how psychological variables may have changed over the time since admission this subject's values for SOCQ difference scores were entered as zero.

At one year post-discharge three subjects omitted to answer a total of four questions on the SOCQ questionnaire, this constituted between 3.33% and 6.67% of the questionnaire data per subject and 0.4% of the overall questionnaire data for this phase of the study. Two subjects omitted to answer three questions on the CSQ, constituting between 4.9% and 2.4% of data for this questionnaire per subject and 0.2% of the overall data for this questionnaire for this phase of the study. No two subjects missed the same question and due to this and the small amount of data missing data it was treated as missing completely at random (White, 2011; Graham, 2009; Schurch *et al.*, 2007). 'Last observation carried forward' was applied in that value for the individual question given during admission was entered in to the data set for the questionnaire at one year post-discharge (White, 2011).

### **F.3. Data Distribution and Normality**

#### **F.3.1. Establishing Distribution of Data**

Descriptive statistics will be utilised to outline the demographic and clinical profiles of the subjects as well as to demonstrate distribution of the data. Where measures of central tendency (mean, median or mode) are reported the appropriate measure of dispersion (Interquartile range, range of scores and standard deviation) will be reported. A 95% confidence interval will also be reported for parametric continuous data and the identified mean should be within the confidence limits given.

In order to establish if continuous data deviated from a normal distribution the absolute value (z value) of skew was calculated by dividing the value of skew by the standard error of skewness (Field, 2009). A z value above 1.96 was viewed to be significant 0.05 and the data viewed as significantly skewed (non-parametric).

A further test applied to identify if data deviated from a normal distribution was the Kolmogorov-Smirnov Test (*D*). As the sample size was not large there would be less chance of a significant result being produced with a small deviation from normality (Field, 2009).

Where continuous data items were not normally distributed the appropriate non-parametric tests were used.

### **F.3.2. Violation of Assumptions of Normality**

Levene's test ( $F$ ) is a means of identifying if there is homogeneity of variance between groups of parametric continuous data. When independent t-tests are performed the results of Levene's test will be reported. When reporting results of Levene's test convention is to report: 'As Levene's statistic was not significant ( $F=?$ ???,  $p=?$ ???) there was an equal level of variation between the two groups.' In the results chapters of this thesis the results of many statistical analyses will be reported. In order to assist the reader when reading through these sections the results of Levene's test will be presented with the t-test report in the following manner ( $t=2.852$  ( $df27$ ),  $p=0.008$ , ( $F=0.013$ ,  $p=0.909$ ),  $N=29$ ) unless the results of Levene's test are significant, in which case they will be presented conventionally and comment made.

Outliers in continuous data have the potential to significantly influence results of analyses. Means of dealing with these include removal of the data for the subject with the outlier. This is acceptable in the situation where only one subject has outlying data or the group is large. However when there are several outliers removal of their data can significantly reduce the power of any analyses performed.

An alternative method of dealing with outliers is to perform log transformation. This calculates the logarithm of data values and replaces the data with these logarithms. Log transformation can also help to reduce positive skew. One difficulty with log transformations is where data has a value of zero. As it is not possible to calculate a logarithm for zero, one was added to all values prior to the logarithm being calculated.

### **F.4. Data Analysis Methods Adopted in this Thesis**

Two tailed tests will be performed unless otherwise indicated (Altman, 1990). A probability ('p') value of 0.05 or less (less than 5% likelihood that the result occurred by chance) will be viewed as significant, a probability value of 0.001 or less viewed as highly significant. The actual probability values achieved from analyses will be reported.

Descriptive statistics were utilised to outline the demographic and clinical profiles of the subjects. Comparisons between groups of subjects were also performed to establish if there were significant differences between groups. Wherever variables contained categories with only one subject similar category groups were combined wherever viable to permit meaningful data analyses. Table 4.6. summarises methods of data analyses utilised in this research

Type of Data	Normality	Test Utilised	Additional/Post-hoc test if significant result
Continuous	Parametric	Pearson's correlation coefficient ( <i>r</i> )	<i>R</i> <sup>2</sup> converted to %
	Non-parametric (with potential data ties)	Kendall's tau-b tests ( $\tau$ )	Strength of association identified by $\tau$
Continuous and categorical (between subjects)	Non-parametric	Mann-Whitney U test (U statistic)	Effect sizes ( <i>r</i> ) z/sq root of N
		Kruskal-Wallis test (H(df) statistic)	Jonckheere's test (J). Effect sizes ( <i>r</i> ) z/sq root of N
	Parametric (2 categories)	Independent t-test ( <i>t</i> statistic) including Levene's test ( <i>F</i> statistic)	Effect sizes ( <i>r</i> ) $r = \sqrt{t^2 / (t^2 + df)}$
Continuous and categorical (within subjects)	Non-parametric	Wilcoxon signed rank test.	n/a
	Parametric (2 categories)	Dependent t-test ( <i>t</i> statistic)	n/a
Categorical (between subjects)	n/a	Chi-square test ( $\chi^2$ (df)) (including Fishers exact test)	Cramer's V statistic (V) and odds ratio where 2x2 contingency tables are used.

Table 4.6. Summary Of Data Analysis Methods Utilised.

#### F.4.1. Identifying Associations

The Chi-square test ( $\chi^2$  (df)) was used to examine the associations between groups of subjects on a variety of categorical variables. Fishers exact test was for categorical analyses where Chi-square test assumptions were violated (Kinnear, 2000). Where significant results were obtained for 2x2 contingency tables, odds ratios were using the formula: Odds =  $\frac{P(\text{event})}{P(\text{no event})}$

Where significant results were obtained for larger contingency tables the Cramer's V statistic (V) was used to measure the strength of significant associations between the categorical variables. Similar values for strength of association were utilised to those used for the Mann Whitney test.

- Values between 0 and 0.3 indicated a small association.
- Values between 0.3 and 0.5 indicated a moderate association.
- Values of 0.5 and above indicated a strong association.

## **F.4.2. Establishing Variations and Similarities between Groups**

### *Type I and Type II errors*

Type I errors occur when a result is deemed to be significant and a genuine effect to be occurring but this is not true, in other words the result is a false positive.

A type II error occurs when a result suggests that there is no effect occurring but there actually is, that is the result is a false negative.

All statistical tests have the potential to make type I and type II errors and this needs to be considered when results are viewed particularly in the case of rejecting null hypotheses.

### *Parametric Tests*

Where continuous data were parametric independent samples t-tests ( $t$ ) were performed for between subject analyses. Post-hoc effect sizes were calculated for significant results and evaluated according to the following ratings.

- Values between 0 and 0.3 indicated a small effect.
- Values between 0.3 and 0.5 indicated a moderate effect.
- Values of 0.5 and above indicated a strong effect.

If Levene's test indicates that the level of variance occurring in the groups is not homogenous then the t-test results with adjusted degrees of freedom will be reported (Field, 2009). Boxplot graphs will be presented showing central tendency and distribution for significant t-test results.

T-tests are assumed to robust violations of assumptions to have relatively low type I error rates. Dependent t-tests were performed when within subject (paired sample) parametric data was analysed.

### *Nonparametric Tests*

To compare non-parametric continuous data over two independent groups the Mann-Whitney U test ( $U$ ) was used. Where a significant relationship was identified effect sizes ( $r$ ) were calculated to establish the size of the difference between the two groups.

- Values between 0 and 0.3 indicated a small effect.
- Values between 0.3 and 0.5 indicated a moderate effect.
- Values of 0.5 and above indicated a strong effect.

To compare continuous data over more than two independent groups the Kruskal-Wallis test ( $H(df)$  statistic) was used. Where a significant group effect was identified a post-hoc test for trend for an ordered pattern to the medians of the groups under comparison was performed using Jonckheere's test ( $J$ ).

Confirmatory analysis of results by parametric test was not generally performed as: the data was not normally distributed, it did not meet the assumptions of a t-test and there was a reduced chance of a type II error (Field, 2009).

Where comparisons of non-parametric data were made between subjects (paired samples) the Wilcoxon signed rank test was utilised.

#### **F.4.3. Identifying relationships**

##### *Bivariate Correlations*

Where two sets of continuous parametric data were analysed to establish relationships the Pearson's correlation coefficient ( $r$ ) was computed. In addition to significance of the correlation coefficient the coefficient was interpreted using the following values to indicate strength of relationship:

- Values between 0 and 0.3 (0 and -0.3) indicate a weak positive/negative linear relationship
- Values between 0.3 and 0.7 (0.3 and -0.7) indicate a moderate positive/negative linear relationship
- Values between 0.7 (-0.7) and above (below) indicate a strong positive/negative linear relationship via a firm linear rule.

The strength of the effect ( $R^2$ ) was also calculated and converted in to a percentage.

If non-parametric correlations were computed and it was not possible to eliminate the possibility of a large number of data ties Kendall's tau-b tests ( $\tau$ ) were used (Field, 2009). In addition to significance of the correlation coefficient the coefficient was interpreted using the values quoted for Pearson's correlation coefficient to indicate strength of relationship. However it needs to be acknowledged that Kendall's tau often returns a lower correlation coefficient value than either Pearson or Spearman correlations which are the tests for which these strength of relationship values were established (Field, 2009).

## **Appendix G: Main Project Paperwork and Report**



***Patient Information Sheet***

**THE EFFECTS OF PROVISION OF RESOURCES ON  
REINTEGRATION OUTCOMES IN SPINAL CORD INJURY**

We would like to invite you to take part in a research study that is currently being undertaken in the hospital. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully and discuss it with anyone you feel you need to. If you have any questions or would like to receive more information then the lead researcher will be happy to talk to you before you make your decision. (Details of how the lead researcher can be contacted are at the end of this sheet). The purpose of this information sheet is to explain to you what information will be collected if you agree to participate.

**What is the purpose of this research project?**

This research project is a long term study looking at how patients progress through their rehabilitation and eventual return to their home and life. It has been suggested that delays in providing services such as housing, training, etc. can affect the ability of a person with spinal cord injury to resume their life in the community. It can potentially lead to higher costs, for both the individual and the state, in terms of increased number of complications, increased need for care, lower levels of independence to name but a few. Through this study we would hope to be able to demonstrate how and when services should be provided to people who have sustained a spinal cord injury for them to be able to get the best out of their lives. From that we hope to be able to lobby to make sure that services are provided effectively.

**What is this study about?**

This study will look at how the services that people with spinal cord injury receive or do not receive may affect their ability to resume their life.

**Why have I been approached to take part in this study?**

You have been approached because you have sustained a spinal cord injury and so are one of a unique group of people who may be able to contribute to this study. You are important as an individual because it is only by obtaining information from individuals that we can hope to compile enough information to show general trends and so make possible recommendations and suggestions.

**What will happen to me if I take part?**

***Stage One***

Initially, we will ask you to complete 2 brief psychological questionnaires. The purposes of these are to look at how people normally deal with situations in their lives and how this may be affected by the support they receive in the future. We need to stress at this point that we will not be looking at your results as an individual, we will be attempting to look at trends in groups of people and how they may be affected by external factors.

We may ask you to complete one of these questionnaires again in a week or 2. We need you to do this so we can show that responses to this questionnaire will not change over such a short period of time.

Appendix G: Main Project Paperwork

### **Stage Two**

This is the information gathering stage and does not require any direct input from you. Information will be collected by us from your hospital records for this research study. This will include details focussing on your current situation, what your future needs will be and how these are met. A full list of the information we will gather throughout this research project is available if you wish to have it.

Only the research study personnel will have access to the information we gather. Your identity will be protected.

### **Stage Three**

This will happen just before your discharge. We will need you to complete the psychological questionnaires that were completed in Stage One again. This is so that we can see how people's perceptions and ways of dealing with things may change over time.

### **Stage Four**

On your discharge from hospital we will record details of your independence levels, support needed, type of discharge accommodation, and how the care and equipment you require are provided. We will also make a note of any of your needs that still have to be met. If your discharge was delayed, we will establish how long this was for and why it happened. We will also include information on how your rehabilitation progressed and any issues that limited the scope of your rehabilitation, e.g. complications, service issues, etc. Once again we will not require your direct participation at this stage. All of this information is normally recorded as part of your discharge process we would ask for your permission to use it as part of this research study.

### **Stage Five**

At your Outpatient follow-up, approximately 1 year following your discharge, we will ask you to fill in the psychological questionnaires again. The reason for this is because people's perceptions and ways of dealing with things may change following their discharge and we need to chart how this may be affected by the support they have received.

In one further questionnaire will ask you to rate how able you feel to access the environment inside and outside your home and whether your housing meets your needs, as well as how you feel this impacts on your ability to live your life. We will ask what vocational activities you undertake, e.g. work, further education or job training, hobbies or family responsibilities, and how important you rate some activities to be to you. We will also ask for details of the support you require and whether you feel that the support you have received meets your needs. During the first year of your discharge we will record any problems that you have experienced because your needs have not been met fully.

### **Do I have to take part?**

It is up to you whether you take part or not. If you feel that you need more information to make that decision one of the researchers will be happy to talk to you and provide you with specific details of the information that will be collected if you require. You will be asked to sign a consent form, if you decide to take part. Your original consent form and a copy of this information sheet will be given to you to keep.

### **What if I do not want to take part?**

Participation in this study is entirely voluntary and your decision either way will not affect the care you will receive from this hospital. Just advise the researcher of your decision when they approach you. We are grateful for your time in considering this study.

You are welcome to withdraw from this study at any time without giving a reason.

### **What are the possible disadvantages, side effects and risks of taking part?**

We do not anticipate any disadvantages, side effects or risks from taking part in this study.

### **What are the possible benefits of taking part?**

This is a long-term study that will be carried out over the next 3 years. Although participation in this study is unlikely have a direct effect on the services you receive. We hope that the results from this study will change services for spinal cord injured people to their advantage both during their rehabilitation and in the community.

### **Will my taking part in this study be kept confidential?**

The Spinal Injuries Unit Team have been informed of this study and instructed to presume that either all patients are taking part or none are taking part.

The researchers are required to ensure that all information is kept confidential and in accordance with the both Data Protection Act and Research Governance requirements. If you agree to take part in this study you will be given a subject identification number, whilst we are collecting your data we will also hold your hospital number in order that we can make sure that data is linked to the right subject. Once we have collected all of the data we need any information that may be able to identify you (e.g. your hospital number, your date of injury and admission) will be removed and your data will be completely anonymous. When results are published only information for the groups of subjects and the group as a whole will be available.

### **Contact for further information**

This research project has been approved by RNOH and Brunel University ethics committees. It is being funded through an RNOH Research & Development Committee Grant.

Lead Researcher      Janine Khare  
Contact details:      020 8909 5582 (internal ext: 5582)  
Email: [janine.khare@rnoh.nhs.uk](mailto:janine.khare@rnoh.nhs.uk)

Please feel free to contact the Lead Researcher if you have any queries or would like to discuss this research study. If you have any queries regarding this research that can not be resolved by the lead researcher they can be addressed to one of the supervisors listed below.

Academic supervision is via Professor L DeSouza, Centre for Rehabilitation Research, Brunel University (Tel: 01895 268847) and **Professor M Ferguson-Pell, Faculty of Rehabilitation Medicine, University of Alberta, Canada (email: [martin.ferguson-pell@ualberta.ca](mailto:martin.ferguson-pell@ualberta.ca) )**

Clinical supervision is via Dr **Jan Gawronski, Consultant in Rehabilitation Medicine, Spinal Cord Injury Centre, RNOH (Internal ext: 5596).**

Thank you for your time and consideration.



**CONSENT TO PARTICPATE IN RESEARCH STUDY**

**The effects of provision of resources on reintegration outcomes in spinal cord injury**

Investigators: Janine Khare, Case Manager  
Prof L DeSouza, Centre for Rehabilitation Research, Brunel University, UK  
Prof. M Ferguson-Pell, Faculty of Rehabilitation Medicine, University of Alberta, Canada  
Dr Jan Gawronski, Consultant in Rehabilitation Medicine, Spinal Cord Injuries Centre, RNOH

- 7 I have read the information sheet and I understand what will be required of me if I take part in this study.
- 8 My concerns regarding this study have been answered by.....
- 9 I understand that at any time I may withdraw from this study without giving a reason and without affecting my normal care and management.
- 10 I understand that information from this study may be published in scientific journals, but that I will not be identified.
- 11 I understand that participation in this study is entirely voluntary.
- 12 Please delete one of the following as appropriate:
  - a I agree to take part in this study.
  - b I agree to take part in this study but do not wish to complete the psychological questionnaires.

Patient's signature or independent witness .....

Name in BLOCK LETTERS .....

Date .....

Investigator's signature .....

Name in BLOCK LETTERS .....

Date .....



Is the patient a first generation immigrant to the UK?

Yes  No  N/A

**9.0 Please state patients reported religious group:** \_\_\_\_\_

**10.0 Employment status on injury:**

Employed  Self-Employed  Retired  
 Student  Unemployed  Full time care giver  
 Unpaid/voluntary work

If working/volunteering/student please state no of hours/week \_\_\_\_\_

Please state job title of current/last job \_\_\_\_\_

**11.0 Educational status:**

Basic state level (up to age 16)  Full high school education  
 Graduate (including primary (A levels etc.)  
professional qualification – diploma etc)  Post graduate

**12.0 Social situation at the time of injury:**

Single (including divorced)  Widowed  Married/cohab  
 In relationship but not cohabiting

**Who did patient live with at the time of injury?**

Family (parents and siblings)  Family (Spouse &/or children)  
 Friends  Partner  Alone (incl. with carer)/Shared accommodation

**13.0 Accommodation type**

House  Flat  Bedsit  Room

**13.1. Tenancy/ownership**

Owner/ occupier  Rented –private  Rented - HA/LA  
 Rented – sublet  Tied accommodation  
 Family Home – please state who owns it: \_\_\_\_\_

**13.2. Is the property occupied to its capacity – including an ‘office room’ if necessary?**  Yes  No

**14.0 Social support network reported by patient:**

Family only  Family and small network of friends  
 Family & wide network of friends  Friends only  
 Socially isolated

**For completion by researcher**

CSQ score: RatCop \_\_\_\_\_ Det/EmCop \_\_\_\_\_ AvCop \_\_\_\_\_  
SOCQ Score: PE \_\_\_\_\_ IPC \_\_\_\_\_ SPC \_\_\_\_\_

**Discharge Data Collection Tool**

**Reintegration Outcomes following Spinal Cord Injury**

**Discharge - Staff form**

**1.0 Neurology and demographics**

<b>Discharge ASIA level</b>		<b>Classification</b>	
-----------------------------	--	-----------------------	--

**1.1. Social situation at time of discharge:**

- Single (including divorced)  Widowed  
 In relationship but not cohabiting  Married/cohab (including not going to Nursing Home)  
cohab as

**1.2. If the patient is not being discharged to a Nursing Home please indicate who they will be living with.**

- Family (parents and siblings)  Family (Spouse &/or children)  
 Partner  Friends  Alone/Shared accommodation

**1.3. Vocational activities:**

- Returning to previous job/studies within 2 months/plan for return in place  
 Returning to previous job/studies but no date for return yet  
 Working for your previous employer in a new role  
 I have a new job (employed or self employed)  
 Retraining/actively job hunting  Retraining being considered  
 Retraining declined at present  Full time caregiver  
 Performing voluntary work  Previously retired or retired since injury

**2.0 Length of stay, rehabilitation and delaying factors**

**2.1. Discharge date:** \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

**2.2. If discharge was delayed please specify number of days** \_\_\_\_\_

**2.2.1. Please specify reason for delayed discharge:**

- Accommodation-adaptations required – Approx cost of works £ \_\_\_\_\_  
 Accommodation – no housing available  Funding of care package  
 'Home starter' funds required  Patient/family refusal  
 Carer recruitment/training  Other (specify) \_\_\_\_\_

**2.3. Was the patient diagnosed with any other condition during their stay (e.g. memory deficits, heart condition, etc.)? If yes please specify.** \_\_\_\_\_

**2.3.1. Does this impact on their functional abilities?** Yes  No

**2.4. Were any goals outstanding on discharge?** Yes  No

**2.4.1. If yes then indicate type/s:**

- Mobility  Continence  Self-care  
 Education  Vocational  Medical/surgical

**2.4.2. Reason for outstanding goals:**

- Patient choice  Patient stamina  Patient cognitive/psych issues  
 medical (further investigation/treatment time required)  
 medical (specialist intervention required - PMH)  
 medical (specialist intervention required - SCI)  
 other (specify) \_\_\_\_\_

**3.0 Compensation Issues – If not applicable please state n/a**

Date legal audit performed (state n/a if not done) \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

- 3.1. Frequency of liaison with solicitor (if applicable).  Regular  
 Attended meetings only  One-off contact  None

3.1.1. If no involvement state reason for this:

- Patient choice  Solicitor choice  Not known

- 3.2. Frequency of liaison with insurance company  Regular  
 Attended meetings only  One-off contact  None

3.2.1. If no involvement state reason for this:

- Patient choice  Insurance co choice  Not known

- 3.3. Has an interim payment been made? Yes  No

- 3.4. If yes please indicate if it has been used to fund any of the following?

Care	
Equipment	
Accommodation	
Adaptations	

**4.0 Care Package - If discharged to a nursing home please go to qu 5**

No. of DN visits per week \_\_\_\_\_

- 4.1. Reason for Visits  Bowel Management  Skin Issues  
 Monitor/supervision  Other

4.2.

No of paid care hours received per week	Tick box if 24/7 <input type="checkbox"/>
No of informal care hours given per week	Tick box if 24/7 <input type="checkbox"/>
No of hours/week that 2 carers are required	Tick box if 24/7 <input type="checkbox"/>
Does an informal carer act as second carer?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Approx cost of care package (obtain from Care Manager)	

4.3. Please indicate the areas of activity that care is required and the reason

Area of need	Reason		
Personal care	Physical restrictions	Cognitive issues	Psychological issues
Mobility	Physical restrictions	Cognitive issues	Psychological issues
Domestic care	Physical restrictions	Cognitive issues	Psychological issues
Social activities	Physical restrictions	Cognitive issues	Psychological issues
Employment activities	Physical restrictions	Cognitive issues	Psychological issues
Child care	Physical restrictions	Cognitive issues	Psychological issues

4.4. Please indicate source of funding for care package: *Note: Private Provision includes only any contribution above the statutory minimum contribution made by all.*

- Public – SSD  Public – NHS  Public – SSD & NHS  
 Public & private  Private only – individual  Private only – interim payment

4.5. No. of care hours due to home/outside environment being inaccessible ...

4.6. Is the Care Agency a Specialist SCI Agency? Yes  No

4.7. Is care provision at a higher or lower level than advised by RNOH?: Higher   
Lower  : N/A

4.7.1. Also please specify the reason for this:

Patient request  Transitional support  Community team decision

**5.0 Accommodation and Environment:**

5.1. Discharge destination.

**Previous home**  Temporary  Permanent  **NHS transfer**

**New Accommodation**  Temporary  Permanent

**Nursing/residential home as:**  Permanent accommodation

Interim – permanent accommodation identified – no adapts required

Interim – permanent accommodation identified – adapts required

Interim - no accommodation identified

5.2. **Source of Accommodation**  Owner/Family owned

Private rental:  Public Sector Rental  ASPIRE property

**5.3. Adapataions**

**Not Required**  **Perfomed – private funding**

**Perfomed – state funding**  **Outstanding (private funds)**

**Outstanding (interim payment)**  **Outstanding (public funds)**

6.0 Is patient able to access the following? Please answer yes if assistance to do this is required due to the level of injury rather than environment.

	Yes	No
The whole of the inside of their home		
The outside of their home		
GP surgery		

**7.0 Mobility and equipment**

Please specify the nature of equipment provision on discharge:

<b>Wheelchair:</b>	Temporary wheelchair provided	Powered	Manual
	Recommended wheelchair provided – state provision		
	Recommended wheelchair provided – private provision (including joint purchase through voucher scheme)		

7.1. If any equipment is outstanding and not agreed/on order please state. \_\_\_\_\_

7.2. Does patient have their own vehicle that they can access? Yes  No

7.3. Do they drive/intend to drive when car available? Yes  No

**8.0 Social support and Community activities:**

Number of times over the past month patient reports that they have:

	Not at all	1-5 times	5-10 times	10 or more
Had Family visiting:				
Had Friend visiting				
Had a social outing from the unit (incl weekend leave)				

**9.0 Community Support:**

**9.1. Please indicate if they will have ongoing contact with any of the following Community professionals**

Social Services Care Manager	
Dept of Employment Advisor	
District Nurse	
Physio	
Community OT	
Support/link worker	
External Case Manager	
Intermediate care/community rehab team	

**9.2. If they will receive outpatient therapy input please indicate the reason:**

Standing	
Brief intervention due to issues/complications	
Ongoing functional/neuro improvement	
Carer training	

Tick if attending RNOH to stand (with carer if needed)

**10.0 Is readmission to RNOH for further rehab planned?**

Yes  No

**For completion by researcher**

**CSQ score: RatCop \_\_\_\_\_ Det/EmCop \_\_\_\_\_ AvCop \_\_\_\_\_**

**SOCQ Score: PE \_\_ IPC \_\_\_\_\_ SPC \_\_\_\_\_.**

**Post-Discharge Phase Booklet**  
**Reintegration Outcomes Following Spinal Cord Injury Study**

**Post-Discharge Phase**

*Now that you have been discharged from the SCIC for one year we need to ask you some questions about where you live, the support you are receiving, what problems you have had and how you have managed over the past year. We also need to ask you to complete the 2 brief psychological questionnaires again.*

*At this stage in the study we are not only looking at how the equipment, care, medical issues, etc you have can affect what you can do but also how it can affect your perceptions. Once again we are trying to observe the 'trends', both good and bad that will only become apparent from many peoples answers. However, your answers as an individual are extremely important to us because if individuals do not answer these questions then we have no means of obtaining information about the group as a whole.*

*Please read the instructions at the beginning of each questionnaire carefully before completing it. Once you have finished please go back through your answers and make sure that you have responded to each item. You may find that some of the questionnaires appear to ask similar questions, but we would be grateful if you could answer all the questions. Leaving a few questions unanswered in any scale will limit the usefulness of the rest of the information in this scale and in others.*

*Please note that all of the information obtained from participants will be kept confidential. Only researchers working on the project will have access to this information.*

*Thank you for your continued support of this research project. We would be grateful if you could take the time to complete the following questionnaires and bring them with you to your clinic appointment. If you require assistance to complete the questionnaires then please contact the primary researcher on 07843 056054 at least 48 hours before your appointment and support will be arranged for you.*

**PLEASE RETURN TO JANINE KHARE, c/o CASE MANAGERS, SCIC.**

**1.0 Your accommodation & environment:**

**1.1. Where do you live?**

- In a property owned by you
- In a property owned by your family
- In accommodation rented from a private landlord
- In accommodation rented from Housing Association or Council
- In a nursing or residential home
- ASPIRE property

**1.2. Is this temporary or permanent accommodation?**

- Temporary accommodation
- Permanent accommodation

**1.3. Who do you live with?**

- On your own (including with a live-in carer)
- With friends
- With parents or close relative
- With partner and/or children

**1.4. Are adaptations to your home still outstanding?**

- Yes
- No
- A permanent property has not been identified for me yet

**1.5. Are you able to access the following places? Please tick 'Yes' if assistance to do this is required due to the level of your injury rather than the environment you are in.**

	Yes	No	Not known /never visited
The whole of the inside of where you live			N/A
The outside of where you live			N/A
GP surgery			
Dentist			
Local shops/food store			
Chemist			
Leisure shopping facilities (i.e. mall, etc)			
Local public transport system			
Local leisure facilities (cinema, sports centre, etc.)			
Your place of work or study			

**Please let us know here if there is anything significant happening in your physical environment at the moment.** For example: the council are digging up the road outside your home, the outside temperature is very hot or very cold, you are having building work done at home, etc.

**2.0 Equipment**

**2.1. Do you have an environmental control unit yet?**

- Yes
- No
- Not applicable

**2.2. Do you have a standing frame or tilt table? (If you can stand independently please tick not applicable and go to question 2.3)**

- Yes
- No
- Not applicable

2.2.1. If not, then are you able to attend a day centre or physio gym to stand regularly?

Yes  No

2.3. Is there any equipment you have still not been provided with?

Yes  No

If yes then please state what this is.

**3.0 Care or assistance required (If you live in a Nursing Home please go straight to question 4.)**

**On average how many hours per week do you receive care or assistance?** (Tick this box if you have a carer 24 hours a day ) \_\_\_\_\_ Hours/week

How many of these hours are due to you not being able to access all of your home?  
\_\_\_\_\_ Hours/week

3.1. **Who provides this care?** Tick as many boxes as are applicable

Paid Carer  District Nurse  Family member or friend

3.2. **Not counting the standard contribution from your DLA/benefits, who funds your care package?**

Social Services (including direct payments)  Health services  
 Social Services and Health Services  
 Private (e.g. your own funds or money from an interim payment)  
 Social Services and Private (e.g. your own funds or money from an interim payment)  
 Not known

3.3. **Please indicate the areas of activity that you need assistance with:**

Tick as many boxes as are applicable.

Personal care  Child care  Domestic care  
 Social activities  Employment activities  Mobility

3.4. **Has the amount of care or support you receive reduced since you were discharged?**  Yes  No  Not applicable

3.5. **Has the amount of care or support you receive increased since you were discharged?**  Yes  No  Not applicable

3.6. **Has the amount of care/assistance you need on a day to day basis changed since you left the unit?**  Yes  No  Not applicable

3.7. **Has the amount of care or support you receive been reduced against your wishes?**  Yes  No  Not applicable

3.8. **Do you feel that you have sufficient control over how and when your care is provided?**  Yes  No  Not applicable

#### **4.0 Social Activities**

4.1. **How often, on average, do you go to work or to college/a training course?**

Not at all  Daily or every few days  Once a week  Once a month or less

4.1.1. What level of importance do you give this activity?

High importance  Medium importance  Low importance

4.1.2. Do you work from home?  Yes  No  Not applicable

**4.2. How often, on average, do you go shopping for daily needs (food, etc.)?**

Not at all  Daily or every few days  Once a week  Once a month or less

**4.2.1. What level of importance do you give this activity?**

High importance  Medium importance  Low importance

**4.3. How often, on average, do you have members of your family visiting you at home?**

Not at all  Daily or every few days  Once a week  Once a month or less

**4.3.1. What level of importance do you give this activity?**

High importance  Medium importance  Low importance

**4.4. How often, on average, do you have friends visiting you at home?**

Not at all  Daily or every few days  Once a week  Once a month or less

**4.4.1. What level of importance do you give this activity?**

High importance  Medium importance  Low importance

**4.5. How often, on average, are you seen by community professionals in your home? (Not counting any live-in carer you may have.)**

Not at all  Daily or every few days  Once a week  Once a month or less

**4.5.1. What level of importance do you give this activity?**

High importance  Medium importance  Low importance

**4.6. How often, on average, do you leave your home for social or leisure/sporting activities? (E.g. visiting friends, going to cinema, etc.)**

Not at all  Daily or every few days  Once a week  Once a month or less

**4.6.1. What level of importance do you give this activity?**

High importance  Medium importance  Low importance

**4.7. If you leave your home only once a week or less please specify why this is.**

For example: no transport, no assistance available, you do not wish to leave house more frequently, etc.

**5.0 Mobility and Transport**

**5.1. If you need a wheelchair, do you have your permanent wheelchair?**

Yes  No  Not applicable

**5.1.1. If so what proportion of the cost did Wheelchair Services cover?**

All of the cost  Part of the cost  None of the cost

**5.2. Do you drive?**  Yes  No

**5.3. Do you have your own vehicle that you can access (with help if needed)?**

Yes  No

**5.4. If you own/have access to a car but do not drive then please indicate the average amount of time per week that you have access to a driver:**

1-5 hours  More than 5 hours but not daily  
 All of the time  Depends on the carer's ability to drive

**6.0 Your employment status**

6.1. **Please tick which one of these statements you feel most applies to you.**

- Returned to your previous job or college/school course
- Returning to your previous job or college/school course in the future
- Working for your previous employer in a new role
- I have a new job (employed or self employed)
- Actively job hunting
- Attending retraining or further education courses
- Unemployed and considering retraining or further education courses
- Full time caregiver
- Performing voluntary work
- Unemployed and not considering retraining or job hunting at present
- Retired prior to or since your injury

6.2. **If you are working (either voluntarily or paid) or studying/retraining, please specify the average number of hours that you do this per week:**

\_\_\_\_\_ Hours/week

**7.0 Community and Hospital professionals**

7.1. **Please indicate if you still have contact with any of the following.** Tick all that are applicable.

- Social Services Care Manager     Employment Advisor
- District Nurse     Physiotherapist     Support/link worker
- Community Occupational Therapist     Another rehab team
- Case Manager (not your Case Manager from the Spinal Centre)

7.2. **If you are currently receiving outpatient physiotherapy or occupational therapy please indicate the reason for this:**

- Standing     Brief intervention due to issues/complications
- Carer training     Functional/neurological improvement

7.3. **Please indicate roughly how many times you have seen or had to call your GP since discharge other than for routine issues such as repeat prescriptions.** \_\_\_\_\_ Times

7.4. **Please indicate roughly how many times you have seen or had to contact with Spinal Unit staff since discharge other than for routine queries, outpatient appointments/ follow-up visits etc.** \_\_\_ Times

8.0 **Complications: Have you frequently or persistently experienced any of the following complications since your discharge? Tick as many as are applicable to you.**

Unmanageable Spasms	Skin Issues	
Frequent breakdown of care package	Bowel management problems	
Autonomic Dysreflexia	Urinary tract infection/bladder management issues	
Pain	Reduction of function	
Other significant issue (please specify)		

8.1. **Have you been admitted to hospital since your discharge because of any of the above issues?**     Yes     No - Go to question 9

**8.2. Please indicate how many times you have had to go to hospital because of these problems since discharge and if you were admitted to hospital:**

Issue	No of times at hospital	Were you admitted? (yes/no)	If Yes then number of admissions	Length of longest admission (days)
Unmanageable Spasms				
Skin Issues				
Breakdown of care package				
Bladder Issues				
Bowel management problems				
Autonomic Dysreflexia				
Reduction of function				
Pain				
Other significant issue				

**9.0 Pain.**

9.1. **How would you rate your level of pain today?** Place a cross on the line to indicate.

None	Moderate to severe	Extremely bad
------	--------------------	---------------

9.2. **Please rate the worst pain that you have experienced in the last 24 hours.** Place a cross on the line to indicate.

None	Moderate to severe	Extremely bad
------	--------------------	---------------

9.3. **How much do you feel that your pain limits your ability to do things?** Place a cross on the line to indicate.

No limitation	Occasionally limits abilities	Extremely limits abilities
---------------	-------------------------------	----------------------------

**10.0 Spasms/spasticity.**

10.1. **How would you rate the level of your spasms today?** Place a corss on the line to indicate.

None	Moderate to severe	Extremely bad
------	--------------------	---------------

10.2. Please rate the worst spasm that you have experienced in the last 24 hours.

Place a cross on the line to indicate.

None	Moderate to severe	Extremely bad
------	-----------------------	------------------

10.3. How much do you feel that your spasm limits your ability to do things?

Place a cross on the line to indicate.

No limitation	Occasionally limits abilities	Extremely limits abilities
------------------	----------------------------------	----------------------------------

**11.0 Quality of Life:**

11.1. On the scale below please rate the level that you feel your general quality of life was before your injury

1	2	3	4	5	6	7	8	9	10
Very poor									Extremely good

11.2. On the scale below please rate the level that you feel your general quality of life is now

1	2	3	4	5	6	7	8	9	10
Very poor									Extremely good

11.3. What do you think could have been done differently during your inpatient stay that would have made a significant improvement to how you are now?

11.4. What do you think could have been done differently since your discharge that would have made a significant improvement to how you are now?'

11.5. Please list below the things that you feel add to your quality of life and the things that you feel make your quality of life worse

Things that add to my quality of life	Things that make my quality of life worse

12.0 Have any significant events happened in your life since your discharge? For example: the birth of your child, getting married, the death of someone close to you?

No                       Yes

If yes then please state what this was \_\_\_\_\_

**13.0 Would you be willing for us to continue collecting this information from you in the future?**

Yes

No

If you would be willing to contribute the above data to this research project on a yearly/two yearly basis, then please sign below or ask a witness to sign below to indicate your consent and tick the appropriate box to indicate what you are consenting for. *Please note: As before, you can withdraw your consent at a later date if you wish to.*

I would like to continue to contribute all data to this research project

I would like to only contribute the above information to this research project – not the psychological questionnaires data.

Signed: \_\_\_\_\_

## ***Psychological Questionnaires Information***

In this following section we need you to give answers to the questions on 2 brief psychological questionnaires. These are the CSQ - Coping Styles Questionnaire (Roger 1996) and the SOCQ – Spheres of Control Questionnaire (Paulhus 1981 & 1990). The Coping Styles Questionnaire, as the name suggests measures how you normally deal with stressful situations. As you can imagine your way of coping with situations will vary greatly from the time of your admission, to discharge and then to one year post-discharge. We want to try and track these changes and show if they are affected by how support and services are provided or not provided.

The Spheres of Control Questionnaire examines where you feel that the control is in your life for example you may feel that you have no control at all and others (be it your family or government) control what you do and when you do it. Alternatively you may feel that you are responsible for absolutely everything in your life. As you can appreciate neither of these situations is ideal and we want to measure if certain situations may push people to perceive control one way or the other and how this may then affect their ability to live their lives.

Both of these questionnaires have been validated for use in the general population and have been extensively researched. The Coping Styles Questionnaire has also been validated for use in Spinal Cord Injured Persons. The Spheres of Control Questionnaire has not but measures elements that the researchers feel will be of high importance to Spinal Cord Injured People and so part of this research project will be validation of this questionnaire for use in this group.

We need to stress at this point that we will be looking at *trends* in the data that is collected i.e. how the *group* of subjects as a whole generally respond to the questions, not individual responses. By the time your questionnaires are scored you will be an anonymous 'number' and so not identifiable. However, if you wish to know your 'scores' on these questionnaires please ask when you are submitting them and the lead researcher can arrange to score the questionnaire with you and go through what the results suggest with you.

### Coping Styles Questionnaire - CSQ(3)

**Instructions:** Although people may react in different ways to different situations, we all tend to have a characteristic way of dealing with things which upset us. How would you describe the way you typically react to stress? Circle or cross out: **Always (A)**, **Often (O)**, **Sometimes (S)**, or **Never (N)** for each item below:

- |    |  |   |   |   |   |
|----|--|---|---|---|---|
| 1  | Feel overpowered and at the mercy of the situation.                    | A | O | S | N |
| 2  | Work out a plan for dealing with what has happened.                    | A | O | S | N |
| 3  | See the situation for what it actually is and nothing more.            | A | O | S | N |
| 4  | Become miserable or depressed.   | A | O | S | N |
| 5  | Feel that no-one understands.  | A | O | S | N |
| 6  | Do not see the problem or situation as a threat.                       | A | O | S | N |
| 7  | Feel that you are lonely or isolated.                                  | A | O | S | N |
| 8  | Take action to change things.  | A | O | S | N |
| 9  | Feel helpless - there's nothing you can do about it.                   | A | O | S | N |
| 10 | Try to find out more information to help make a decision about things. | A | O | S | N |
| 11 | Keep things to myself and not let others know how bad things are.      | A | O | S | N |
| 12 | Feel independent of the circumstances.                                 | A | O | S | N |
| 13 | Sit tight and hope it all goes away.                                   | A | O | S | N |
| 14 | Take my frustrations out on the people closest to me.                  | A | O | S | N |
| 15 | Resolve the issue by not becoming identified with it.                  | A | O | S | N |
| 16 | Respond neutrally to the problem.                                      | A | O | S | N |
| 17 | Pretend there's nothing the matter, even if people ask.                | A | O | S | N |
| 18 | Get things into proportion - nothing is really that important.         | A | O | S | N |
| 19 | Believe that time will somehow sort things out.                        | A | O | S | N |
| 20 | Feel completely clear-headed about the whole thing.                    | A | O | S | N |
| 21 | Try to keep a sense of humour – laugh at myself or the situation.      | A | O | S | N |
| 22 | Keep thinking it over in the hope that it will go away.                | A | O | S | N |
| 23 | Believe that I can cope with most things with the minimum of fuss.     | A | O | S | N |
| 24 | Daydream about things getting better in future.                        | A | O | S | N |
| 25 | Try to find a logical way of explaining the problem.                   | A | O | S | N |
| 26 | Decide it's useless to get upset and just get on with things.          | A | O | S | N |
| 27 | Feel worthless and unimportant.  | A | O | S | N |
| 28 | Trust in fate - that things will somehow work out for the best.        | A | O | S | N |
| 29 | Use my past experience to try to deal with the situation.              | A | O | S | N |
| 30 | Try to forget the whole thing has happened.                            | A | O | S | N |

31	Become irritable or angry.	A	O	S	N
32	Just give the situation my full attention.	A	O	S	N
33	Just take on one thing at a time.	A	O	S	N
34	Criticise or blame myself.	A	O	S	N
35	Pray that things will just change.	A	O	S	N
36	Think or talk about the problem as if it did not belong to me.	A	O	S	N
37	Talk about it as little as possible.	A	O	S	N
38	Prepare myself for the worst possible outcome.	A	O	S	N
39	Look for sympathy from people.	A	O	S	N
40	See the thing as a challenge that must be met.	A	O	S	N
41	Be realistic in my approach to the situation.	A	O	S	N

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Paulhus Spheres of Control Scale  
(Version 1 and 3 Composite)

Please circle or cross a number to indicate how much you agree with each statement.

	Disagree		Neutral			Agree	
1. I can usually achieve what I want if I work hard for it.	1	2	3	4	5	6	7
2. -Even when I'm feeling confident about most things, I still seem to lack the ability to control interpersonal situations.	1	2	3	4	5	6	7
3. By taking an active part in political and social affairs we, the people can control world events.	1	2	3	4	5	6	7
4. Once I make plans, I am almost certain to make them work.	1	2	3	4	5	6	7
5. I have no trouble making and keeping friends.	1	2	3	4	5	6	7
6. The average citizen can have an influence on government decisions.	1	2	3	4	5	6	7
7. -I prefer games involving some luck over games requiring pure skill.	1	2	3	4	5	6	7
8. -I'm not good at guiding the course of a conversation with several others.	1	2	3	4	5	6	7
9. -It is difficult for people to have much control over the things politicians do in office.	1	2	3	4	5	6	7
10. I can learn almost anything if I set my mind to it.	1	2	3	4	5	6	7
11. I can usually establish a close personal relationship with someone I find sexually attractive.	1	2	3	4	5	6	7
12. -This world is run by the few people in power and there is not much the little guy can do about it.	1	2	3	4	5	6	7
13. My major accomplishments are entirely due to my hard work and ability.	1	2	3	4	5	6	7
14. When being interviewed I can usually steer the interviewer toward the topics I want to talk about and away from those I wish to avoid.	1	2	3	4	5	6	7
15. With enough effort we can wipe out political corruption.	1	2	3	4	5	6	7
16. -I usually do not set goals because I have a hard time following through on them.	1	2	3	4	5	6	7
17. -If I need help in carrying out a plan of mine it is usually difficult to get others to help.	1	2	3	4	5	6	7
18. One of the major reasons we have wars is because people don't take enough interest in politics.	1	2	3	4	5	6	7
	Disagree		Neutral			Agree	

19. -Bad luck has sometimes prevented me from achieving things. 1 2 3 4 5 6 7
20. If there's someone I want to meet, I can usually arrange it. 1 2 3 4 5 6 7
21. -There is very little we, as consumers, can do to keep the cost of living from going higher. 1 2 3 4 5 6 7
22. Almost anything is possible for me if I really want it. 1 2 3 4 5 6 7
23. -I often find it hard to get my point of view across to others. 1 2 3 4 5 6 7
24. -When I look at it carefully I realise it is impossible to have any really important influence over what politicians do. 1 2 3 4 5 6 7
25. -Most of what happens in my career is beyond my control. 1 2 3 4 5 6 7
26. -In attempting to smooth over a disagreement, I usually make it worse. 1 2 3 4 5 6 7
27. -I prefer to concentrate my energy on other things rather than on solving the world's problems. 1 2 3 4 5 6 7
28. -I find it pointless to keep working on something that's too difficult for me. 1 2 3 4 5 6 7
29. I find it easy to play an important part in most group situations. 1 2 3 4 5 6 7
30. In the long run, we the voters are responsible for bad government on a national as well as a local level. 1 2 3 4 5 6 7

**For completion by researcher**

**CSQ score: RatCop** \_\_\_\_ **Det/EmCop** \_\_\_\_ **AvCop** \_\_\_\_

**SOCQ score: PE** \_\_\_\_ **IPC** \_\_\_\_ **SPC** \_\_\_\_

<b>ASIA level (if changed)</b>		<b>Classification</b>	
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# Appendix H: All Potential Subjects Comparison Data

## H.1. Pathway and Age Information for All Potential Subjects

	Age at Injury	Length of Stay (working days)	Time to Admission (working days)
N	120	120	120
Mean	46.31	<i>95.52</i>	<i>41.80</i>
Median	45.00	<i>86.00</i>	<i>24.00</i>
Std. Deviation	18.64	<i>55.23</i>	<i>58.78</i>
Skewness	.392	<i>1.54</i>	<i>3.23</i>
Minimum	19.00	<i>15.00</i>	<i>.00</i>
Maximum	89.00	<i>331.00</i>	<i>368.00</i>

Numbers in italics relate to non-parametric data.

Table H.1: All potential subjects demographics

## H.2. Comparisons between Consenting and Non-Consenting Groups

### H.2.1. Categorical Data Comparisons

Injury grouping	If consented		Total
	not consented	Consented	
Ventilator Dependent Tetraplegic	2	2	4
C3 - C5	5	18	23
C6 - C8	4	6	10
IncTetra (D)	7	17	24
Para (A-C)	11	21	32
Inc UMN Para (D)	10	10	20
Amb Cauda Eq.	7	0	7
Total	46	74	120

Table H.2.: Injury Group differences

Comparison of the categorical data of the consenting and non-consenting patients established that there were significant differences between the two groups on only one variable - injury grouping, Fishers exact ( $\chi^2(6) = 16.399, p < 0.05$ ) Cramers V = 0.370,  $p < 0.05$  suggests a medium, significant association between the Length of stay injury group and whether an individual consented or not, no odds ratio is given as there were too many cells. No significant differences were found between the two groups of consenting or non consenting individuals on the following variables:

Marital Status on Injury	If consented		Total
	not consented	Consented	
Single (incl divorced)	17	39	56
Widowed	4	4	8
Married/LT Cohab	25	31	56
Total	46	74	120

Table H.3.: Marital Status differences

No significant differences between the two groups on marital status ( $\chi^2(2) = 2.911, p > 0.05$ ).

Mode of Injury	If consented		Total
	not consented	Consented	
Fall	15	19	34
Industrial Accident	1	4	5
Self Harm	0	2	2
Violence/Assault	0	6	6
Medical Accident	0	3	3
RTA	11	16	27
Sport/Leisure	3	8	11
Non-traumatic	16	16	32
Total	46	74	120

Table H.4.: Mode of Injury Group Differences

No significant differences between the two groups on mode of injury ( $\chi^2(7) = 9.404, p > 0.05$ ).

Gender	If consented		Total
	not consented	Consented	
Male	36	56	92
Female	10	18	28
Total	46	74	120

Table H.5.: Gender Group Differences

No significant differences between the two groups on gender ( $\chi^2 (1) = 0.106, p > 0.05$ ).

Ethnic Group	If consented		Total
	not consented	Consented	
White British	25	49	74
Black British	1	4	5
British Asian	2	4	6
British Turk/Greek/Cypriot	1	0	1
African	4	3	7
Asian	5	3	8
White Eastern Europe	3	2	5
White Central Europe	2	0	2
Black Caribbean	1	3	4
White Irish	0	2	2
South Asian	1	1	2
Kenyan Indian	0	1	1
White South African	0	1	1
White USA	0	1	1
Total	45	74	119

Table H.6.: Ethnicity Group differences

No significant differences between the two groups on ethnic group representation ( $\chi^2 (13) = 12.987, p > 0.05$ ),

Employment Status on Injury	If consented		Total
	not consented	Consented	
Employed	18	39	57
Self-Employed	8	9	17
Retired	9	16	25
Student	1	5	6
Unemployed	8	4	12
Full Time Care Giver	2	1	3
Total	46	74	120

Table H.7.: Employment Status Group Differences

No significant differences between the two groups on employment status at the time of injury ( $\chi^2 (5) = 7.729, p > 0.05$ ), no odds ratio is given as there are too many cells

Complete or Incomplete SCI	If consented		Total
	not consented	Consented	
Complete	16	36	52
Incomplete	30	38	68
Total	46	74	120

Table H.8.: Complete/Incomplete Group Differences

No significant differences between the two groups on completeness of SCI ( $\chi^2 (1) = 2.221, p > 0.05$ ).

Paraplegic or Tetraplegic	If consented		Total
	not consented	Consented	
Paraplegic	28	32	60
Tetraplegic	18	42	60
Total	46	74	120

Table H.9.: Paraplegic/Tetraplegic Group Differences

No significant differences between the two groups on whether they were paraplegic or tetraplegic ( $\chi^2(1) = 3.525, p > 0.05, p > 0.05$ ).

Level of education was not available for the non-consenting group consistently and so was not analysed.

#### H.2.2. Continuous Data Comparisons

No significant difference was found between the two groups for age at the time of injury, ( $t(118) = 1.036, p > 0.05$ ). See Table 4.1.10 and 4.1.11 below.

Similarly mean time to admission for those who consented or did not consent ( $U = 1,901, z = 1.075; p > 0.05, r = 0.098$ ) was not found to be significant. However a t-test found that differences were significant ( $t(118) = -2.467, p < 0.05$ , equal variances not assumed (Levene  $F(11,380), p = 0.001$ ) perhaps this is because this data is skewed in the consenting group but not in the non-consenting group (see tables below).

However, significant differences were found between the two groups on Length of stay ( $U = 2,135.5, z = 2.340; p < 0.05, r = 0.213$ ) and t-test also confirmed this ( $t(118) = -1.937, p > 0.05$ ). Levene's statistic confirmed homogeneity of variance between the two groups (Levene  $F(0,424), p = 0.516$ ).

	Age at Injury	LOS (working days)	Injury to Admission Working Days
Number	46	46	46
Mean	48.54	83.28	28.00
Median	48.50	72.50	21.50
Std. Deviation	17.04	52.46	25.57
Skewness	0.19	1.78	0.97
Std. Error of Skewness	0.35	0.35	0.35
Minimum	19.00	18.00	0.00
Maximum	89.00	278.00	90.00

Table H.10 Non Consented Group Continuous Statistics

	Age at Injury	LOS (working days)	Working Days Injury to Admission
Number	74	74	74
Mean	Mean	103.14	50.38
Median	Median	88.00	25.50
Std. Deviation	Std. Deviation	55.88	70.96
Skewness	Skewness	1.51	2.67
Std. Error of Skewness	Std. Error of Skewness	0.28	0.28
Minimum	Minimum	15.00	0.00
Maximum	Maximum	331.00	368.00

Table H.11 Consented Group Continuous Statistics

Test of Homogeneity of Variance		Levene Statistic	df1	df2	Sig.
Age at Injury	Based on Mean	1.650	1	118	0.202
Length of Stay (working days)	Based on Mean	.424	1	118	0.516
Working Days from Injury to Admission	Based on Mean	11.380	1	118	0.001

Table H.12 Comparison of Continuous Data for Consenting and Non-Consenting Subjects

## Appendix H: All Potential Subjects' Comparison Data

# Appendix I: Consenting Subject Detailed Demographics

## Demographics

No significant differences for gender were found across injury grouping ( $\chi^2(df4)=1.874, p=0.792$ ), mode of injury ( $\chi^2(df7)=5.314, p=0.623$ ) or whether the subject had sustained a NTSCI or traumatic (TSCI) injury ( $\chi^2(df1)=0.632, p=0.470$ ).

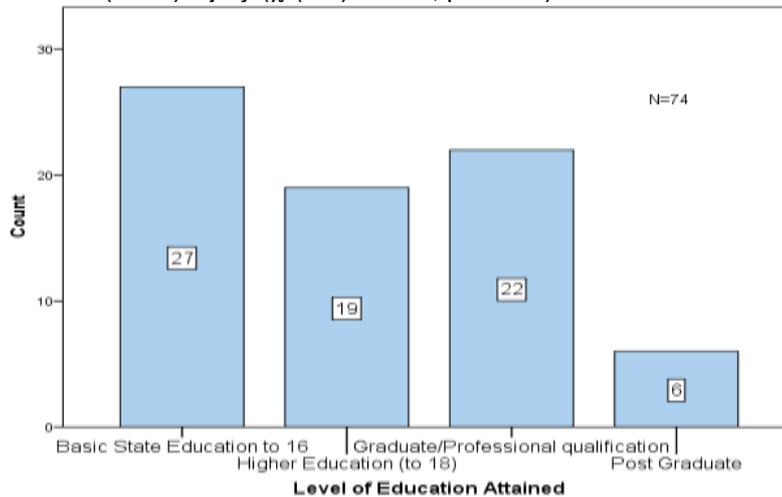


Figure I.1 Educational Level Attained Prior To Injury

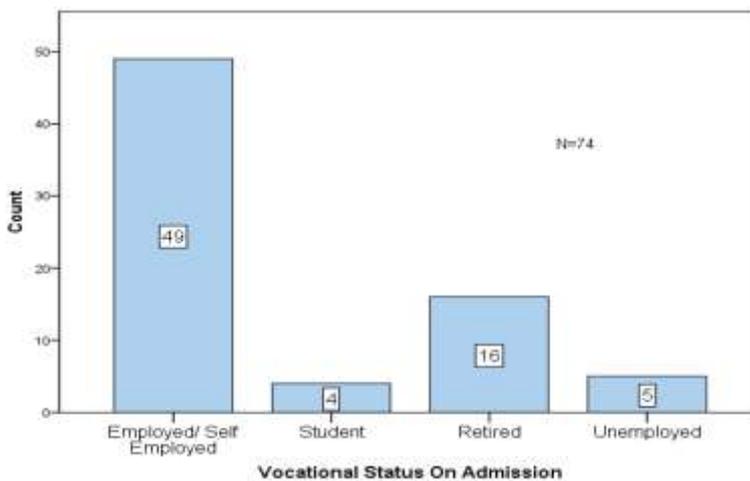


Figure I.2 Vocational Status on Injury

66.2% (N = 49) who were employed or self-employed at the time of injury, including those who described themselves as full time carers (Figure I.2). The mean number of hours working/studying was 25.91 (Std Dev 16.82).

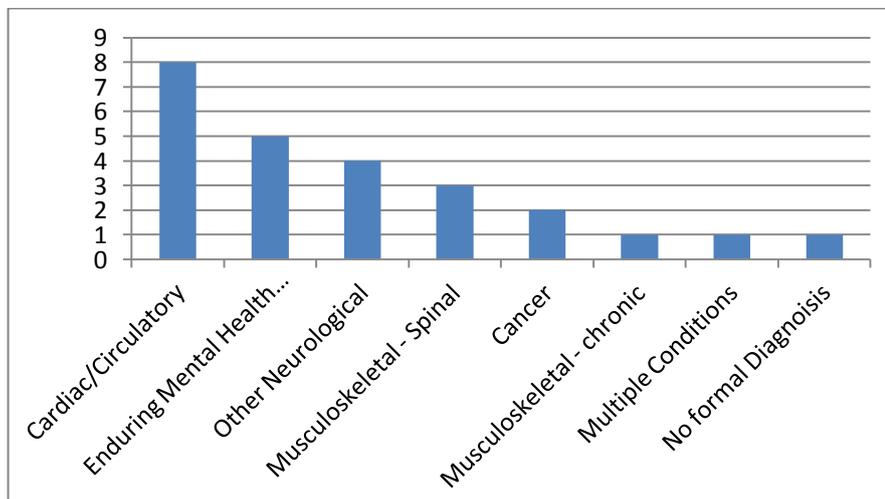


Figure I.3. Types of Previous Medical Conditions Subjects Had On Admission

33.8% (N=25) of subjects had a significant pre-existing medical condition prior to admission. Information on the type of condition was missing in 22.6% of cases.

77% of subjects were British (white British N=49, Black British N=4 and British Asian N=4). The remainder of subjects were mainly from a range of European, African and Asian locations, with no group containing more than 3 individuals. 23% (N=17) of subjects were first generation immigrants to the UK.

Ethnic Group	Frequency	Percent
White British	49	66.2
Black British	4	5.4
British Asian	4	5.4
African	3	4.1
Asian	3	4.1
White Eastern Europe	2	2.7
Black Caribbean	3	4.1
White Irish	2	2.7
South Asian	2	2.7
Other (Groups of One)	2	2.7
Total	74	100.0

Table I.1. Ethnic Groups of Subjects

	Admission	Discharge
Single (including divorced)	30	34
Widowed	4	4
Significant Relationship but not cohabiting	5	3
Married/Long Term Cohabit	35	33
Total	74	74

Table I.2. Subject's Marital Status at the Time of Injury and Discharge

Injury group	Admission	Discharge
C1-5 Tetraplegic A-C	23	22
C6-8 Tetraplegic A-C	4	4
Paraplegic A-C	28	25
Tetraplegic D	16	16
Paraplegic D	3	7

Table I.3 Injury Groups on Admission and at Discharge

Who Subject Lived With at Injury	Frequency	Percent
Family (parents, etc)	9	12.2
Family (spouse & kids)	15	20.3
Partner	21	28.4
Friends	7	9.5
Alone (incl HMO)	22	29.7
Total	74	100.0

Table I.4. Who Subjects Lived with at the Time of Injury

Accommodation Type	Frequency	Percent
House	44	59.5
Flat	26	35.1
Room	4	5.4

Table I.5. Type of Accommodation Subject Lived In At Time of Injury

55.4% (N=41) of subjects lived in a property owned by either them or their family (Figure 5.4). 59% (N=44) lived in a house and only 5.41% (N=4) lived in a rented room in a shared house. 60.8% (N=45) of subjects lived in a property that was occupied to maximum capacity.

## Appendix I: Consenting Subjects' Detailed Demographics and Interactions

Status of Residency	Frequency	Percent
Owner/Occupier	34	45.9
Family Home	7	9.5
Rented - Private	22	29.7
Rented - state	9	12.2
Rented - sublet	1	1.4
Tied Accom	1	1.4
Total	74	100.0

Table I.6. Source of Accommodation at Time of Injury

AIS Grading	Grade on Admission		Grade on Discharge	
	Frequency	Percent	Frequency	Percent
A	34	45.9%	32	43.2%
B	10	13.5%	7	9.5%
C	11	14.9%	12	16.2%
D	19	25.7%	23	31.1%

Table I.7. AIS Grade of Subjects at Admission

### Demographic interactions

Interaction	Test statistic	df	p
Type of Complications on Admission: Injury Grouping on Admission	$\chi^2=19.958$	16	0.309
Presence of Complications on Admission: TSCI or NTSCI	$\chi^2=0.967$	1	0.490
Presence of Complications on Admission: Mode of Injury	$\chi^2=8.412$	7	0.255

Table I.8 Non-significant Interactions between the Presence and Type of Complications on Admission and Injury Demographics

Whether the subject's injury was due to TSCI or NTSCI was not significantly related to the presence of complications on admission, nor was the specific mode of injury, suggesting that complications were no more likely to occur following any specific mode of injury (Table I.14).

### Injury to Admission Pathway

	Days From Injury To Referral (N=65)	Days From Referral to Admission (N=65)	Number of Days to Admission (N=74)
Injury Groups on Admission	$H=5.818$ (df4)	$H=1.769$ (df4)	$H=1.970$ (df4)
	$p=0.213$	$p=0.778$	$p=0.741$
Complication Type on Admission	$H=4.585$ (df4)	$H=9.238$ (df4)	$H=4.955$ (df4)
	$p=0.333$	$p=0.055$	$p=0.292$

Table I.9 Non-Significant Interactions between Times to Referral and Admission and Injury Groupings

### Referral Information

Comparison of the groups with or without referral date found no significant differences for gender ( $\chi^2(df1)= 0.025$ ;  $p=1.00$ .), mode of injury ( $\chi^2(df7)= 6.093$ ;  $p=0.426$ ), injury grouping ( $\chi^2(df4)= 0.643$ ;  $p=1.00$ ), number of days to admission ( $t(df7.449)=0.051$ ,  $p=0.961$ ,  $F=5.108$ ,  $p=0.029$ ) or age ( $U=181.00$ ,  $z=-1.845$ ,  $p=0.065$ ) across the two groups. Therefore the missing data was treated as missing completely at random (Graham, 2009) and a complete case analysis conducted. In the case of NTSCI the date of injury was taken as the first day of the month in which symptoms were reported.

### Discharge Demographics

Additional Condition Diagnosed	Frequency (N)
Pulmonary Emboli	6
Head Injuries	2
Significant Mental Health Condition	2
Cardiac Issues	2
Syrinx	1
Epilepsy	1
Heterotopic Ossification	1
Visuospatial Neglect	1
Shoulder Condition	1

Table I.10. Additional Conditions Diagnosed in Subjects during Admission

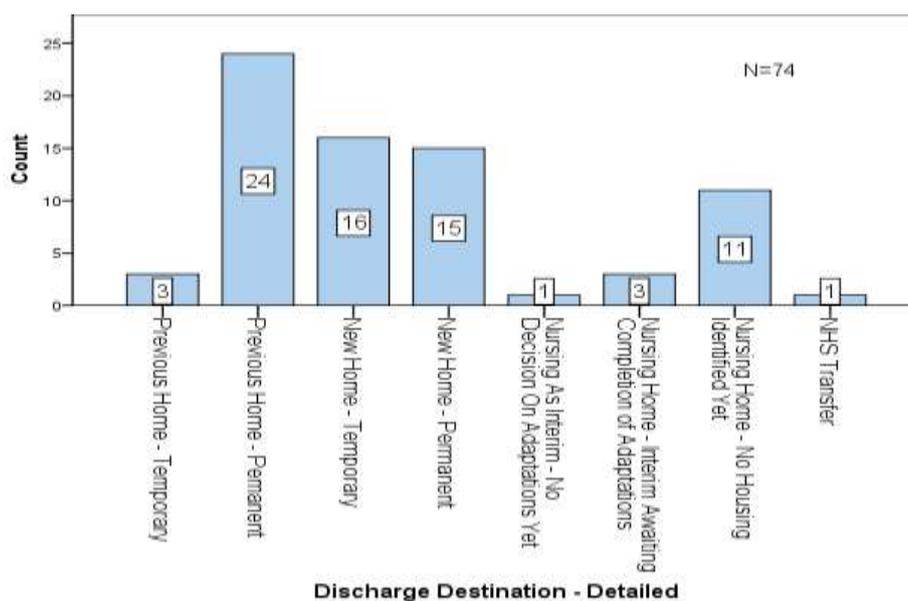


Figure I.4 Discharge Destination of Subjects – Detailed

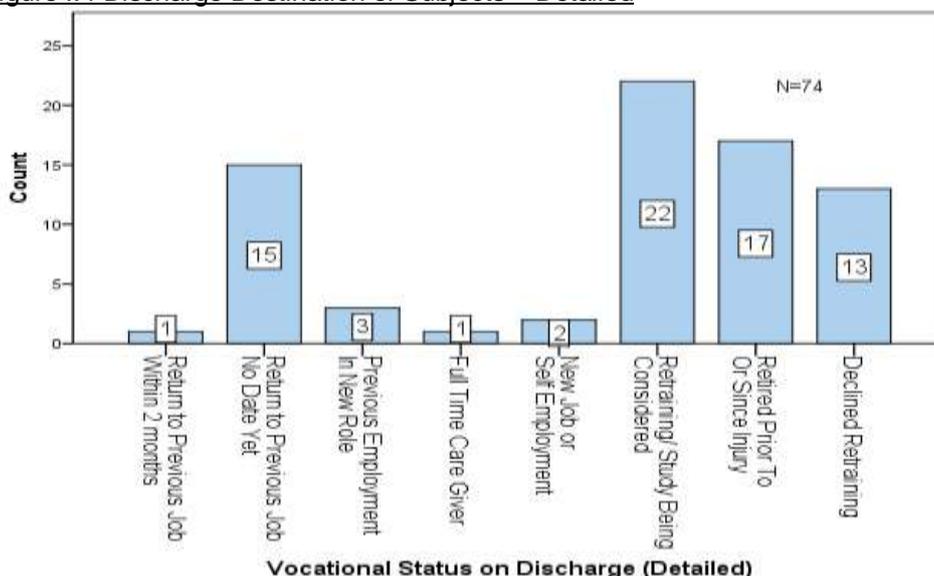


Figure I.5 Detailed Vocational Status on Discharge

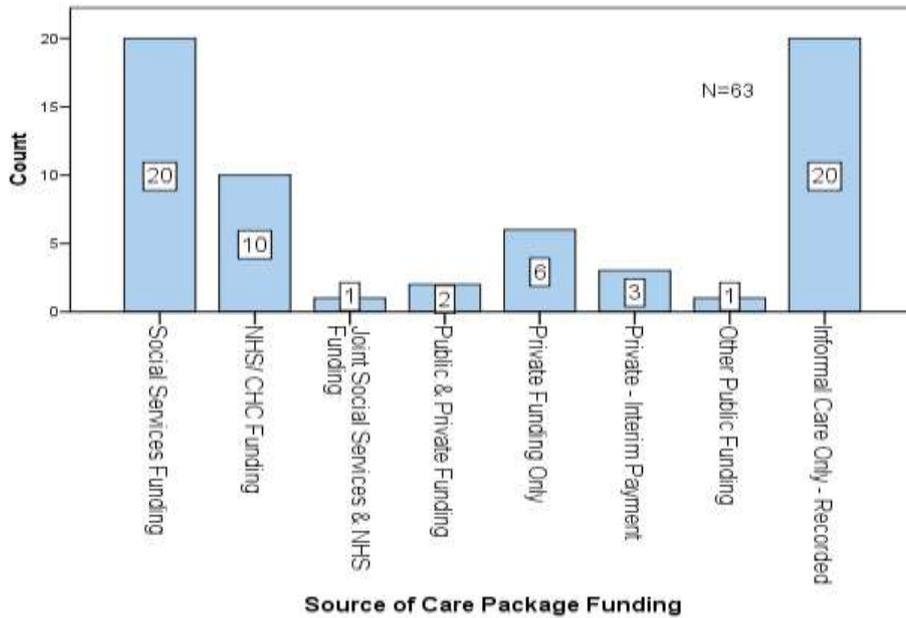


Figure I.6 Source of Care Package/Placement Funding

	Hours of Care Received Per Week	Weekly Cost of Care Package (£)	Hours of Informal Care Received Per Week
Mean	108.09 (95% CI 74.97, 141.20)	884.35 (95% CI 638.43, 1130.26)	1.27 (95% CI 0.7, 1.834)
Std. Dev	76.58	568.67	1.89
Median	168.00 (IQR=154.0)	1000.0 (IQR=1139.6)	0 (IQR=2.0)
Skew	-0.492 (z=-1.02)	-0.014 (z=-0.03)	2.884 (z=8.14)
Min.	7.00	123.20	0.00
Max.	168.00	1800.00	10.00
Mode	168.00	1000.00	0.00

Table I.11 Amount and Costs of Care Provided to Subjects on Discharge

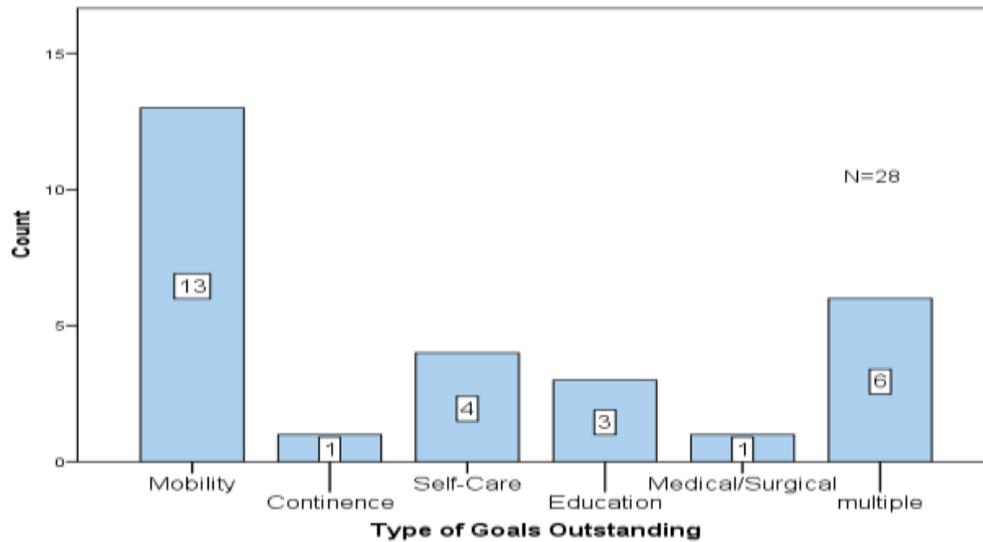


Figure I.7 Type of Outstanding Rehabilitation Goals

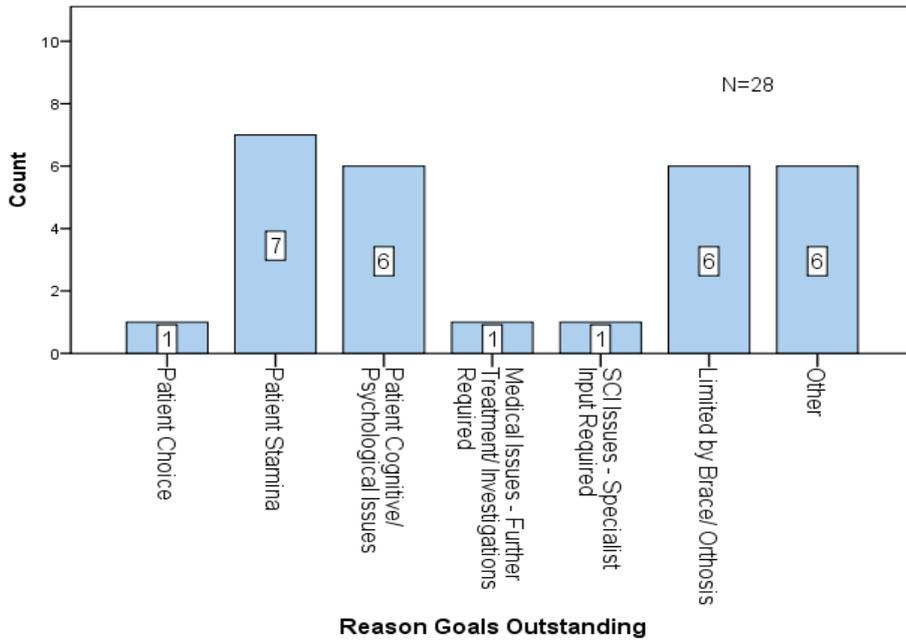


Figure I.8 Reason Rehabilitation Goals Were Outstanding

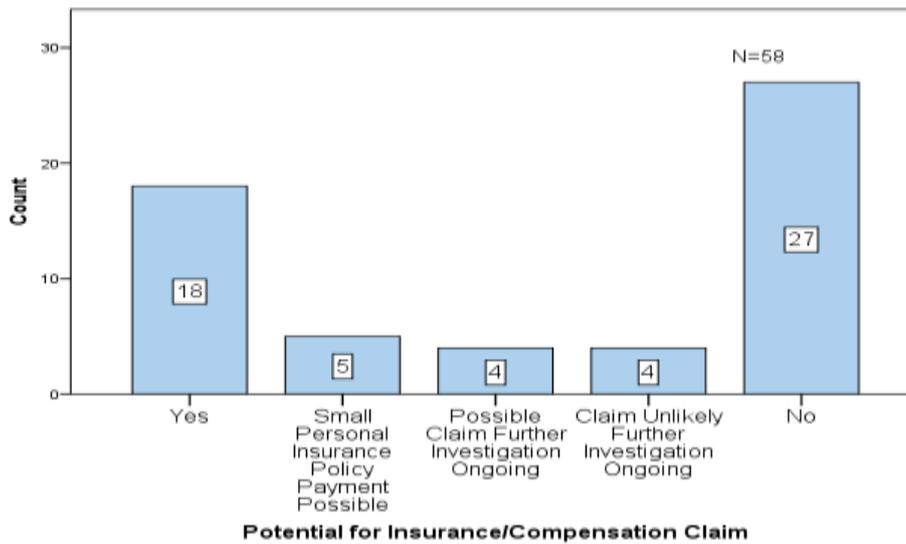


Figure I.9 Subjects Seen by Legal Support Service with the Potential for Compensation/Small Insurance Policy Payment

**Discharge Demographic Interactions**

Interactions With Overall LOS	Test Statistic	z	p
Significant Pre-Existing Condition (N=74)	U=681.5,	0.164	0.869
Whether Admitted Within 30 Days Or Not	U=696.5	0.218	0.828
Additional Condition Diagnosed During Admission	U=601	1.297	0.134

Table I.12 Non-significant differences in Overall LOS across Demographic Groups

	If a Condition Diagnosed During Admission	Completed Rehab Within or Over Target LOS	Age
Goal Attainment	$\chi^2=0.105$ (df1) $p=0.781$	$\chi^2=0.696$ (df2) $p=0.883$	U=688.5, z=0.496 $p=0.620$

Table I.13 Non-Significant Interactions between Goal Attainment and a Range of Subject and Discharge Demographics

Injury Group at Discharge	Reason for Discharge Delay and numbers delayed			
	Discharge not delayed (N)	Housing/ Adaptations (N)	Care or Placement issues/ funding (N)	Other (N)
Tetraplegic A-C	9	4	11	2
Paraplegic A-C	11	9	5	0
Tetraplegic D	13	2	0	1
Paraplegic D	4	2	0	1
Total number of subjects	37	17	14	4
Total discharge delay days	0	510	1054	75

Table I.14 Reasons for Discharge Delays and Numbers Delayed by Injury grouping

## **Appendix J Comparison of Demographics of Subjects Who Did and Did Not Contribute Data at One Year Post-Discharge**

Contingency tables were viewed for these categorical data items to identify potential explanations for significant differences in contribution of data at one year post-discharge.

Variable	$\chi^2$ Value (and type)	df	p	Cramer's V
Gender	0.802 (Pearson)	1	0.280	0.106
Mode Of Injury	12.827 (Fisher)	7	0.69	0.425
Delay In Admission?	0.73 (Pearson)	1	1.00	0.032
Vocational Status On Discharge	4.813 (Fisher)	4	0.316	0.258
Marital Status On Discharge	5.450 (Fisher)	3	0.112	0.287
Potential Compensation Claim?	3.018 (Fisher)	4	0.569	0.215
If There Was A Delay In Discharge	1.823 (Pearson)	1	0.211	0.160
Reason Discharge Delayed	2.757 (Fisher)	2	0.309	0.287
Accommodation Source On Injury	9.421 (Fisher)	5	0.54	0.367
Discharged To Temporary or Permanent Accommodation	3.430 (Fisher)	1	0.078	0.220
Injury Group On Discharge	3.929 (Fisher)	3	0.280	0.241
Paraplegic/Tetraplegic	0.485(Pearson)	1	0.612	0.083
Ethnicity	9.617 (Fisher)	8	0.197	0.373

Table J1 Variables On Which Subjects Who Did And Did Not Contribute Data Did Not Significantly Vary.

Variable	$\chi^2$ Value (and type)	df	p	Cramer's V
Vocational Status At Injury	8.870 (Fisher)	3	0.022	0.348 (p=0.034)
Educational Level Attained At Injury	10.448 (Fisher)	3	0.012	0.375 (p=0.017)
Discharge Destination	9.639 (Fisher)	3	0.015	0.361 (p=0.016)
Accommodation Source On Discharge	14.101 (Fisher)	6	0.014	0.463 (p=0.013)

Table J.2. Categorical Variables On Which Subjects Who Did And Did Not Contribute Data Significantly Varied.

The age of the subject at the time of injury was significantly related to whether they contributed data at one year post-discharge (U= 718.0, z=2.041, p=0.041), those who contributed data being older (Median age=44.5) than those who did not (Median age=30.0), although the effect size of this relationship was small (r= 0.242). Additionally the Median age of the group as a whole was 43.0 (Mean= 43.69) which is closer to the median age of those who contributed data. The modal age for both the group who did contribute data and the whole subject group was 24.

Source of Discharge Accommodation	Contributed Data At One Year Post-Discharge?		
	No	Yes	Total
Nursing Home	7	8	15
Family Home	0	4	4
Own Property	4	20	24
Rented - Private Sector	4	6	10
Rented - Public Sector	3	9	12
ASPIRE Property	4	0	4
Hotel	1	1	2
Total	23	48	71

Table J.3. Subjects within Categories of Source of Accommodation on Discharge Who Did or Did Not Contribute Data

In the 'Source of Accommodation on Discharge' category the largest group of subjects were discharged to their own property (33.8% of subjects) and a large proportion of these subjects contributed data (83.3%), as Table J.4. shows. However the majority of subjects in all groups contributed data at one year post-discharge, apart from those discharged to Aspire

accommodation. In all but one, small, group of subjects (those discharged to the Aspire property) there was a positive variation in favour of subjects contributing data.

Discharge Destination	Contributed Data At One Year Post-Discharge?		
	No	Yes	Total
Previous Home	3	23	26
New home	13	17	30
Nursing Home - Interim	7	7	14
NHS Transfer	0	1	1
Total	23	48	71

**Table J.4. Subjects within Categories of Discharge Destination Who Did or Did Not Contribute Data**

As shown in Table J.4. two large groups were present ('Discharged to a New Home' and 'Discharged to Previous Home', 42.3% and 36.6% respectively) in the Discharge Destination category and a significant proportion of one of those groups ('Discharged to Previous Home', 88,5%) contributed data at one year post-discharge. Those who were discharged to an Aspire property or hotel would have been classified as being discharged to a new home, a category in which the majority of subjects contributed data at one year post-discharge. For the majority of the categories of subjects there is a positive variation in favour of subjects contributing data, however for the group of subjects who were discharged to a nursing home (N=14) the subjects were as likely to contribute data as not contribute data.

Level of Education Attained At Injury	Contributed Data At One Year Post-Discharge?		
	No	Yes	Total
Basic State Education to 16	12	13	25
Higher Education (to 18)	6	13	19
Graduate or Professional Qualification	2	20	22
Post Graduate	3	2	5
Total	23	48	71

**Table J.5. Subjects within Categories of Level of Education Attained At Injury Who Did or Did Not Contribute Data**

For the majority of the categories of level of education attained prior to injury shown in Table J.5. there is a positive variation in favour of subjects contributing data however for the small group of subjects with a post-graduate qualification one subject more did not contribute data than did.

Vocational Status At Injury	Contributed Data At One Year Post-Discharge?		
	No	Yes	Total
Employed/Self Employed	17	31	48
Student	3	1	4
Retired	1	14	15
Unemployed	2	2	4
Total	23	48	71

**Table J.6. Subjects within Categories of Vocational Status at Injury Who Did or Did Not Contribute Data**

As shown in Table J.6. 67.6% of the original sample was in employment at the time of injury, and of these subjects. 64.6% contributed data at one year post discharge. In the two largest categories of vocational status there is a positive variation in favour of subjects contributing data. However this is not the case in the two smallest category groups where three out of four subjects who were a student did not contribute and two out of four of those who were unemployed did not contribute data.

## Appendix J: Comparison of Subjects Who Did and Did Not Contribute Data at One Year Post-Discharge

## Appendix K One Year Post-Discharge Detailed Demographics and Interactions

	In original sample (n=74)	In sample available at one year post-discharge (N=71)	In responding (one year post-discharge) sample (N=48)
% Male	75.7%	76%	72.9%
Age at injury	43.93	43.69	47.00
Median LOS	89.5 days (IQR 40.25)	-	85.5 days (IQR 35)
% under/on Target LOS	55.4% (N=41)	-	56.3% (N=27)
% Delayed Discharge	50% (N=37)	-	43.8% (N=21)
Median discharge delay	0.5 days (IQR 30)	-	0 days (IQR 18)
Tetraplegic A-C	35.1% (N=26)	-	25% (N=12)
Paraplegic A-C	33.8% (N=25)	-	37.5% (N=18)
Tetraplegic D	21.6% (N=16)	-	27.1% (N=13)
Paraplegic D	9.5% (N=7)	-	10.4% (N=5)

Table K.1 Differences between Original Sample Population and Those Contributing Data at One Year Post-Discharge

How often go to local shop?	Number (%)	Importance Ascribed	Number (%)
Not at all	17 (35.4%)	Low	12 (25.0%)
Monthly or less	8 (16.7%)	Medium	15 (31.3%)
Once a week	13 (27.1%)	High	19 (39.6%)
Daily/every few days	10 (20.8%)	Declined to answer	2 (4.2%)
Total	48 (1000%)		48 (1000%)

Table K.2 Frequency of Visits to Local Shops and Importance Ascribed

How often have a social/leisure outing?	Number (%)	Importance Ascribed	Number (%)
Not at all	3 (6.3%)	Low	2 (4.2%)
Monthly or less	12 (25.0%)	Medium	14 (29.2%)
Once a week	10 (20.8%)	High	31 (64.6%)
Daily/every few days	22 (45.8%)	Declined to answer	1 (2.1%)
Total	47 (97.9%)		48 (1000%)

Table K.3 Frequency of Social/Leisure Outings and Importance Ascribed

Issue	No. of Subjects with Issue	No. of Hospital Visits	No. of Subjects Admitted	No. of Admissions	Longest LOS	Total Admission Days
Spasms	3	4	1	2	4	>4*
Skin	5	8	3	3	21	36
Bladder	9	15	6	6	18	37
Bowel	6	9	5	5	12	>24*
Autonomic Dysreflexia	1	2	1	2	28	>28*
Function Reduction	2	2	1	1	21	21
Pain	2	2	0	0	0	0
Other	7	8	7	7	25	72

\*= The total number of days for both admissions is not known as only details of the longest admission were requested or the subject did not give information.

Table K.4 Primary Reasons for Hospital Visits and Admissions

Source of Accommodation on Injury	Source of Accommodation at One Year Post-Discharge					Total
	Own Property	Family Home	Rented - Private Sector	Rented - Public Sector	Nursing home	
Own Property	20	0	2	2	3	27
Family Home	0	2	2	0	1	5
Rented – Private Sector	2	1	0	7	0	10
Rented – Public Sector	1	0	0	4	0	5
Rented – Sublet	0	0	0	1	0	1
Total	23	3	4	14	4	48

Table K.5 Comparison of Source of Accommodation at Injury and One Year Post-Discharge

	Relationship	Test statistic	df	p
Relationships Between Vocational Status at One Year Post-Discharge and:	Level of Education (N=27)	$\chi^2=5.751$	2	0.072
	Gender (N=27)	$\chi^2=0.224$	1	0.696
	Marital Status on Discharge (N=27)	$\chi^2=2.026$	3	0.909
	Ethnicity (N=27)	$\chi^2=6.351$	6	0.365
	Mode of Injury(N=27)	$\chi^2=4.036$	7	0.953
	TSCI or NTSCI (N=27)	$\chi^2=0.675$	1	0.569
	Injury Group (N=27)	$\chi^2=5.474$	6	0.505
	Paraplegic or Tetraplegic (N=27)	$\chi^2=4.516$	2	0.98

Table K.6 Non-significant Relationships between Vocational Status and Non-Modifiable Subject and SCI Demographics

How often have family visiting?	Number (%)	Importance Ascribed	Number (%)
Not at all	6 (12.5%)	Low	4 (8.3%)
Monthly or less	7 (14.6%)	Medium	16 (33.3%)
Once a week	8 (16.7%)	High	28 (58.3%)
Daily/every few days	27 (56.3%)	Declined to answer	0 (0%)
Total	48 (1000%)		48 (1000%)

Table K.7 Frequency of Visits from Family and Importance Ascribed

How often have friends visiting?	Number (%)	Importance Ascribed	Number (%)
Not at all	1 (2.1%)	Low	4 (8.3%)
Monthly or less	12 (25.0%)	Medium	20 (41.7%)
Once a week	15 (31.3%)	High	23 (47.9%)
Daily/every few days	19 (39.6%)	Declined to answer	1 (2.1%)
Total	47 (97.9%)		48 (1000%)

Table K.8 Frequency of Visits from Friends and Importance Ascribed

Type of Frequent and Persistent Issue/Complication	Number of Subjects and % of 48
Nil Issues	3 (6.3%)
Skin	22 (43.8%)
Care Issues	4 (8.3%)
Bowels	24 (50%)
Bladder	29 (60.4%)
Pain	37 (77.1%)
Spasms	34 (70.1%)
Autonomic Dysreflexia	5 (10.4%)
Function Reduction	6 (12.5%)
Two Issues	6 (12.5%)
Three or More Issues	28 (58.3%)

Table K.9 Types of Issues and Complications Experienced

	Pain Rating Today	Rating - Worst Pain in 24hrs	Extent Pain Limits Abilities
Mean	3.84 (CI 2.71 – 4.91)	4.46 (CI 3.32 - 5.59)	3.91 (CI 2.75 - 5.06)
Std. Dev	3.69	3.89	3.97
Median	2.75 (IQR 6.38)	5.0 (IQR 6.38)	3.00 (IQR 6.00)
Minimum	0.00	0.00	0.00
Maximum	12.00	12.00	12.00
Skewness	0.582 (z=1.70)	0.386 (z=1.12)	0.531 (z=1.55)
Mode	0	0	0

Table K.10 Subject Reported Levels and Impact of Pain.

	Spasm Rating Today	Worst Spasm in 24hrs	Extent Spasm Limits Abilities
Mean	3.33 (CI 2.34 - 4.33)	3.86 (CI 2.74 – 4.99)	2.84 (CI 1.76 – 3.92)
Std. Dev	3.42	3.87	3.72
Median	2.00 (IQR 6.00)	3.5 (IQR 6.75)	0.50 (IQR 6.00)
Minimum	0.00	0.00	0.00
Maximum	12.00	12.00	11.50
Skewness	0.838 (z=2.44)	0.562 (z=1.64)	1.003 (z=2.92)
Mode	0	0	0
Key:	Items in italics are non-parametric data		

Table K.11 Subject Reported Levels and Impact of Spasm.

	Ability to Drive	Car Ownership	Access to Public Transport
Vocational Status at One Year Post-Discharge	$\chi^2=3.410$ (df1) p=0.121	$\chi^2=1.561$ (df1) p=0.257	$\chi^2=0.704$ (df1) p=0.628

Table K.12 Non-Significant Relationships between Vocational Status and Transport Factors

		Test statistic	df	p
Differences Between Groups with or without Outstanding Adaptations and:	Care Hours Received (N=46)	H=0.945	2	0.623
	Care Hours Due to Environmental Issues (N=47)	H=2.646	2	0.266

Table K.13 Non-significant Differences/Relationships between Those with or Without Outstanding Adaptations/Access in the Home and Care Received and Social Outings

No significant differences were found in either the number of care hours received at one year post-discharge or the number of care hours received due to environmental issues between those who did or did not have adaptations outstanding at one year post-discharge (Table 6.26).

Potential For A Compensation Claim?	Number of Subjects	Percentage
None	22	45.8
Highly likely	15	31.3
Potentially a claim – under investigation	3	6.3
Claim unlikely – under investigation	3	6.3
Small Personal Insurance Payment Possible	5	10.4

Table K.14 Evaluation of Potential for Compensation Claim or Insurance Policy Payment on Discharge

	Number of Contacts with GP	Number of Contacts with SCIC staff
Mean	5.81 (CI 3.74, 7.89)	2.35 (CI 1.12, 3.58)
Std. Dev	6.73	3.99
Median	3 (IQR=5)	1 (IQR=3)
Skewness	1.907 (z=5.28)	2.675 (z=7.41)
Minimum	0	0.00
Maximum	30	20
Mode	2	0
Key:	IQR = Inter-quartile range CI = 95% Confidence Interval Items in italics are non-parametric data	

Table K.15 Number of Times Subject Contacted GP or SCIC staff (in addition to routine review or prescription requests)

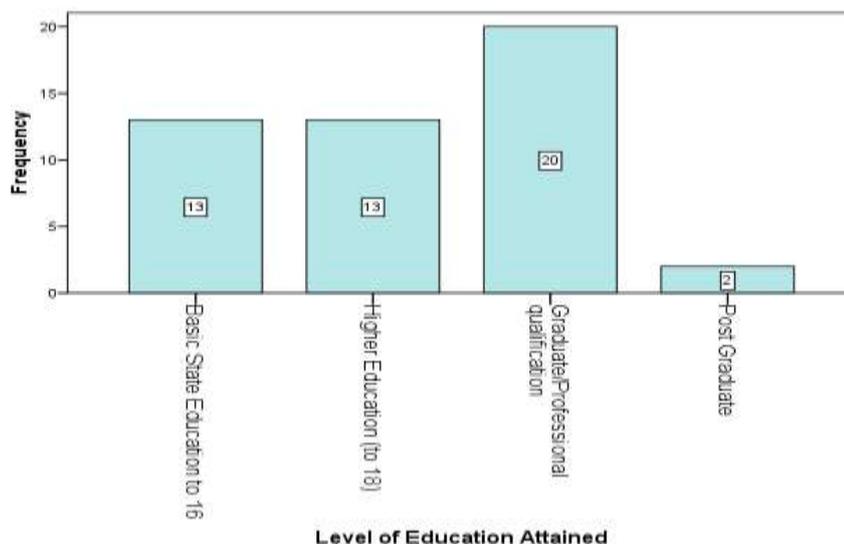


Figure K.1 Level of Education Attained Prior to Injury

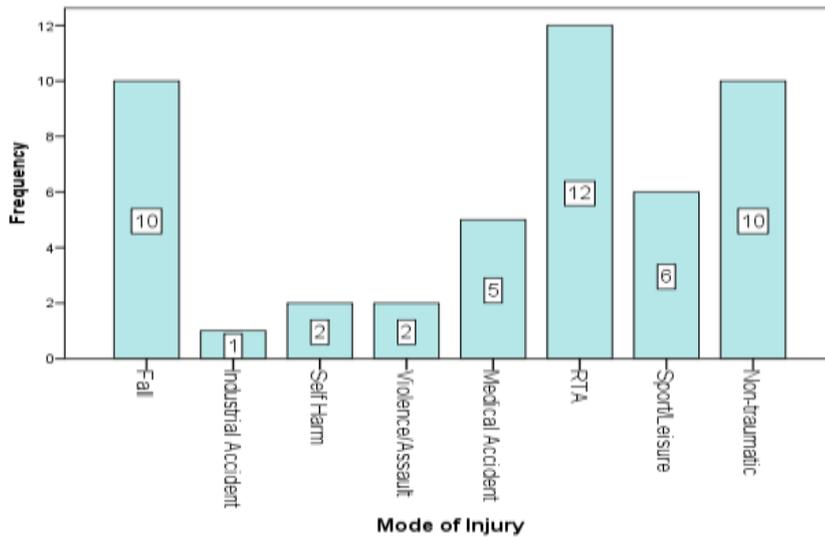


Figure K.2 Mode of Injury

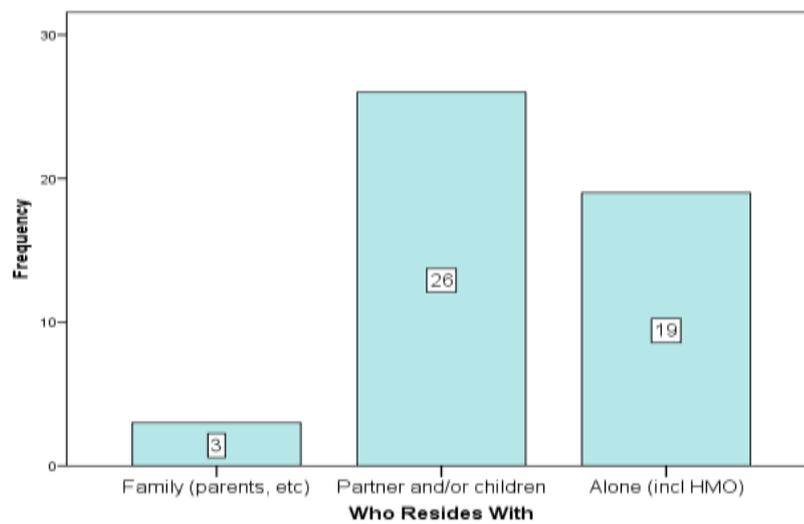


Figure K.3 Residential Situation at One Year Post Discharge

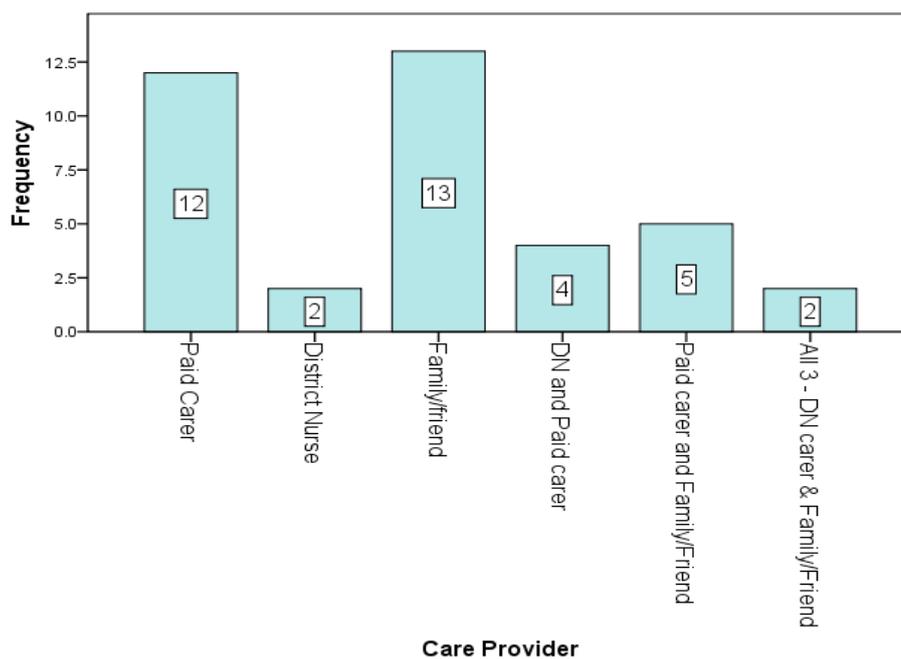


Figure K.4 Sources of Care/Providers

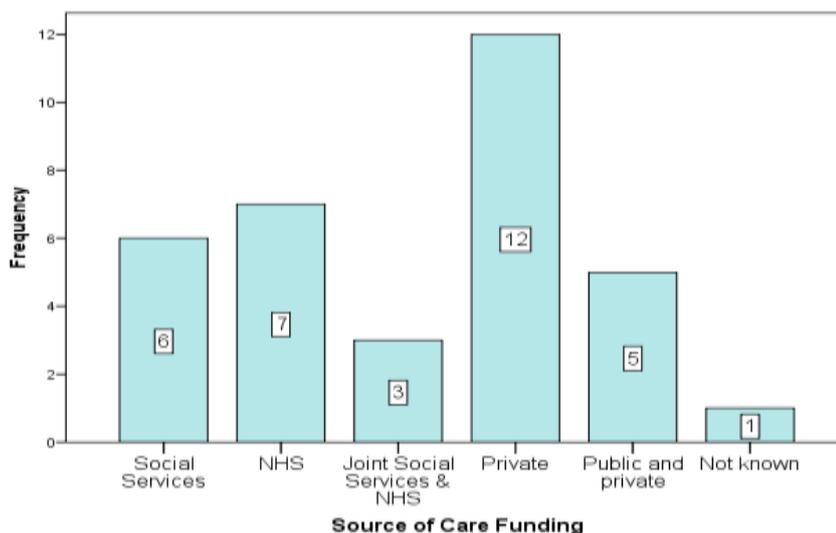


Figure K.5 Source of Care Package Funding

	Hours of Care Received/Week	Weekly Cost of Care Package (£)	Care Hours Due to the Environment	Cost of Care Due to the Environment (£)
Mean	79.58 (CI 53.31, 105.84)	676.71 (CI 475.81, 877.61)	2.07 (CI 0.3, 3.8)	30.03 (CI 3.92, 56.14)
Std. Dev	79.00	602.56	5.44	87.93
Median	27.00 (IQR=162.0)	457.20 (IQR=994.40)	0 (IQR=0.3)	0 (IQR=0.00)
Skew	0.245 (z=0.63)	0.544 (z=1.40)	3.357 (z=8.76)	3.743 (z=10.69)
Min.	1.00	17.60	0.00	0.00
Max.	168.00	1800.00	27.00	475.20
Mode	168.00	1000.00	0.00	0.00
Key:	IQR = Inter-quartile range CI = 95% Confidence Interval Items in italics are non-parametric data			

Table K.16 Average Care Provision and Cost Details

## Appendix L Psychological Variables Detailed Demographics and Interactions

### Demographics of Subjects contributing Psychological Data during Admission Phase

47 subjects (63.5%) agreed to complete the psychological questionnaires in addition to contributing data to the study during admission. Demographics for these subjects are as follows: 79% of were male, 51.1% were married at the time of injury and 48.9% were married at the time of discharge. 68.1% were employed at the time of injury and 20.2% at the time of discharge. 36.2% had a degree or professional diploma and 29.8% had only basic high school education. 25.5% were first generation immigrants, all of who had been in the UK for 10+ years and were fluent English speakers. 46.8% experienced delays to discharge and 40.4% were discharged to a new home.

Comparisons of the subjects who consented and did not consent to complete the psychological through Mann Whitney U and Chi squared tests were performed to determine if there were significant differences in demographic profiles between the two groups. No significant differences were identified between the two groups of subjects in a range of health care systems outcomes, demographic or SCI related variables: as illustrated in Tables L.1 and L.2.

	Relationship	Test statistic	df	p
Relationship with Consent or non-Consent to psychological measures (N=74)	Injury Group on Admission	$\chi^2=3.035$	4	0.568
	Mode of Injury	$\chi^2=7.623$	7	0.358
	Marital Status	$\chi^2=3.409$	3	0.340
	Gender	$\chi^2=0.650$	1	0.574
	Level of Education	$\chi^2=4.444$	3	0.221
	Vocational Status	$\chi^2=1.582$	3	0.710

Table L.1 Non-Significant Relationships between Whether Subjects Consented to Complete Psychological Data and Demographic and Injury Characteristics

	Differences	Test statistic	z	p
Differences between Consent or non-Consent to psychological measures (N=74):	Age	U=634.5	0.000	1.00
	Number of Days to Admission	U=572.5	0.697	0.486
	Number of Days to Mobilisation	U=669.5	0.395	0.693
	Overall LOS	U=587.0	0.533	0.594

Table L.2 Non-significant Differences in Age and Health System Variables between Subjects Who Consented to Complete Psychological Data

Those who sustained their SCI due to traumatic causes were more likely to contribute psychological data than those who had sustained their SCI by non-traumatic means ( $\chi^2(df1)=5.629$ ;  $p=0.024$ , Cramers V=0.276,  $p=0.024$ ). The odds ratio suggests that those with traumatic SCI (TSCI) were 4.52 times more likely to contribute psychological data than those with non-traumatic SCI (NTSCI). However, as previously mentioned, 83.8% of subjects had TSCI and therefore this difference is likely to be a reflection of the demographics of the subject group as a whole rather than subject willingness to contribute psychological data.

Those subjects who had complications on admission were also significantly more likely to contribute psychological data ( $\chi^2(df1)= 6.236$ ;  $p=0.016$ ). Cramers V suggested a moderate relationship (Cramer's V=0.290,  $p=0.016$ ) between completion of the psychological questionnaire and the presence of complications on admission. The odds ratio identified that subjects admitted with complications were 4.96 times more likely to consent to complete the psychological questionnaire than those who were admitted without complications. 18 of these 47 subjects were admitted with complications and in 13 cases these were skin issues. As only 27% of subjects were admitted with complications this finding is worth noting as potential factors around

increased length of acute stay, prolonged periods of bed rest or the impact of the complication experienced may influence psychological variable outcomes.

#### 7.4.1 Admission Phase Results

##### 7.4.1.1 Descriptive Statistics and Correlations

Descriptive statistics for the psychological questionnaire outcomes during admission are given in Table L.3.

	CSQ RatCop Max=27	CSQ D/EmCop Max=66	CSQ AvCop Max=30	SOCQ PC Max=70	SOCQ IPC Max=70	SOCQ SPC Max=70
Mean	19.17	41.63	9.57	51.87	50.52	33.85
Confidence Interval	17.95-20.40	39.52-43.74	7.85-11.28	49.08-54.66	48.01-53.03	30.48-37.21
Median	19	42	8	53	51	33.50
IQR	6	10	9	17	12	14
Mode	8	44	19	47	49	27
Skew	0.163 (z=0.46)	0.188 (z=0.54)	0.404 (z=1.15)	-0.379 (z=1.08)	0.265 (z=0.75)	-0.751 (z=2.15)
Min	12	27	0	26	31	13
Max	27	55	23	67	69	66
Key:	CSQ = Coping Styles Questionnaire RatCop = Rational Coping D/EmCop = Detached/Emotional Coping AvCop = Avoidance Coping SOCQ = Spheres of Control Questionnaire PC= Personal Control IPC =Interpersonal Control SPC = SocioPolitical Control Items in italics are non-parametric data					

Table L.3 Descriptive Statistics of Psychological Questionnaire Results During Admission

Although the z values given in Table L.3 indicate that only SOCQ SocioPolitical locus of control was significantly skewed, a Kolmogorov-Smirnov test (Field, 2009) indicated a significant deviation from normality in the data for CSQ Rational coping (Z=0.149; p=0.012) and a near significant deviation from normality in CSQ Avoidance Coping (Z=0.129; p=0.054). Examination of box plots and histograms confirmed this and also showed deviations from normality (significant skew) and outliers on all CSQ and SOCQ variables apart from SOCQ Interpersonal Control which skewed when the variable was split in to gender and then injury groupings. For this reason non-parametric tests will be utilised to analyse the psychological measures data

	Age	CSQ RatCop	CSQ D/EmCop	CSQ AvCop	SOCQ PC	SOCQ IPC
CSQ RatCop (N=47)	$\tau=0.083$ $p=0.432$					
CSQ D/EmCop (N=47)	$\tau=0.157$ $p=0.131$	$\tau=0.412^{**}$ $p=0.000$				
CSQ AvCop (N=47)	$\tau=-0.174$ $p=0.095$	$\tau=-0.247^*$ $p=0.021$	$\tau=-0.224^*$ $p=0.034$			
SOCQ PC (N=46)	$\tau=-0.101$ $p=0.333$	$\tau=0.283^{**}$ $p=0.008$	$\tau=0.097$ $p=0.361$	$\tau=-0.264^*$ $p=0.013$		
SOCQ IPC (N=46)	$\tau=0.007$ $p=0.947$	$\tau=0.288^{**}$ $p=0.007$	$\tau=0.224^*$ $p=0.034$	$\tau=-0.394^{**}$ $p=0.000$	$\tau=0.497^{**}$ $p=0.000$	
SOCQ SPC (N=46)	$\tau=-0.137$ $p=0.190$	$\tau=0.144$ $p=0.178$	$\tau=0.173$ $p=0.102$	$\tau=0.027$ $p=0.797$	$\tau=0.069$ $p=0.512$	$\tau=0.112$ $p=0.283$

Key:	N=Number of subjects contributing data to the analysis Significant correlations are in bold. **=Correlation is significant at the 0.001 level. *=Correlation is significant at the 0.05 level. CSQ = Coping Styles Questionnaire RatCop = Rational Coping D/EmCop = Detached/Emotional Coping AvCop = Avoidance Coping SOCQ = Spheres of Control Questionnaire PC= Personal Control IPC =Interpersonal Control SPC = SocioPolitical Control
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**Table L.4 Correlation Matrix (Kendall's Tau b) of Psychological Measures during Admission and Age at Injury**

The correlation matrix in Table L.4 reports the relationships when Kendall's Tau b correlations were performed on the SOCQ and CSQ data and subject age at the time of injury. Age at injury was not significantly correlated to any of the psychological variables measured.

As illustrated in Table L.4, subjects who had a more internal locus of Interpersonal control utilised more Detached (and therefore less emotional) coping styles as well as more Rational coping styles and had a more internal locus of Personal control including a greater sense of self efficacy. Those subjects who utilised greater levels of Avoidance coping styles utilised significantly less Rational and more Emotional coping styles and had a more external locus of Personal and Interpersonal Control. Subjects who utilised greater levels of Rational coping styles would also utilise greater levels of Detached coping styles and have a more internal locus of Personal Control. SocioPolitical locus of control was not significantly associated with any of the variables in the correlation matrix (Table L.4.).

#### 7.4.1.2 Admission Phase Interactions

##### *Psychological Variables and Demographic Variables*

Differences	Gender	Marital Status on Discharge	Injury Groups on Discharge	If Admission Delayed	If Admitted within 30days
Detached/Emotional Coping	<b>U=93.5, z=-2.285; p=0.017, r=0.33</b>	H(df3)=3.151 p=0.369	H(df3)=0.076 p=0.995)	U=213.5, z=-0.179; p=0.858	U=267.5, z=-0.054; p=0.957
Avoidance Coping	U=165.5, z=-0.508; p=0.611	H(df3)=4.134 p=0.247	H(df3)=6.987 p=0.072	U=210.0, z=-0.262; p=0.793	U=296.5, z=0.572; p=0.567
Rational Coping	U=151.0, z=-0.890; p=0.374	H(df3)=0.391 p=0.942)	H(df3)=3.161 p=0.367)	U=224.5, z=0.084; p=0.933)	U=297.0, z=0.585; p=0.559
Personal Control	U=188.0, z=0.213; p=0.831	H(df3)=0.985 p=0.805	H(df3)=0.734 p=0.865	U=210.5, z=-0.098; p=0.922	U=199.0, z=-1.354; p=0.176
Interpersonal control	U=162.5, z=-0.467; p=0.641	H(df3)=2.774 p=0.428	H(df3)=1.011 p=0.799	U=231.0, z=0.403; p=0.687	U=223.0, z=-0.821; p=0.412
SocioPolitical control	U=142.5, z=-1.0; p=0.317	H(df3)=2.159 p=0.540	H(df3)=1.482 p=0.686	U=207.5, z=-0.171; p=0.864	U=258.5, z=-0.033; p=0.973

**Table L.5 Differences between Demographic Groups on Psychological Questionnaires**

A significant difference was found between males and females for rating on the Detached/Emotional coping scale with a moderate effect (r=0.33) confirm the assertions of the scales author that males use more Detached coping strategies than females (Roger, Jarvis and Najarian, 1993). On all of the other psychological scales there were no significant differences between males and females (Table L.5). No significant differences were found on any of the psychological variables between marital status groups at discharge, SCI injury groups at discharge, if subject experienced delays in admission or if subjects were admitted within 30 days of injury (Table L.5).

The presence of complications on admission was found to be significantly related to the perception of SOCQ SocioPolitical locus of control during admission (H(df1)=4.254; p=0.039). Those admitted without complications had a significantly higher rating (Median =37) of

#### Appendix L: Psychological Variables Detailed Demographics and Interactions

SocioPolitical control ( $J=156.0$ ,  $z=-2.062$ ;  $r=0.3$ ) than those who were admitted with complications (Median = 27). This suggests that the presence of complications on admission results in the subject having a more external locus of SocioPolitical control.

A significant difference was noted in the use of Avoidance coping styles according to the mode of injury ( $H(df7)=16.498$ ;  $p=0.021$ ). With a trend for those with certain modes of SCI to utilise Avoidance coping styles more than those with other modes of SCI ( $J=16.498$ ,  $p=0.021$ ) in the order of: Industrial Accident ( $N=1$ , Median=23), Violence (Median=15), Fall (Median=12.5), Sport/Leisure (Median=11), Medical Accident (Median=7), Self Harm (Median=6), RTA (Median=4.5) and Non-traumatic causes (Median=4). These significant differences were sustained when mode of injury was viewed in the more simplistic form of TSCI or NTSCI. Subjects with TSCI used significantly more ( $U=137.5$ ,  $z=1.970$ ;  $p=0.049$ ,  $r=0.29$ ) Avoidance coping styles (Median=10) and less ( $U=21.5$ ,  $z=-2.476$ ;  $p=0.009$ ,  $r=0.40$ ) Rational (Median=19) coping styles than those with NTSCI (avoidant coping Median=4, Rational coping Median=24.5). These findings suggest that subjects sustaining SCI employ different coping strategies during admission dependent on their mode of injury, particularly in respect of TSCI or NTSCI causes.

As these measures were primarily intended to be used to identify changes at one year post-discharge further analyses were not performed.

**Analysis of Differences between Psychological Variable Scores during Admission and At One Year Post-Discharge**

		Test Statistic	df/ Standardised Test Statistic	Sig. (2- tailed)
Pair 1	Rational Coping Admission - Rational Coping 1yr	$t=0.142$	$df\ 29$	0.888
Pair 2	Detached/Emotional Coping Admission - Detached/Emotional Coping 1yr	$t=-0.516$	$df\ 29$	0.610
Pair 3	Avoidance Coping Admission – Avoidance Coping 1yr	$W=175.00$	$z=1.129$	0.259

Table L.6 Results Of T-Test and Wilcoxon Rank Sum Test Analyses for Coping Styles Questionnaire Rating Comparisons

		Test Statistic	df/ Standardised Test Statistic	Sig.(2- tailed)
Pair 1	Personal Control Admission - Personal Control 1yr	$t=1.454$	$df\ 29$	0.157
Pair 2	Interpersonal Control Admission - Interpersonal Control 1yr	$t=0.280$	$df\ 29$	0.782
Pair 3	SocioPolitical Control Admission – SocioPolitical Control 1yr	$W=153.00$	$z=-0.256$	0.798

Table L.7 Results Of T-Test and Wilcoxon Rank Sum Test Analyses for Spheres of Control Questionnaire Rating Comparisons

N=30	Delay in Admission?	Delay in Discharge?	Is Subject Paraplegic or Tetraplegic
CSQ RatCop 1yr	$t=1.019(df28)$ $p=0.317$ $F=0.019$ , $p=0.893$	$t=0.325(df28)$ $p=0.748$ $F=0.329$ , $p=0.571$	$t=-1.052(df28)$ $p=0.302$ $F=2.066$ , $p=0.162$
CSQ D/EmCop1yr	$t=-1.135(df28)$ $p=0.266$ $F=0.156$ , $p=0.696$	$t=0.150(df28)$ $p=0.882$ $F=0.958$ , $p=0.336$	$t=-0.609(df28)$ $p=0.548$ $F=0.215$ , $p=0.646$
CSQ AvCop 1yr	$H=0.944(df1)$ $p=0.331$	$H=0.030(df1)$ $p=0.863$	$H=1.361(df1)$ $p=0.243$
SOCQ PC 1yr	$t=-1.035(df28)$ $p=0.266$	$t=-0.641(df28)$ $p=0.527$	$t=-0.679(df28)$ $p=0.503$

	F=2.956, <i>p</i> =0.097	F=0.251, <i>p</i> =0.620	F=0.215, <i>p</i> =0.646
SOCQ IPC 1yr	<i>t</i> =-0.645( <i>df</i> 28) <i>p</i> =0.309 F=2.956, <i>p</i> =0.541	<i>t</i> =-0.727( <i>df</i> 28) <i>p</i> =0.473 F=0.075, <i>p</i> =0.786	<i>t</i> =-1.548( <i>df</i> 28) <i>p</i> =0.133 F=0.023, <i>p</i> =0.880
SOCQ SPC 1yr	<i>H</i> =1.805 ( <i>df</i> 1) <i>p</i> =0.179	<i>H</i> =0.446 ( <i>df</i> 1) <i>p</i> =0.504	<i>H</i> =0.225 ( <i>df</i> 1) <i>p</i> =0.635
Current QOL N=47	<i>t</i> =-0.167( <i>df</i> 45) <i>p</i> =0.868 F=0.019, <i>p</i> =0.890	<i>t</i> =0.364( <i>df</i> 45) <i>p</i> =0.718 F=0.331, <i>p</i> =0.568	<i>t</i> =-1.110( <i>df</i> 45) <i>p</i> =0.273 F=0.428, <i>p</i> =0.516
Change in QOL N=47	<i>t</i> =-1.063( <i>df</i> 45) <i>p</i> =0.294 F=0.211, <i>p</i> =0.648	<i>t</i> =0.426( <i>df</i> 45) <i>p</i> =0.672 F=0.253, <i>p</i> =0.617	<i>t</i> =-1.078( <i>df</i> 45) <i>p</i> =0.287 F=0.020, <i>p</i> =0.887
Key:	CSQ = Coping Styles Questionnaire RatCop = Rational Coping D/EmCop = Detached/Emotional Coping AvCop = Avoidance Coping SOCQ = Spheres of Control Questionnaire PC= Personal Control IPC =Interpersonal Control SPC = SocioPolitical Control		

Table L.8 Analyses Of QOL and Psychological Variables with Injury and Pathway Variables

	Current QOL	Perceived Change in QOL
If Having Significant Bladder Management Issues	<i>t</i> =0.311 ( <i>df</i> 45) <i>p</i> =0.757 F=1.646, <i>p</i> =0.206 N=47	<i>t</i> =0.617 ( <i>df</i> 45) <i>p</i> =0.540, F=1.404, <i>p</i> =0.242 N=47

Table L.9. Analyses of Relationships between Bladder issues and QOL Variables

Current QOL did not vary significantly (*t*=1.705 (*df*41), *p*=0.096, N=43) between those who had outstanding adaptations at one year post-discharge (Mean Current QOL=4.41) and those who did not (Mean Current QOL=5.52) suggesting that outstanding adaptations did not significantly impact on the subject's QOL although there is an 11.1% difference in the ratings of current QOL. However in addition to the potential impact of small subject numbers, the issues with subject perceptions of the needs for adaptations discussed in Chapter 6 may have influenced this finding.

It has been asserted that those individuals living in the parental home may have a more external perception of locus of control (Bergmark, Winograd and Koopman, 2008). There were only a small number of subjects who lived with their parents (N=3) or in a nursing home (N=3) at one year post-discharge, compared to 24 living in other forms of accommodation. This is likely to present difficulties in obtaining meaningful or significant results, therefore this issue will not be investigated further.

20 of the 24 subjects in receipt of care stated that they perceived that they had control over how their care was provided. This is likely to skew results notably and present difficulties in obtaining meaningful or significant results, therefore this issue will not be investigated further.

	If own/have access to a car	If can access public transport	If leaves their home once a week or less
CSQ RatCop 1yr	<i>t</i> =-0.365 ( <i>df</i> 27) <i>p</i> =0.718, N=29 F=0.237, <i>p</i> =0.630	<i>t</i> =-1.275 ( <i>df</i> 20) <i>p</i> =0.217, N=22 F=1.508, <i>p</i> =0.234	<i>t</i> =0.645 ( <i>df</i> 28) <i>p</i> =0.524, N=30 F=0.484, <i>p</i> =0.645
CSQ D/EmCop1yr	<i>t</i> =1.292 ( <i>df</i> 27) <i>p</i> =0.207, N=29 F=0.188, <i>p</i> =0.668	<i>t</i> =-0.622 ( <i>df</i> 20) <i>p</i> =0.541, N=22 F=1.061, <i>p</i> =0.315	<i>t</i> =-0.233 ( <i>df</i> 28) <i>p</i> =0.818, N=30 F=0.205, <i>p</i> =0.655
CSQ AvCop 1yr	<i>H</i> =0.19 ( <i>df</i> 1) <i>p</i> =0.890, N=29	<i>H</i> =2.508 ( <i>df</i> 1) <i>p</i> =0.113, N=22	<i>H</i> =0.697 ( <i>df</i> 1) <i>p</i> =0.404, N=30
SOCQ PC 1yr	<i>t</i> =0.514 ( <i>df</i> 27)	<i>t</i> =-0.969 ( <i>df</i> 20)	<i>t</i> =0.886 ( <i>df</i> 28)

Appendix L: Psychological Variables Detailed Demographics and Interactions

	$p=0.611$ , $N=29$ $F=4.116$ , $p=0.052$	$p=0.344$ , $N=22$ $F=0.882$ , $p=0.359$	$p=0.383$ , $N=30$ $F=0.096$ , $p=0.758$
SOCQ IPC 1yr	$t=-0.487$ ( $df27$ ) $p=0.630$ , $N=29$ $F=0.649$ , $p=0.427$	$t=-0.508$ ( $df20$ ) $p=0.617$ , $N=22$ $F=0.829$ , $p=0.373$	$t=0.844$ ( $df28$ ) $p=0.406$ , $N=30$ $F=0.020$ , $p=0.888$
SOCQ SPC 1yr	$H=1.596$ ( $df1$ ) $p=0.207$ , $N=29$	$H=0.212$ ( $df1$ ) $p=0.645$ , $N=22$	$H=0.140$ ( $df1$ ) $p=0.708$ , $N=30$
Current QOL	$t=-0.967$ ( $df44$ ) $p=0.339$ , $N=46$ $F=0.074$ , $p=0.786$	$t=-1.345$ ( $df32$ ) $p=0.188$ , $N=34$ $F=0.121$ , $p=0.730$	$t=1.969$ ( $df45$ ) $p=0.055$ , $N=47$ $F=0.046$ , $p=0.831$
Change in QOL	$t=1.144$ ( $df44$ ) $p=0.489$ , $N=46$ $F=1.144$ , $p=0.291$	$t=-0.687$ ( $df32$ ) $p=0.497$ , $N=34$ $F=0.738$ , $p=0.397$	$t=1.293$ ( $df45$ ) $p=0.203$ , $N=47$ $F=0.294$ , $p=0.590$
Key:	CSQ = Coping Styles Questionnaire RatCop = Rational Coping D/EmCop = Detached/Emotional Coping AvCop = Avoidance Coping SOCQ = Spheres of Control Questionnaire PC= Personal Control IPC =Interpersonal Control SPC = SocioPolitical Control		

Table L.10 Analyses Of Psychological Variables, QOL and Community Activity Variables

	Do Family Only Visit Once A Week Or Less?	Do Friends Only Visit Once A Week Or Less?
Rational Coping	/	$t=2.457$ ( $df27$ ) $p=0.021$ , $N=29$ $F=0.129$ . $p=0.722$
Interpersonal Control		$t=2.852$ ( $df27$ ), $p=0.008$ , $N=29$ $F=0.013$ . $p=0.909$
Current QOL	$t=-0.974$ ( $df45$ ) $p=0.335$ , $N=47$ $F=0.767$ , $p=0.386$ (Mean less frequent visits=4.67, Mean more frequent visits=5.29)	$t=0.487$ ( $df44$ ) $p=0.629$ , $N=46$ $F=2.779$ , $p=0.103$ (Mean less frequent visits =4.81, Mean more frequent visits=5.13)
Change in QOL	$t=1.039$ ( $df45$ ) $p=0.304$ , $N=47$ $F=0.058$ , $p=0.811$ (Mean less frequent visits=-4.62, Mean more frequent visits=-3.88).	$t=-0.067$ ( $df44$ ) $p=0.203$ , $N=46$ $F=0.294$ , $p=0.590$ (Mean less frequent visits=-4.24, Mean more frequent visits=-4.29).

Table L.11 Analyses of Quality of Life and Social Contact Variables

## **Appendix M Email Communications**

-----Original Message-----

From: Dr D. Roger [<mailto:D.Roger@psych.york.ac.uk>]

Sent: 11 July 2003 12:30

To: janine.lockwood@moh.nhs.uk

Subject: PhD

Janine, I've e-mailed Jeremy Miles to ask if he'd be interested - I'd be surprised if he isn't. If not, there are others I can approach.

Regarding the ECQ, it has now been translated into a half-dozen languages by colleagues working elsewhere, and is quite widely used, most recently by a team in Denmark. They were specifically interested in the role of rumination in health, and ECQ rumination (called rehearsal in the original) was very significantly implicated - for example, high ruminators had suppressed immune function, assessed by pha challenge and NK cell activity. The scale is also widely used in forensic settings.

We've recently re-visited the original 4-factor scale, and have focused on just rumination and inhibition to develop a new inhibition-rumination scale. It has been extensively validated and the structure confirmed using CFA, but the paper reporting it is as yet still in preparation. You'd be welcome to use either version as a research tool.

We've also worked on coping, having been very critical of conventional scales - many claim multiple factors, but in fact there are only 3, rational, emotional and avoidance. The first two are inversely correlated and thought to comprise ends of a bi-polar dimension, but it seemed unlikely to us that people would use rational strategies under stress. We devised a new scale using a scenario technique, and obtained a fourth 'detachment' factor. When the structure is squeezed to 3, it is detached and emotional that mmerge into a bi-polar, and this has proved very significant in health work. This is also in preparation, and we have a staged model of emotional response style, from sensitivity to inhibition to rumination/detachment.

In any event, I'll send a selection of the journal and conference papers, and I've attached the old and new versions of both the ECQ and CSQ. As I mentioned, I'm taking early retirement shortly to live in NZ, but I will have honorary appointments here and there, and this e-mail will remain in operation.

Best wishes,  
Derek

>Dr Roger

>

>I left a message on your answerphone a few days ago and am writing to  
>give you some background on why I was phoning.

>

>I currently manage the Reintegration Department at the Stanmore Spinal Unit. We are looking at doing research into the effective reintegration of  
>our patients through provision of resources such as housing, care  
>equipment, vocational assistance, etc. where they are needed when they  
>are needed through interim payments from compensation claims. As  
>opposed to the usual situation of fractured services, no wheelchair

Appendix M: Email Communications

>accessible housing so the patient either goes to a nursing home or stays in hospital, etc. etc.

>

>

We are looking at various outcome measures but as effective  
>reintegration is such a difficult thing to measure it is obvious we are  
>likely to need several tools. With that in mind I thought it would be  
>possibly be useful to use the ECQ - I vaguely remember lectures  
>regarding bringing the resolution point closer to the event point and  
>how ECQ can measure the emotional state/coping strategies and through  
>structured use measure how far along someone is on this. Through this,  
>I would hope, that we can show effective provision of resources not  
>only reduces costs, avoids bed blocking, facilitates return to work,  
>etc. but also assists in the long term reintegration and psychological  
functioning of our patients.

>

>This is a very rough sketch of what we are looking at and we are still  
>formulating our ideas but I would appreciate the opportunity to talk  
>with you further on this and maybe arrange for the consultant and I to  
>meet with you. My work no. is 020 8909 5582, reply email:  
>janine.lockwood@rnoh.nhs.uk

>

>Thanks for your time on this.

>

>Regards

>

>Janine Lockwood-Johnson

>(Psych 90-93)

**From:** Alex Rankin [alex.rankin@aspire.org.uk]  
**Sent:** 14 September 2009 10:18  
**To:** jani.k@btinternet.com  
**Subject:** housing briefing paper  
**Attachments:** Housing results.doc

As discussed

Alex Rankin  
Head of Services

020 8420 6736

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Rikki Khare