

An Investigation of Musculoskeletal (MSK) Upper Limb Injuries Sustained from Manual Wheelchair Use: Implications of Pain and the Medical and Rehabilitative Approaches to Treatment



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DISSEMINATION

Elements of this research programme have been disseminated at local and national level, including oral and poster presentations.

Planned paper publications in peer reviewed journals:

- A Systematic Review of Observational Manual Wheelchair Skills Tests Available in the Literature
- Manual Wheelchair Skills Training for Young Manual Wheelchair Users: A Pilot Study
- Prevalence of Upper Limb Pain in Manual Wheelchair Users with Spinal Cord Injury: A Systematic Review
- The Long-term physical and psychosocial effects of sustained manual wheelchair use in spinal cord injury: a mixed method study

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Oral Presentations

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- **McCann, Adrienne P**, Hannon-Fletcher, Mary P and Kerr, Daniel P. (2017) Wheelchair Skills Programme for Children: A Pilot Study. In: 4th Annual Social Care Conference Northern Ireland, Belfast, Northern Ireland.
- **McCann, Adrienne P**, Hannon-Fletcher, Mary P and Kerr, Daniel P. (2018) “The Long-term physical and psychosocial effects of sustained manual wheelchair use in spinal cord injury: a mixed methods study”. In: Ulster University Festival of Research, Jordanstown, Northern Ireland. June 2018.

SUMMARY

Upper limb pain in manual wheelchair users negatively affects participation in social and recreational activities, completion of Activities of Daily Living (ADLs), sleep and vocational activities. Treatment of upper limb pain in manual wheelchair users can often prove difficult; as with any injury relative rest is required in order for the upper limb to recover. As the upper limb is required for mobility on a daily basis, often this is not feasible. The overall aim of this thesis was to explore the impact of upper limb injuries sustained by Spinal Cord Injured (SCI) manual wheelchair users, the medical and rehabilitative approach to treatment, the perspectives of SCI patients as to how upper limb pain affects daily life and the perspectives of clinicians involved in the treatment of these injuries. In addition, a wheelchair skills training project was piloted with young manual wheelchairs to assess the feasibility of delivering skills training in a community setting.

In study 1 (Chapter 2), a systematic review following the Preferred Reporting Items of Systematic Reviews and Meta-Analysis (PRISMA) guidelines was conducted to examine the prevalence of upper limb injuries in the SCI population. Prevalence rates of upper limb pain varied widely, with the shoulder the most common site of pain investigated. Pain was significantly associated with length of time since injury but not age. Pain was exacerbated primarily by outdoor wheeling, pushing up ramps and inclines and wheelchair transfers. Little information was available regarding treatments prescribed, however in those studies that did report treatment interventions, medication was primarily used to manage pain. Treatment recommendations included education of participants on joint protection and energy conservation to preserve the upper limb, and education on correct wheelchair techniques to avoid abnormal movements which contribute to the development of upper limb pain. Recommendations from the review stated that further research is required to establish the causation of injuries and the functional limitations of pain.

In study 2 (Chapters 3 and 4), a mixed methods study was undertaken to establish the prevalence of upper limb injuries in the SCI population of Northern Ireland, the treatments availed of by this cohort and the perspectives of SCI participants in relation to the impact pain has on their daily lives, and the perception of healthcare professionals involved in their care. Shoulder pain was again the most prevalent site of pain reported, followed by neck,

back, elbow, hand and finger pain. Prevalence of pain was poorly reported in the medical notes, with little to no information regarding any treatments availed of by participants documented. During one-to-one interviews, participants reported that pain affected them in all aspects of daily life and this was reflected in that 24/32 domains of the “ICF core set for SCI: chronic setting” were referenced during interviews. In relation to treatment, participants primarily reported self-managing their pain. Participants reported a lack of specialised services to provide them with advice on managing their pain. Participants reported good benefits from attending allied health services such as physiotherapy and occupational therapy, unfortunately they reported only short term relief from treatments availed of overall. The majority of participants had a particularly negative view of the Regional SCI (RSCI) centre. Many had not been called for review in over ten years, and one participant’s medical notes were unable to be located.

Only three healthcare professionals were agreeable to interview (3 occupational therapists). Their sentiments echoed that of the SC participants in that there are no specialised SCI services in the community. Participants reported a distinct sense of responsibility in treating their patients as they are consciously aware that once they leave the RSCI they may never receive the same level of specialised treatment in the community. Participants felt that upper limb pain was not a priority for patients on leaving the RSCI. Upper limb pain was more prevalent in the tetraplegic population where their upper limb pain was attributed to their level of injury, not an overuse injury as is investigated in this study. Wheelchair skills training was identified as a key element of rehabilitation. Participants identified this as crucial to a patient’s recovery, in that if they could not propel their chair, they could not attend therapy, therefore slowing down their recovery.

The concept of wheelchair skills training was highlighted in both chapters 1 and 3 as being key to both SCI patient’s recovery and their ability to be independent. Following this a systematic review following PRISMA guidelines of wheelchair skills test was undertaken to identify the most reliable and valid tool to measure wheelchair skill ability in manual wheelchair users (Chapter 5). The review highlighted ten different skill tests, each measuring various aspects of wheelchair use. The most comprehensive skills tests included a battery of skills focused on propulsion, ramps, sprints and transfers while also incorporating

practical tasks such as picking an item off the ground, crossing a road and propelling a wheelchair while carrying an item in one hand. The majority of tests had been tested with a variety of conditions and diagnoses and were therefore suitable for use with a wide population of manual wheelchair users.

In Chapter 6, a wheelchair skills training programme was designed by the Regional Wheelchair Skills training therapist and was implemented as an assessment graded for use with children, to assess skill level pre and post an eight month skills training programme. All participants showed a significant increase in the intermediate and advanced levels of the skills assessment. Participant feedback was mainly positive via the impact questionnaire and participants reported improvement in their confidence and independence. Overall, the programme was feasible to deliver and enabled participants to mobilise independently while increasing their confidence as a wheelchair user. This programme is also currently being rolled out across Northern Ireland with a number of occupational therapists now trained in the delivery of wheelchair skills training.

In conclusion, this thesis contributes knowledge to an evidence based approach of identifying factors relating to upper limb pain in manual wheelchair use. It established that upper limb pain is prevalent, however with the small sample size utilised in all studies, results should be interpreted with caution. It obtained information regarding the treatment pathway for the treatment of upper limb injuries, the functional impact pain has on daily life for SCI manual wheelchair users, and the clinical perspectives of what can be done to ensure patients are better supported in the community. In addition, it examined the efficacy of delivering wheelchair skills training in the community, and found participants not only showed an improvement in skill level, but they also felt more confident and independent as a wheelchair user going forward.

ABBREVIATIONS

AC	Acromioclavicular
ADL	Activities of Daily Living
AMC	Adrienne McCann
AP	Anteroposterior
BMI	Body Mass Index
CHART	Craig Handicap Assessment and Reporting Technique
COPM	Canadian Occupational Performance Measure
CTS	Carpel Tunnel Syndrome
DADL	Domestic Activities of Daily Living
DK	Dr Daniel Kerr
DSNI	Disability Sport Northern Ireland
DJD	Degenerative Joint Disease
ER	Emma Regan
FIM	Functional Index Measure
MHF	Dr Mary Hannon-Fletcher
MMT	Manual Muscle Testing
MR	Magnetic Resonance
MRI	Magnetic Resonance Imaging
MSK	Musculoskeletal
MWST	The Manual Wheelchair Slalom Test
Para	Paraplegia
PASIPD	Physical Activity Scale for Individuals with Physical Disabilities
Physio	Physiotherapy
PIS	Participant Information Sheet
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analysis
RCT	Rotator Cuff Tear
ROM	Range of Movement
RSCI	Regional Spinal Cord Injury centre
SCI	Spinal Cord Injury
SIP68	Sickness Impact Scale

SRQ	Shoulder Rating Questionnaire
Stat	Statistic
TA	Thematic Analysis
TAI	The Transfer Assessment Instrument
Tetra	Tetraplegia
TOWM	Test of Wheeled Mobility
UE	Upper Extremity
UL	Upper limb
WAIMS	The Wheelchair Assessment Instrument for People with Multiple Sclerosis
WPT	The Wheelchair Propulsion Test
WST	The Wheelchair Skills Test
WUSPI	Wheelchair Users Shoulder Pain Index
5-AML	The 5 Additional Mobility and Locomotor test

DECLARATION

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Adrienne McCann

CHAPTER 1

INTRODUCTION

1.0 Independent Mobility

The concept of being independent refers to being able to achieve tasks on one's own without the assistance of others. Independence stems from a sense of dignity and pride of not relying on others to assist in the completion of activities of daily living (Sapey et al. 2005). Broadly, dependence can be the result of an individual being hindered by illness, disease or pain. The resulting effect is that the person must seek alternative means to mobilise; whether that be via the use of an assistive device such as crutches, walking frame, wheelchair or reliance on another person for physical assistance (Sanford et al. 2006). Impaired physical mobility is defined as "*the state in which an individual has a limitation in independent purposeful physical movement of the body, or of one or more extremities*". (Gattinger et al. 2017, pg. 506). Often in the case where lower limb mobility is impaired, such as in the case where the spinal cord has been damaged, wheelchairs are the most commonly prescribed mobility device, and often the most cost effective to the National Health Service (NHS) (Fuhrer et al. 2007).

Wheelchairs are the most effective solution for individuals with a spinal cord injury with impaired mobility, enabling these individuals to be functionally independent, without the assistance of a carer (Sim et al. 2017). Although wheelchairs provide a level of independence, use of them can result in adverse effects. Manual wheelchair users often experience persistent and chronic pain of the upper limb, primarily attributed to the overuse of the structures and muscles of the upper limb (Finley et al. 2004), where excessive force is required during wheelchair propulsion and wheelchair transfers. Upper limb pain in manual wheelchair users negatively affects participation in social and recreational activities, completion of activities of daily living (ADLs), sleep and vocational activities (Rice & Rice 2017). Treatment of upper limb pain in manual wheelchair users can often prove difficult; as with many injuries, relative rest is required in order for the upper limb to recover. As the upper limb is required for mobility on a daily basis for manual wheelchair users, relative rest is difficult to achieve.

1.1 Manual wheelchair mobility

1.1.1 Wheelchair Propulsion

Wheelchair mobility primarily refers to the tasks of wheelchair propulsion and wheelchair transfers (Taylor et al. 2015). Manual wheelchair propulsion can be classified into two phases; the push phase and the pull phase. The push phase refers to mechanical power delivered to the handrim with the elbow flexed at the beginning of the push, or downward force with the elbow in full extension as the handrim begins to turn, in order to increase or maintain velocity of the wheelchair (Guo et al. 2013). At the end of the push phase, the recovery phase begins when the hand leaves the handrim in a loop motion and returns to the beginning of the push phase in preparation for the next push cycle, with no force applied to the handrim. The pull phase refers to the stopping the wheelchair while mobilising (Toor et al. 2017). The hand gripping the handrim is required to place upward motion and pull backwards towards the rear of the wheelchair in order to prevent the wheels' turning motion (Sanderson and Sommer 1985). This motion can be replicated to slow down the wheelchair also, rather than coming to a full stop where the hands are then positioned to begin a new propulsive phase.

The movement of the hands are a visible indicator of an individual's propulsion technique or stroke pattern (Slowik et al. 2016). Stroke pattern refers to the hand trajectory observed during the push phase. During the push phase, the hand applies force to the handrim to propel the wheelchair in one specific direction however, during the recovery phase, the hands leave the handrim and can return to any point of the handrim to change the direction of the wheelchair (Zukowski et al. 2017). Four primary stroke patterns have been identified in the literature (Shimada et al. 1998, Boninger et al. 2002), adopted by manual wheelchair users:

- a) Arcing; the hand makes a "pumping" motion and follows the trajectory along the arcing of the handrim in the recovery phase
- b) Single looping; the hands move higher than the hand rim during the recovery phase and return to the starting point
- c) Semi-circular; the hands move lower than the hand rim during recovery phase and return to the starting point

- d) Double looping over propulsion; the hands move higher than the hand rim, then cross over and drop lower than the hand rim during the recovery phase

Several studies have investigated the relationship between stroke pattern and the associated shoulder loading, and upper limb injuries during propulsion (Dalyan et al. 1999, Ballinger et al. 2000, El-Essi et al. 2012). The increased loading of the shoulder joint during fast and inclined propulsion has been suggested to increase the likelihood of compression of the subacromial structures as they pass under the acromion (Kulig et al. 1998). Additional muscles such as the biceps brachialis and triceps brachialis also play a key role in propulsion in determining the direction of wheelchair propulsion (Guo et al. 2003). During the push phase, the elbow lies at a 90-degree angle with activation of the biceps brachialis (Veeger et al. 1989). The anterior deltoid is also activated at this point and provides the main driving force at the initial push phase. The pectoralis major provides a lower force during the push phase however continues for a longer duration to subsequently return the hand to the handrim during the recovery phase (Rogers et al. 1994).

Collinger et al. (2008) has suggested that an increased Body Mass Index (BMI) influences shoulder forces, where a higher BMI results in more force required to propel the wheelchair, thus causing more strain on the upper limb. Additionally, Mulroy et al. (1996) hypothesised that fatigue of major muscles involved in wheelchair propulsion, specifically the rotator cuff, resulted in compensatory activation of smaller muscles unable to manage the shear force required to propel the wheelchair, thus resulting in the overuse of the muscles. They also found that in the case of weakness or overuse of the rotator cuff muscles, contraction of the deltoid resulted in movement of the humeral head against the subacromial arch, with subsequent impingement of the supraspinatus tendon.

As a wheelchair user ages and after years of propulsion, they often maintain significant upper limb strength. The major muscles of the upper limb such as shoulder flexors, internal rotators and adductors are often very well developed however, many of the minor muscles and tendons may not be as well developed, such as external rotators and thorascapular muscles (Dellabiancia et al. 2013). In this case, an imbalance of muscles exists where the wheelchair user may constantly rely on these muscles repetitively, leading to an increased

risk of subacromial impingement. Each of the above described biomechanical movements of the upper limb have the potential to result in the manifestation of pain and a reduction in function to a manual wheelchair user.

1.1.2 Wheelchair Transfers

Transfers are a key aspect of independent mobility for manual wheelchair users. Manual wheelchair users complete between 14-18 transfers in an average day (Finley et al. 2005). Transferring out of bed, into a shower and into a car, are just some examples of daily transfers to complete for most active wheelchair users, all before they leave their house. Transfers are one of the most strenuous tasks for manual wheelchair users where the individual is required to take their full body weight through the upper limbs, turn and reposition onto another surface (Alm et al. 2008). The shoulder is required to adopt a position of flexion, abduction and internal rotation bringing the glenohumeral head in contact with the acromion (Finley et al. 2005). The lateral movement of transferring over and back can cause impingement at the acromion resulting in soft tissue damage and pain (Yanai et al. 2006).

Gagnon et al. (2008) reported that the shoulder undergoes significantly higher peak forces than any other upper limb structure during the transfer movement. High peak posterior forces have also been observed at the shoulder and elbow joints during transfers, which are thought to contribute to the instability of the shoulder during transfers (Koontz et al. 2011). These posterior forces are also associated with tendinopathies and capsulitis of the shoulder (Campbell & Koris 1996). Additionally, the repetitive transfer movement can have debilitating effects on upper limb function increasing the risk of shoulder impingement (Finley & Rodgers 2004).

Although the shoulder is the primary weight bearing structure in the upper limb, the wrist also undergoes significant strain during transfers. The positioning of the wrist during transfers is that of extension where the weight distribution moves from the shoulder initially, then to the wrist as the torso is seated on the surface. Hyperextension of the wrist can occur during this movement also causing further strain at the elbow joint (Sie et al. 1992). Literature has highlighted that the hyperextension of the wrist at this point may

contribute to an exacerbation of current wrist injuries such as carpal tunnel syndrome, further limiting upper limb functioning for manual wheelchair users (Mercer et al. 2006).

1.2 Upper limb pain and injury

1.2.1 Causation of upper limb pain and injury in manual wheelchair users

Several authors (Pentland and Twomey 1994, Alm et al. 2008, Requejo et al. 2008) have highlighted the repetitive nature of propulsion and transferring as the primary contributing factors of upper limb pain and injury in the manual wheelchair user population. Between 49% and 73% of manual wheelchair users with a spinal cord injury (SCI), develop carpal tunnel syndrome and between 31% and 71% report shoulder pain (Toosi et al. 2010). To put this into context, a study by Fliess-Doeur et al. (2012) found that of 24 predefined skills outlined in a survey, the most essential skill of wheeled mobility was that of transferring the wheelchair in and out of a car. Particularly for active wheelchair users, having to lift a minimum of 11-15kgs in and out of a car several times a day can cause considerable strain on the upper extremity.

1.2.2 Functional implications of upper limb pain

The associated pain and loss of function attributed to upper limb pain can result in an overall reduction in performance in everyday activities. Over time, the overuse of the upper limb may result in secondary upper limb injuries, including rotator cuff tears, carpal tunnel syndrome and muscular strains (Borgens et al. 2012). Research highlights that these injuries occur throughout the life span of wheelchair users and are a common occurrence, particularly in those whose wheelchair use has spanned decades (Asheghan et al. 2015); a more common occurrence as life expectancy increases in this population. Pain has the ability to impact on an individual's ability to engage in wider recreational pursuits therefore limiting their interaction and acting as a barrier to participation. Dalyan et al. (1999) determined that of SCI patients experiencing upper limb pain, 26% required additional help with functional activities and 28% reported limitations of independence. This may have serious implications for functional mobility, sleep and living life independently (Widerstrom-Noga et al. 2001).

1.2.3 Management of upper limb pain

A minimal loss of upper limb function can have a magnified impact on a manual wheelchair user's independence. Strategies such as surgical intervention or steroid injections have been identified in the literature to manage upper limb pain (van Strateen et al. 2017), however undergoing these interventions can often result in long periods of inactivity or bedrest, resulting in further loss of independence (Dalyan et al. 1999). For patients, interventions may also result in financial loss from periods away from work or the purchasing of additional equipment to assist while recovering (Wong et al. 2016). Additionally, a lighter wheelchair may be easier to propel or lift in/out of a car, however lighter wheelchairs are also less stable than standard wheelchairs; thus, they are only prescribed to advanced wheelchair users (Wolf 2015). Preventative measures have been highlighted as the most beneficial method of addressing upper limb injuries therefore, ensuring they do not occur in the first instance. Preventative strategies have also been favoured due to the relatively ineffective results observed from surgical intervention where the potential for these injuries to manifest again is common as the causation of pain has not been addressed (Paralyzed Veterans of America Consortium for Spinal Cord Medicine 2005).

1.2.4 Clinical Guidelines for management of upper limb pain

Clinical practice guidelines relating to the treatment of upper limb injuries associated with SCI were first published in 2005, by Boninger et al. The guidelines focused on the preservation of upper limb function in manual wheelchair users, specifically patients with an SCI. The guidelines were formulated from a panel of experts involved in spinal cord medicine and were the first to address the increasing prevalence of upper limb injuries in the SCI population. The report was part of a review recognising the different healthcare needs for the SCI population and compiled 35 specific recommendations in relation to the identification and treatment of upper limb pain. Recommendations from the report highlighted a lack of research in the area of upper limb injury and a need for further research into the benefits of management (Connolly et al. 2014).

Ten years on from this publication, Sawatzky et al. (2015) called for an update of these guidelines due to the ever-changing needs of patients with an SCI. The authors believed that although the clinical guidelines provided sufficient knowledge of the acute and sub-acute

phases of upper limb injuries, a broader perspective was required in relation to upper limb injury prevention in children and elderly manual wheelchair users. Recommendations of this position article aimed to ensure the most up-to-date evidence was incorporated to make recommendations clinically relevant, with the hope that recommendations may be applicable to all manual wheelchair users. Upper limb injuries resulting from poor wheeling practice have been documented in both those who began wheeling as adults or as children, implying that young manual wheelchair users are also at risk of developing injuries later in life (van Drongelen et al. 2006, Kennedy et al. 2006, Rice et al. 2009).

In a population where almost half of manual wheelchair users do not learn correct transfer technique during rehabilitation (Fliess-Douer et al. 2012), it is difficult to foresee a reduction in the prevalence of these injuries without correct education on wheeled mobility techniques and joint protection. Pain can have a debilitating effect on manual wheelchair users' mood, dependence and can have financial implications (Mortenson et al. 2012). Preliminary research has found that many manual wheelchair users do not report pain to their therapist highlighting the potential underreporting of these injuries in the literature (McCasland et al. 2006, Goldstein et al. 1997). Additionally, many wheelchair users reported only limited or short term relief from treatments received, highlighting an additional gap in knowledge of the most effective method of treating these injuries (Subbarao et al. 1995, Alm et al. 2008).

1.2.5 Wheelchair skills training

Wheelchair skills training was identified as a key aspect of patients' continuous rehabilitation and plays a key role in upper extremity health (Kilkens et al. 2005). To reduce the overuse of the upper limb, authors recommended patients should be taught the safest and most efficient methods of mobilising as a wheelchair user, to ensure patients can negotiate environments independently, requiring less force or muscle exertion, thus reducing the strain on the upper limb (Rice et al. 2013). Wheelchair skills training has also been positively associated with higher community participation levels and life satisfaction (Hosseini et al. 2012). Thus, wheelchair skills training not only has the potential to reduce upper limb injuries, but also promote social inclusion and participation for manual wheelchair users.

Wheelchair propulsion and transferring are the basic skills required for mobilising in a manual wheelchair, with the upper limb required to generate substantial force to propel the wheelchair (Mercer et al. 2006). Previous research has focused on reducing upper extremity demand during wheelchair propulsion by modifying wheelchair propulsion technique (Boninger et al. 2005, Mulroy et al. 2005, de Groot et al. 2003). Practicing longer, smoother strokes while propelling the wheelchair has been proven to be effective, where larger contact angles reduces cadence (number of revolutions per minute) and minimises peak handrim force during propulsion (Paralyzed Veterans of America Consortium for Spinal Cord Medicine 2005), thus reducing the stress on the upper limb (Rankin et al. 2012). Research has indicated that wheelchair skills training can potentially reduce joint degeneration and adoption of abnormal wheeling techniques, thus reducing the overall strain on the upper limb during wheelchair related activities.

Wheelchair skills training goes beyond the direct provision of equipment and is in-keeping with the International Classification of Functioning, Disability and Health framework (ICF) (World Health Organisation 2007) focus of participation and function within a participant's wider environmental context. Wheelchair skills training has the potential to enable young people to become "expert patients", taking increased responsibility and a more active role in decisions that positively influence their participation in life opportunities. Additionally, providing a more efficient method of independent mobility enables children to conserve energy for more meaningful activities which would normally be used during locomotion (Cox 2003). Young manual wheelchair users are also at the prime age to learn new skills before they develop poor technique. Whilst significant developments have taken place clinically in terms of how the wheelchair service is strategically and operationally delivered in Northern Ireland, there is a gap in the knowledge of the optimal way to ensure wheelchair users know how to get the most from their wheelchair, in the context of where they live, work and play.

Particularly in the spinal cord injured (SCI) population, manual wheelchairs are often the only means of mobility where the level of injury has resulted in permanent paralysis. Wheelchairs are the most effective solution to impaired mobility, enabling those with an SCI to be functionally independent as a wheelchair user, without the assistance of a carer.

1.3 Spinal Cord Injury

The spinal cord consists of nerve bundles connecting the brain to the peripheral nervous system and the rest of the body. The spinal cord is located in the vertebral foramen and is made up of the cervical, thoracic, lumbar and sacral segments. Each division is sub-divided as detailed in Figure 1.2, where the sub-division relates to the function of the specific area of the body. The spinal cord itself is responsible for relaying messages from the brain regarding functions such as movement, pain and temperature, and to the brain from the periphery (Callaghan et al. 2017). A spinal cord injury can be defined as complete or incomplete, with the resulting paralysis dependent on the level of injury and sensory and motor neuron involvement (Waters et al. 1991).

1.3.1 Aetiology of spinal cord injury

Approximately 1,000 people suffer a spinal cord injury each year in the United Kingdom (UK) and Ireland; the highest prevalence of injury occurring between the ages of 15-38 years (Spinal Research, 2011). Data from the United Kingdom specialised SCI centre estimates the prevalence of SCI as 12-16 million of the population (NHS England 2013). Data relating to the causation of spinal cord injuries in the UK is limited. McCaughey et al. (2016) conducted a retrospective cohort study investigating the trends in SCI in Scotland over a 20-year period. During this time, the most common cause of traumatic SCI was falls (51.7%), followed by road traffic collisions (24.4%). Of these, 38% of injuries sustained were to those driving the vehicles, 33% were passengers, 22% were motorcyclists and 7% were pedestrians. Sports related SCIs accounted for 22% of injuries of which cycling was the most prominent sporting activity (22%). Diving or swimming accounted for 26% of sporting related injuries, followed by horse riding (21%) and rugby related injuries (11%). Historically, men were at a greater risk of sustaining an SCI however, recent trends indicate that in the UK and Ireland, incidence of male and female SCI are almost equal, with men still at a slightly higher risk of sustaining an SCI (Aung and Masri 1997, O'Connor and Murray 2006).

1.3.2 Life expectancy in spinal cord injury

Life expectancy in the SCI population has increased significantly in the last century with improved healthcare. Le et al. (1981), reported the mean length of survival post initial SCI in 1955 was 4 years and 4.8 months, which increased to 9 years and 2.5 months by 1963.

Strauss et al. (2006), reported the age at which injury occurs is a crucial factor in estimating life expectancy within the SCI population. Today, the estimated life expectancy of a person injured at age 25 years, with a non-violent, low level and low-grade injury, as measured on American Spinal Injury Association (ASIA) scale is 69.7 years (± 6.8 years dependent on complete/incomplete injury) (Kirshblum et al. 2011). This increase in life expectancy means the possibility to live long and healthy lives for the 1,000 people injured with an SCI in the UK and Ireland per year is very achievable.

1.3.3 Classification of Spinal Cord Injury

The American Spinal Injury Association classifies spinal cord injuries based on the level at which the injury occurs (Maynard et al. 1997). Spinal injuries are classified as either complete or incomplete depending on the level of sensation and muscle movement post injury. A complete SCI involves no voluntary motor or conscious sensory function below the injury site. In comparison, an incomplete SCI is the presence of function several segments below the injury site but the absence of function below a given level (Wyndaele and Wyndaele 2006). Paraplegia can be defined as impairment or loss of motor or sensory function in areas of the body served by the thoracic, lumbar, or sacral neurological segments, owing to damage of neural elements in those parts of the spinal cord (Norton 2010). In comparison, quadriplegia refers to the presence of paralysis in all four limbs, as a result of injury to the cervical segments of the spinal cord (Liverman et al. 2005). The anticipated functional ability and mobility requirements by level of injury are summarized below in Figure 1.1.

Figure 1.1: Anticipated functional ability and mobility requirements by level of injury.

Damage at a particular level usually impairs the functions controlled by all nerves at lower levels, dependent on completeness of injury (OpenStax Rice University 2016 pg. 1097).

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Structure of the spinal cord	Level of injury	Anticipated functional ability	Anticipated mobility requirements
<p>C1 (Atlas) C2 (Axis) C3 C4 C5 C6 C7 Th1 Th2 Th3 Th4 Th5 Th6 Th7 Th8 Th9 Th10 Th11 Th12 L1 L2 L3 L4 L5 Os sacrum Coccyx</p>	C1-C3	No sensation below the neck	Powered wheelchair
	C4	Head and neck sensation with partial function of the diaphragm	Powered wheelchair
	C5	Movement of the head, neck and shoulders with elbow flexion	Powered wheelchair
	C6	Movement of shoulder and wrist extension	Powered or manual wheelchair
	C7-C8	As above with use of some fingers	Manual wheelchair
	T1-T5	Full upper extremity movements and use of thoracic muscles	
	T6-T10	Use of abdominal muscles and trunk control	
	T11-L5	Hip flexion and abduction and flexion and extension of knees	May use crutches/stick or manual wheelchair for longer distances
	S1-S5	Bowel bladder and sexual function	

1.3.4 Functional Implications in spinal cord injury

Damage at a particular level of the spine dictates the level of function persons with an SCI may potentially achieve and the type of mobility device they may be able to use. Injury to cervical segments C1 – C4 results in paralysis in all four limbs, with limited sensation of the head, neck and diaphragm. Due to the level of paralysis, this cohort generally rely on either voice controlled, “sip-n-puff” or chin operated electric wheelchairs (Fehr et al. 2000). Typically, at the C5/6 injury level, the triceps muscle function is inhibited resulting in loss of active elbow extension (Giuffrida and Crago 2005). Intact shoulder abduction and external rotation functions, elbow flexion and variable wrist extension, implies that some patients at this injury level may be able to propel a manual wheelchair dependent on strength (Algood et al. 2004). For the majority of patients injured at this level, the combined loss of elbow extension and low trunk control can make manual wheelchair propulsion difficult to achieve. Manual wheelchair use is therefore more common in those with an injury between T10 – C7 or broadly, patients with paraplegia (Consortium for Spinal Cord Medicine 1999).

1.4 Manual Wheelchair use in Northern Ireland

Statistics relating to wheelchair use in Northern Ireland are limited, with the most recent figures estimating approximately 30,000 of the 1.8 million population of Northern Ireland classified as wheelchair users (DHSSPS 2008). Of this, 27,000 are full time users, with children under 18 making up approximately 2,500 (9.25%) of this population (DHSSPS, 2008). This equates to 1.3% of Northern Ireland population which is less than the National average of 2%. The regional figures are debateable as being an accurate reflection of the true situation. Northern Ireland lags behind the rest of the UK in terms of diagnosing, treating and preventing such conditions (National Audit Office, 2012). The Appleby Report (2005) for instance highlighted Northern Ireland health indices are poorer compared to the rest of the United Kingdom, with Northern Ireland having the highest incidences of birth defects, Multiple Sclerosis and road traffic accidents in Europe, all of which contribute to the incidence of wheelchair use. Hence, it is reasonable to argue that Northern Ireland’s figures are underestimated, or indeed people who would benefit from a wheelchair are not accessing this service, and the true estimate should be closer to the rest of the UK than reported.

1.4.1 Wheelchair Service in Northern Ireland

The majority of wheelchair users in Northern Ireland obtain their wheelchair via the National Health Service (NHS) wheelchair service, or may privately purchase their wheelchair. The wheelchair service in Northern Ireland underwent a review in 2008 to address discrepancies in the services delivered regionally, namely the “Proposals for the reform of the Northern Ireland Wheelchair Service” (2008). Recommendations for service improvements were made following a 2-year review completed from partnership working between healthcare staff and wheelchair service users. Recommendations from this report outlined how wheelchair users should be the centre of the assessment and planning process and that they should be acknowledged as experts regarding their own physical health and lifestyle needs, to ensure social inclusion, maximal quality of life and maximum independence.

Many patients with an SCI will require use of a wheelchair for mobility purposes. Depending on the level of injury this may be powered or manually propelled. Occupational therapists prescribe wheelchairs that are configured to the patient’s needs enabling them to perform everyday activities they would not otherwise be able to undertake, and decrease functional limitations and dependency (Di Marco et al. 2003). Approximately half of SCI wheelchair users are paraplegic (56%), (Noonan et al. 2012), indicating many use a manually propelled wheelchair for mobility. This enables them to live highly independent lives, completing activities of daily living, travelling to and from work and competing in sports. Although wheelchairs provide a significant level of independence, long-term use can result in significant upper limb pain (Ballinger et al. 2000). Manual wheelchair users rely on their upper limbs for the majority of their daily activities such as mobility, washing/dressing and pursuing leisure and social activities. With such a reliance on the upper limb for everyday activities, it is unsurprising that many manual wheelchair users report upper limb pain.

1.4.2 Wheelchair skills training in Northern Ireland

Currently in Northern Ireland, the NHS provides limited wheelchair skills training and to the author’s knowledge, there is no evidence of this documented in the literature. Anecdotal evidence provided by clinicians in the early stages of the development of this research, outlined how formal wheelchair skills training is delivered every 3 months at the Regional

Spinal Cord Injury centre (RSCI), by the “Back Up Trust”; a charity associated with SCI specifically. Further skills training for children is delivered primarily by two charities based in mainland United Kingdom (UK); “Whizz Kidz” and “Go-Kids-go”. Both these charities deliver skills training over the summer months in the form of “summer camps”. Similarly, Disability Sport Northern Ireland (DSNI) also deliver wheelchair sport sessions however, these are primarily in the form of a sport specific summer camp for all young wheelchair users. Although the benefits of wheelchair skills training are documented, there is little evidence in the literature relating to wheelchair skills training with either children or adults in Northern Ireland.

1.5 Theoretical approach to upper limb pain

With such a high importance placed on the role of the patient in the design of services, it seems only right that the patient perspective is central to this research. The objective measurement of health alone is no longer satisfactory in assessing patient’s needs (Sullivan 2003). The most complete research in current health care now generally assesses the client as a whole, including personal, occupational and environmental aspects. The patient perspective is crucial in understanding their condition and aligns the objective symptoms with their subjective responses in order to create a full picture of how the client and their disease/injury interact together. It is the patient who has the authority to judge their quality of life not the health care professional, therefore the patient’s role in communicating their experience with the injury is critical (Robinson et al. 2008).

The most effective method of comprehending the complex nature of upper limb injuries was the use of a conceptual framework to further explore the impact of these injuries. Both the Evidence Based Practice Model (Newhouse et al. 2007) and the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation 2007), have influenced the design of the research presented in this thesis.

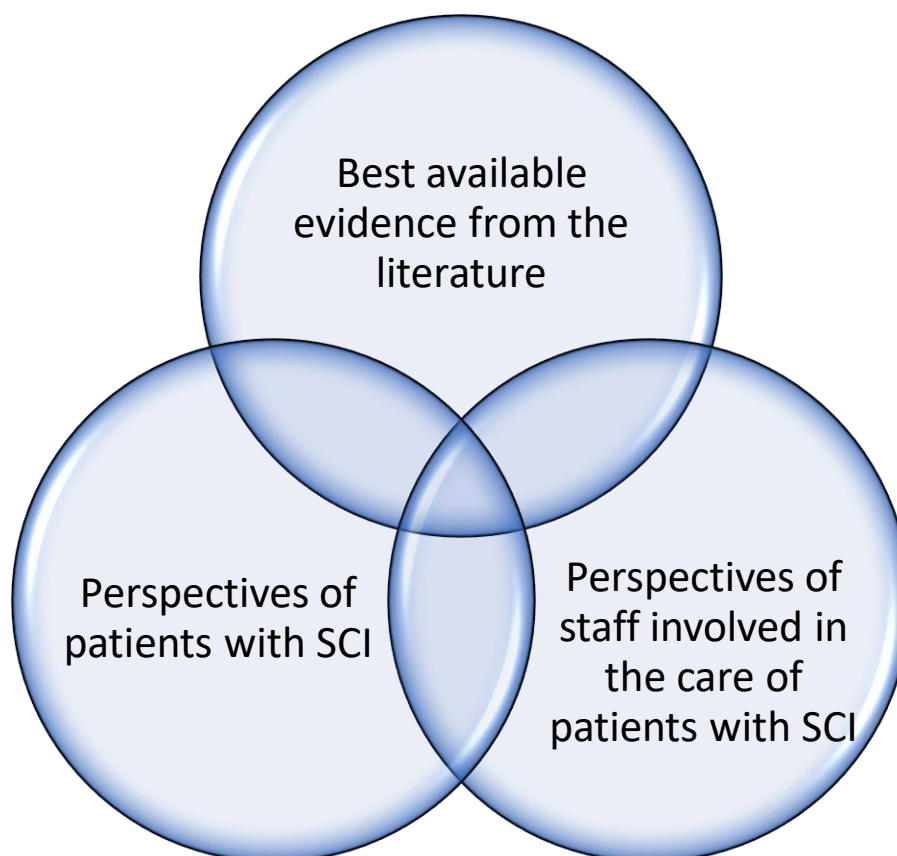
1.5.1 Evidence Based Practice

The evidence based practice model, outlined in Figure 1.2 below, aims to bridge the gap between clinical practice and research, to enhance the knowledge base and improve overall patient care (Newhouse et al. 2007). This approach was used to gain a greater

understanding of the complex nature of upper limb injuries in patients with an SCI. Research is an integral aspect in clinical practice in ensuring the most up-to-date methods are utilised to deliver the most effective care to patients. In using the evidence based practice approach, emphasis was placed on the patient voice, how they perceive their injury's impact on their daily lives and how they have best managed these. Additionally, understanding the views of health care professionals and their perspectives of how upper limb injuries may be managed, may reveal what can be done to better support their patients. The role of research is to provide this evidence base to support their interventions and improve patient outcomes within the SCI population.

Figure 1.2 Evidence Based Practice Approach

Adapted from Armstrong (2003) Evidence Based Medicine Triad

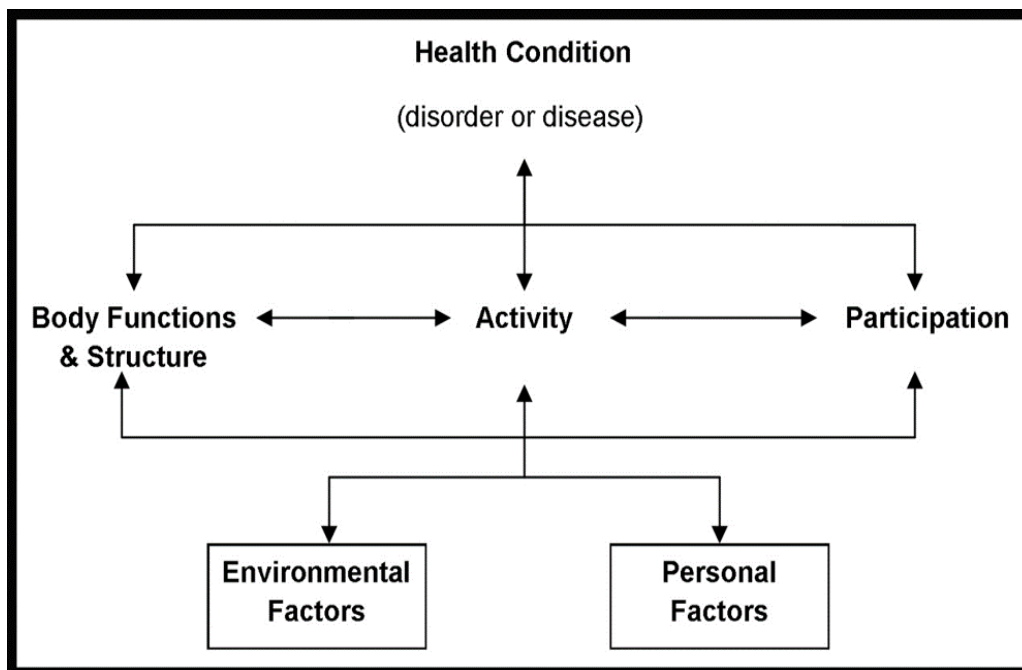


1.5.2 The International Classification of Functioning, Disability and Health

The International Classification of Functioning, Disability and Health (Figure 1.4), also known as ICF, is a classification of the health components of functioning and disability. The ICF has numerous applications including its use as a conceptual framework for research in promoting a person's functioning and disability as a dynamic, including external factors of life rather than a medical diagnosis only (Stucki and Melvin 2007). The framework assists in mitigating social barriers and promoting social supports including personal health care information. A client centred approach was central to this research using the ICF as a framework to establish how upper limb injury affects SCI participants and identify the occupational and social barriers experienced by SCI participants during the qualitative data collection phase (Cieza et al. 2010).

Figure 1.3 The International Classification of Functioning, Disability and Health

(Reproduced with permission; WHO 2001).



1.6 Organisation of thesis

To date, there is no literature focusing on the opinions or perspectives of wheelchair users who experience upper limb pain, what services they have availed of or what they have found most beneficial. Additionally, it is clear having a basic skill level is required to mobilise independently, but what are these specific skills? What skills are the most beneficial? How

are they taught and tested? And how are they implemented? As already stated above and elsewhere, there is no research directly related to the client's perspective of how their upper limb injury impacts on their day-to-day lives, yet services are being provided (or not) based on medical observations only. The purpose of this research was to combine objective reporting of injuries from medical notes with the perspective of the patient and health care professional involved in their care and to understand the overall impact of upper limb injuries sustained specifically from manual wheelchair use. The research presented in this thesis aims to explore the medical and rehabilitation approaches to treatment and to contribute original knowledge to the most effective management of upper limb injuries in this population. A secondary aim in this thesis is to assess the feasibility of delivering a wheelchair skills training programme to young manual wheelchair users to improve wheelchair skill acquisition. This research will attempt to contribute to the evidence base and fill the gap in knowledge relating to manual wheelchair use in Northern Ireland.

1.6.1 Achieving the aims of thesis

In order to achieve the overall aim of this thesis, five studies were conducted. Each study had its own individual methodology, aims and objectives to address the research question, identifying the best available evidence, the patient experience and the healthcare perspectives. The aims outlined above were addressed by the following five studies:

1. A systematic review on the prevalence of upper limb injuries in patients with a spinal cord injury
2. A qualitative exploration of patients with an SCI experience of upper limb pain and the functional impact these have had on everyday life
3. A qualitative exploration of staff involved in the care of patients with an SCI of their perspectives of the medical and rehabilitative approaches to treatment of upper limb pain
4. A systematic review of observational manual wheelchair skills test available in the literature
5. Manual wheelchair skills training for children: a pilot study

1.7 Methodologies of thesis

1.7.1 The systematic review

Chapters 2 and 5 are systematic reviews conducted to identify the most relevant and up to date research in relation to their specific research objective (i) the prevalence of upper limb injuries in patients with an SCI and (ii) the most reliable and valid wheelchair skills test available in the literature. Systematic reviews have been used widely in health care research to critically appraise literature using structured and reproducible methods. The systematic review is a rigorous and comprehensive method, that synthesises evidence according to predefined criteria, using well defined objectives and eligibility criteria, and assessment of validity and quality of studies included (Higgins and Green 2011). Systematic reviews have been identified as the reference standard in health care research due to the methodological rigour implemented (Moher et al. 2015). They are therefore regarded as the most robust method for informing service development in evidence based medicine, providing accurate and reliable information to inform future decision making and service development (Tranfield et al. 2003). To compliment this, the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines add an additional level of rigour; a checklist of 27 items is used to enhance the quality of the research reported (Moher et al. 2009). Findings of these reviews were both used to inform Chapters 3, 4 and 6 to ensure evidence-based practice was incorporated throughout.

1.7.2 The descriptive questionnaire

Chapter 3 combined several methodologies to explore the prevalence of upper limb injuries in patients with an SCI. The descriptive questionnaire was used to capture preliminary evidence on the reporting of upper limb injuries in patients with an SCI. The descriptive survey has been used widely in health care research to elicit quantitative data relating to a specific hypothesis. This method is particularly useful to gather large amounts of information from large samples in a relatively cost effective manner (Edwards et al. 2002). Questionnaires were utilised initially to gain a preliminary understanding of how many patients with an SCI report upper limb pain and the treatments they sought. The questionnaire was adapted from Widerstrom-Noga et al. (2014) "The Spinal Cord Injury Pain Questionnaire" to which further domains were added following consultation with a steering committee of three patients with a SCI. Self-reported questionnaires have been

documented as beneficial in understanding the patient experience, where often patients' feelings, attitudes or beliefs are not documented in the medical notes (Tisnado et al. 2006), therefore enabling the researcher to obtain richer data in relation to the impact of upper limb pain for patients with an SCI.

1.7.3 Audit of medical notes

Self-reported questionnaires although beneficial, can also be limited by error such as recall bias or social desirability bias where an over or under reporting may be observed (Ritter et al. 2001). To counteract this, it has been suggested that the data reported in self-reported outcome measures can be cross checked with that reported in the medical notes, to enhance the validity of findings (Fowles et al. 1998, Kwon et al. 2003). A specifically designed data collection form was used to obtain details relating to the reporting of upper limb pain and hospital admissions to confirm findings from the self-reported questionnaire. From the evidence, it is unclear whether either aspect of the reporting of upper limb pain is more accurate, however it was hypothesised that both methods would compliment each other in understanding the overall impact of upper limb pain for patients with an SCI (Corser et al. 2008).

1.7.4 The qualitative interview

The qualitative interview was used to further explore the patient perspective of upper limb pain. With current emphasis placed on the voice of the patient and the concept of patients being central to the service we deliver, it seemed only right that the patient voice was central to the implementation of this work (Eaton et al. 2015). Qualitative research aims to enable the researcher to gain a greater understanding of a phenomenon by exploring individual perceptions and experiences (Cho and Trent 2006), as conducted in this thesis. One-to-one interviews were utilised specifically due to the nature of the research question. One-to-one interviews provide an element of privacy to participants where they may feel more comfortable disclosing information in a confidential manner to a researcher, rather than in a focus group setting (Jamshed 2014). Interviews were semi-structured to allow a degree of flexibility of topics discussed; a topic guide was utilised to ensure the interview stayed relevant to the research question however, participants were still free to discuss other relevant aspects as deemed necessary (DiCicco-Bloom and Crabtree 2006). The

strength of this approach lies in the validity of the findings through the exploration of first hand patient experiences and perspectives (Greenhalgh and Taylor 1997).

1.7.5 The open-ended questionnaire

Chapter 4 utilised an open-ended questionnaire to capture preliminary views of health care professionals involved in the care of patients with an SCI. An open-ended questionnaire was utilised in this study to obtain a broader understanding of upper limb pain in patients with an SCI from the perspective of the health care professional. The choice to use an open-ended questionnaire was based on perceived time constraints of health care professionals (Legare et al. 2008). The questionnaire was short enough to complete in 30 minutes yet comprehensive to gain rich data of which could not be obtained via a quantitative questionnaire with predefined options (Riiskjaer et al. 2012).

1.7.6 Qualitative interviews with healthcare professionals

Qualitative interviews were then implemented to gain an in-depth understanding of the needs and goals of patients with an SCI while undergoing initial inpatient rehabilitation from the perspective of the healthcare professional. Similar to Chapter 3, it was hypothesised the professional opinions expressed by the healthcare professionals may provide more information in several key areas under investigation; (i) the most beneficial treatment of upper limb injuries; (ii) patient goals during rehabilitation; (iii) the treatment pathway, beginning with the identification of injury to treatment of upper limb pain within the remit of the NHS; and (iv) what therapists felt could be done to further support their patient's needs.

1.7.7 The wheelchair skills study

Following the systematic review conducted in Chapter 5, Chapter 6 aimed to assess the feasibility of delivering wheelchair skills training to young manual wheelchair users, an emerging area of research with little published literature to date. New advances in healthcare research are continually being developed and it is critical to evaluate these interventions for suitability in clinical practice. Assessment is a key component in clinical research to ensure validity and reliability of findings. Following the findings from Chapters 2-5, a wheelchair skills test was implemented pre and post a 6-month wheelchair skills

training programme. The hypothesis was that following the 6-month skills training programme wheelchair skills acquisition in young manual wheelchair users would improve.

1.7.8 Overall findings

Chapter 7 attempted to combine the research findings from Chapters 2-6 in line with the evidence-based practice model; reporting on the best available evidence, the patient experience and the healthcare professional perspective, to make recommendations for service delivery and clinical practice. The research presented in this thesis presents evidence to enhance understanding of upper limb injuries in patients with an SCI, the impact these injuries have on patients' daily lives and the current medical and rehabilitation approaches to treatment of upper limb injuries.

CHAPTER 2

PREVALENCE OF UPPER LIMB PAIN IN SPINAL CORD INJURY: A SYSTEMATIC REVIEW

Abstract

Introduction: Manual wheelchairs are an assistive technology device prescribed by occupational therapists in the case where physical mobility is impaired. Particularly in the spinal cord injured (SCI) population, wheelchairs are often the only means of mobility where the level of injury has resulted in permanent paralysis. Wheelchairs are the most effective solution to impaired mobility, enabling those with an SCI to be functionally independent as a wheelchair user, without the assistance of a carer. Although manual wheelchairs provide a level of independence, they are not without their consequences. Manual wheelchair users often experience persistent and chronic pain of the upper limb, as a result of the excessive force required during wheelchair propulsion and wheelchair transfers. The aim of this study was to investigate the prevalence and treatment of upper limb injuries in the spinal cord injured population.

Objective: To review, evaluate and critically appraise literature pertaining to prevalence and treatment of upper limb pain in the manual wheelchair using spinal cord injured population.

Study design: A systematic review adhering to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al. 2009).

Methods: Data extraction tables were compiled and included study design, objective, sample size, classification of SCI, type of injury/pain reported, outcome measures used and results of each article. Further in-depth data on the types of injury recorded, level of SCI injury, type of wheelchair used, type of treatment sought (if applicable) and the impact on Activities of Daily Living (ADLs) were also recorded. A search was conducted between January - February 2017 for studies reporting on the prevalence of upper limb injuries or pain, in manual wheelchair users with an SCI. Medline (1966 – February 2017), CINAHL (1982 – February 2017), OVID (1966 – February 2017) and PubMed (1971 to February 2017) databases were searched using the terms “spinal cord injur* or SCI” combined with “wrist”, “elbow”, “shoulder”, “neck”, “upper limb”, “carpal tunnel”, “rotator cuff”, “parapleg*”, and “mobil*”, “ambulation”, “propel”, and “pain”. The National Heart, Lung and Blood Institute (NHLBI) Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies tool was used to critically appraise the quality of studies included in this review.

Results: The systematic search returned 994 papers in total, forty-six full text studies were assessed for eligibility by a single reviewer, with fourteen studies included in the final synthesis; four cohort studies and ten cross-sectional studies. The cohort studies scored moderately well on the NHLBI Quality Assessment Tool, ranging between 5-7/10 in terms of quality. The cross-sectional studies also scored positively ranging between 5-7/8. The most common limitations observed within the studies was sampling bias and the use of non-validated outcome measures used to report or measure upper limb pain. Shoulder pain was the most common type of pain reported (30%-71%) followed by wrist pain, hand pain and elbow pain. Functional limitations reported as a result of upper limb pain included interference with mobilising, transferring, and Activities of Daily Living, primarily personal care tasks. The age that SCI occurred in participants was recorded as mean duration since injury, length of time as a manual wheelchair user or mean age that SCI occurred at with several studies finding a significant association between upper limb pain and duration of wheelchair use, however no relation to the age of the wheelchair user. It is difficult to decipher the most common stage post spinal injury that upper limb pain occurs at or factors that may contribute to upper limb injury due to the heterogeneity of these studies.

Conclusion: There is a clear evidence that upper limb pain is prevalent in the SCI manual wheelchair using population and impacts on functional tasks, however there is little evidence relating to how participants manage this. Further research is required to explore the perceptions of those with upper limb pain and techniques used to manage this.

2.0 Introduction

Spinal cord injury is defined as an acute, traumatic lesion of neural elements in the spinal cord, resulting in permanent sensory deficit, motor deficit or bladder and bowel dysfunction (Thurman et al. 1995). The damage may be temporary or permanent depending on type of injury, with the resulting damage translating to loss of muscle function, sensation, or autonomic function in parts of the body below the level of the lesion. Injuries can occur at any level of the spinal cord and can be classified as complete injury; with a total loss of sensation and muscle function, or incomplete; meaning some nervous signals are able to travel past the injured area of the cord (Maynard et al. 1997).

Depending on the location and severity of damage along the spinal cord, the symptoms can vary widely, from pain or numbness to paralysis. Spinal cord injury can be traumatic or non-traumatic and can be classified into three types based on cause: mechanical forces, toxic, and ischemic (Chen et al. 2013). Injuries can occur at the cervical 1–8 (C1–C8), thoracic 1–12 (T1–T12), lumbar 1–5 (L1–L5), or sacral (S1–S5) levels. A person's level of injury is defined as the lowest level of full sensation and function (Finnerup 2013). SCI is also classified by the degree of impairment. The International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI), published by the American Spinal Injury Association (ASIA) (Kirshblum et al. 2011), is widely used to document sensory and motor impairments following SCI. It is based on neurological responses, touch and pinprick sensations tested in each dermatome, and strength of the muscles that control key motions on both sides of the body. The prognosis also ranges widely, from full recovery, in rare cases, to permanent tetraplegia.

Patients with an SCI have seen great improvements in their care since the middle of the 20th century. Treatment of spinal cord injuries starts with stabilizing the spine and controlling inflammation to prevent further damage (Crewe et al. 2009). Other required interventions can vary widely depending on the location and extent of the injury, from bed rest to surgery. In many cases, spinal cord injuries require substantial, long-term physical and occupational therapy in rehabilitation, especially if the injuries interfere with activities of daily living (Simpson et al. 2012). In 1991, the Institute of Medicine (Pope & Tarlov 1991), published a research report that focused on health conditions following SCI. The report was influential in the rehabilitation field by enhancing our understanding of the associations

between the duration of disability and health outcomes in individuals with SCI. The report highlighted premature or accelerated ageing in several organ systems in the SCI population compared to the aged matched general population. In addition, they report that chronic pain and other health conditions increases with the duration of SCI. The primary complications that can occur in the short and long term after SCI include; musculoskeletal (MSK) pain, muscle atrophy, pressure sores, infections, and respiratory issues (Sezer et al. 2015).

The scope of this review is in relation to Musculoskeletal (MSK) pain, specifically of the upper limb. For the purpose of this study, upper limb pain refers to pain or inflammation of the neck, shoulder, elbow, wrist or fingers as well as the corresponding muscles, ligaments and tendons. There is a substantial amount of literature in the area documenting the prevalence of these conditions. Injuries such as shoulder, neck and back pain resulting from poor wheeling practice in the long-term are documented in both those who began wheeling as adults and as children (van Drongelen et al. 2006, Kennedy et al. 2006, Rice et al. 2009). Between 49% and 73% of SCI manual wheelchair users develop carpal tunnel syndrome and between 31% and 71% report shoulder pain (Toosi et al. 2010). This may have serious implications for functional mobility, sleep and living life independently (Widerstrom-Noga et al. 2001).

Management of upper limb pain may prove difficult due to the nature of the treatment. In many cases relative rest may be required in order for the upper limb to recover however this may prove problematic as the upper extremity is used for mobility on a daily basis (Alm et al. 2008). Pain can contribute to overall poorer health in the SCI population, and has been shown to have a negative effect on both physical and psychological aspects of a person's wellbeing (Ma et al. 2014). Further long term pain that is chronic in nature has also been associated with low mood and depressive symptoms in the SCI population (Rintala et al. 1999).

To the author's knowledge, no formal systematic review of the literature relating to the prevalence of upper limb pain in the SCI population has been conducted to date. The aim of

this review is to add further knowledge to the gap in literature relating to the prevalence of upper limb pain in the SCI population.

2.1 Aim

The overall aim of this review is to examine the literature in relation to prevalence of upper limb pain, pain sites reported, treatments available and causation of injuries. This review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al. 2009)

2.2 Methods

2.2.1 Search and study selection

A search was conducted between January - February 2017 for studies reporting on the prevalence of upper limb injuries or pain, in manual wheelchair users with an SCI. Medline (1966 – February 2017), CINAHL (1982 – February 2017), OVID (1966 – February 2017) and PubMed (1971 to February 2017) databases were searched using the terms “spinal cord injur* or SCI” combined with “wrist”, “elbow”, “shoulder”, “neck”, “upper limb”, “carpal tunnel”, “rotator cuff”, “parapleg*”, and “mobil*”, “ambulation”, “propel”, and “pain”. Further literature was obtained by exploring reference lists of papers identified in this search. Each title was screened by a single reviewer for relevance and added to the shortlist if it met the inclusion criteria or if further clarification was required, the abstract or entire paper was reviewed.

2.2.2 Inclusion and exclusion criteria:

Studies were included if they were peer reviewed research studies written in the English language, that directly reported on prevalence of upper limb pain in SCI. Studies were required to include participants with a traumatic SCI only and use a manual wheelchair full time. Other causations of SCI were excluded such as infection or insufficient blood flow, as in these cases participants may regain function and therefore fluctuating prevalence rates of upper limb pain may be observed. Any prevalence rates reported in these studies may be skewed by a participant regaining function or not requiring a wheelchair for mobility purpose therefore would not be an accurate reflection of the true prevalence rates. Studies primarily including wheelchair athletes were also excluded as it is common for athletes to

have higher level of activities compared to a sedentary population and may therefore report higher levels of prevalence rates that could not be generalised to the wider SCI population.

2.2.3 Data collection process

Data extraction tables were compiled (Appendix 1) and included study design, objective, sample size, classification of SCI, type of injury/pain reported, outcome measures used and results of each article. Further in-depth data on the types of injury recorded, level of SCI, type of wheelchair used, type of treatment sought (if applicable) and the impact on ADLs, were also recorded.

2.2.4 Study Quality Appraisal

The National Heart, Lung and Blood Institute (NHLBI) Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies tool was used to critically appraise the quality of studies included in this review. The tool is a widely accepted tool used for appraising observational studies and is particularly useful in identifying methods applied to minimise bias in research literature (Carter 2010). The tool itself is a 14-item scale, with each question scored as “yes” or “no”. If an item on the checklist cannot be clearly identified, the scorer can assign “cannot determine”, “not applicable” or “not relevant”. The tool has been designed as a checklist rather than a scoring scale specifically, however can be used as guidance in determining the methodological quality of studies. All studies were retrieved and reviewed by a single researcher (AMC).

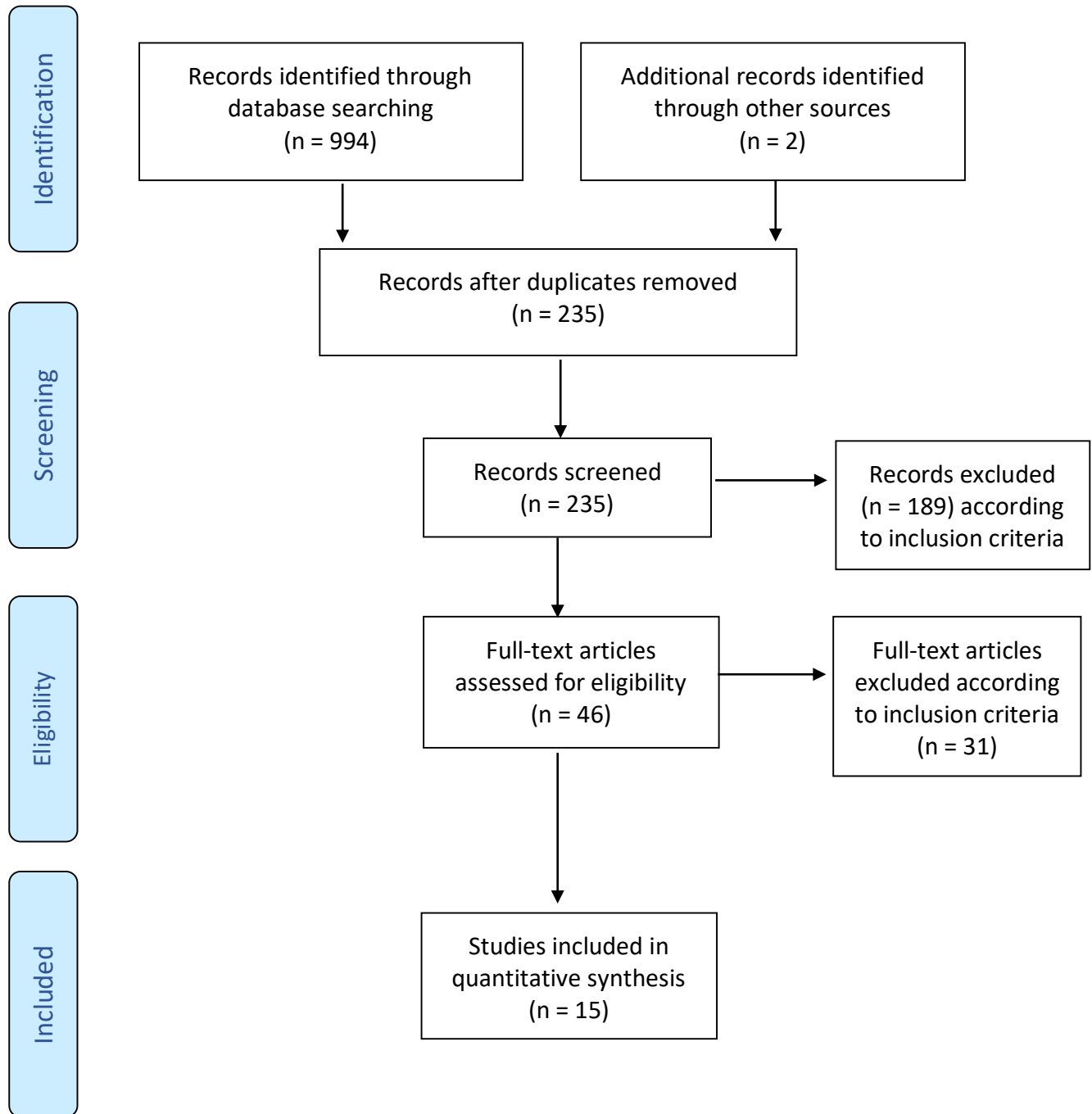
2.3 Results

The systematic search returned 994 papers in total (Figure 2.1: PRISMA Flow Diagram). Two additional papers were found via hand search and review of relevant reference lists in the subject area. Forth-six studies were selected for further reading. After reviewing the full text studies, 31 studies were excluded after not meeting one or more of the inclusion criteria.

The most common inclusion criteria not met was the involvement of part time manual wheelchair users, elite wheelchair athletes or studies not specific to upper limb or extremity injury in the SCI population. The total number of studies included in this review was 15 papers.

Key results for all studies are summarised in Appendix 1. Four studies comprised of cohort methodologies (Ballinger et al. 2000, Eriks-Hoogland et al. 2016, Silfverskiold & Waters 1991, van Drongelen et al. 2006) following patients for 3 years, 5 years, 18 months and 1 year post SCI rehabilitation respectively. The remaining 11 studies were cross-sectional in design (Aljure et al. 1985, Boninger et al. 2001, Dalyan et al. 1999, El Essi et al. 2012, Escobedo et al. 1997, Gironda et al. 2004, Pentland & Twomey 1994, Pentland & Twomey 1991, Samuelsson et al. 2004, Sie et al. 1992, Subbarao et al. 1994). Five studies investigated the prevalence of upper limb pain alone and the remaining 10 studies, included the impact on functional activities.

Figure 2.1: PRISMA Flow Diagram



2.3.1 Demographic Results

Demographic details from each study are outlined in the appendix (Appendix 1). Studies are discussed in further detail below.

Recruitment

Studies were primarily conducted in the United States of America (USA), (n= 9), two studies conducted in the Netherlands, two in Australia, one in Sweden and one in Israel.

Recruitment of participants was primarily conducted via hospital discharge lists (n= 7).

Ballinger et al. (2000) additionally advertised their study with local radio stations and

Boninger et al. (2001) advertised with known wheelchair vendors to improve recruitment.

Eriks-Hoogland et al. (2016), Silfverskiold & Waters (1991) and Van Drongelen et al. (2006), recruited participants while they were undergoing initial inpatient rehabilitation. Pentland & Twomey (1991 & 1994) stated participants were recruited from the community however it is not clear whether this may have been via discharge lists, advertisements in the media or any other approach. Escobedo et al. (1997) and Sie et al. (1992) recruited participants directly on attending a routine medical examination at an outpatient appointment as part of their SCI rehabilitation. The remaining studies (Aljure et al. 1985 and Dalyan et al. 1999) do not state explicitly where participants were recruited from.

Research study settings refers to where the study took place. Settings were classified as either inpatient, outpatient or community based. Five studies were community based (Gironda et al. 2004, Pentland & Twomey 1991 & 1994, Samuelsson et al. 2004, Subbarao et al. 1994). Four studies were outpatient based (Dalyan et al. 1999, El-Essi et al. 2012, Escobedo et al. 1997, Sie et al. 1992). Two studies were inpatient based (Silfverskiold & Waters 1991 and van Drongelen et al. 2006), and three availed of a combination of community and outpatient settings (Eriks-Hoogland et al. 2016, Ballinger et al. 2000, Boninger et al. 2001). Recruitment methods and setting were unclear for one study, Aljure et al. (1985).

Response rates

Response rates were detailed in five studies; Dalyan et al. 1999 = 76.5%, El-Essi et al. 2012 = 86%, Gironda et al. 2004 = 46%, Samuelsson et al. 2004 = 63% and Subbarao et al. 1994 =

66%. Ballinger et al. (2000) reported an oversubscription to their study; 661 participants responded with the authors choosing a sample of 140 participants. Escobedo et al. 1997 and Sie et al. (1992) used a sample of convenience from patients attending routine outpatient appointments and therefore all patients who met the inclusion criteria were included. The remaining studies did not list response rates specifically, however Eriks-Hoogland et al. (2016) reported 60 patients were lost to follow up; 43% dropout rate at the end of the five-year study. The remaining cohort studies do not list details relating to dropout rates or participant retention.

Sample sizes

Sample sizes ranged from 11 participants (Pentland & Twomey 1991) to 669 participants in Girona et al. (2004) cross sectional study. Sample sizes for each individual study are outlined in Appendix 1.

Age

The youngest participant in all studies was aged 17 years (Silfverskiold & Waters 1991), with the oldest participant aged 78 years (Escobedo et al. 1997). Eight studies included age range and mean, six studies reported mean age only and El Essi et al. (2012) was the only study to record age range only. The breakdown of reporting methods for age are outlined below in Table 2.1.

Table 2.1: Reporting of age across studies

Reporting method	Author	Age
Studies reporting age range and mean	Aljure et al. (1985)	Range = 20-73 years, mean = 47.8
	Ballinger et al. (2000)	Range = 19-73 years, mean = 37
	Eriks-Hoogland et al. (2016)	Range = 18-66 years, mean = 34
	Escobedo et al. (1997)	Range = 40-78 years, mean = 59
	Girona et al. (2004)	Range = 20-65 years, mean = 50.6
	Sie et al. (1992)	Range = 17-71 years, mean = 37.4
	Silfverskiold & Waters (1991)	Range = 17-40 years, mean = 25
	Subbarao et al. (1994)	Range = 21-77 years, mean = 53
Studies reporting mean age only	Boninger et al. (2000)	35 years
	Dalyan et al. (1999)	42.2 years \pm 12
	Pentland & Twomey (1994)	44.3 years
	Pentland & Twomey (1991)	42.9 years
	Samuelsson et al. (2004)	49 years \pm 18
	van Drongelen et al. (2006)	59.6 years
Study reporting age range only	El-Essi et al. (2012)	Range = 18-59 years

Gender

Two of the older studies did not provide data relating to gender of participants included in their studies (Sie et al. 1992 and Subbarao et al. 1994). Three studies used a sample composed of male participants only (Aljure et al. 1985, Escobedo et al. 1997 and Pentland & Twomey 1994). The remaining studies all reported a higher percentage of male participants compared to female participants as is reflected in the wider population of SCI patients, where males are twice as likely to suffer an SCI compared to females (Michael et al. 1999). This is primarily attributed to the fact men are more likely to take part in high risk activities such as high speed driving or dangerous sports (Jackson et al. 2004). The higher percentage of males in this review may also be attributed to the study design of several studies included. Three studies were conducted as part of the Veterans Affairs medical centres in the USA. A higher percentage of males enrol in the military in the USA and therefore the potential cohort of participants recruited from may have been male dominated (de Groot

2001). Pentland & Twomey (1991) were the only study to include a female only sample. Apart from this study, the highest percentage of female participants was observed in Boninger et al. (2001) study with 32% female, albeit a small sample size (n=32).

Level of injury

The reporting of level of injury varied widely between studies. The terms quadriplegia and tetraplegia both refer to the same classification of injury and are based on the terminology used by individual authors and reflects differences in language used around the world. For the purpose of this study, the term tetraplegia will be used. Six studies referred to participants as either patients with paraplegia or tetraplegia. Four of these studies included participants with paraplegia only; Aljure et al. (1985), Boninger et al. (2001), El-Essi et al. (2012) and Samuelsson et al. (2004). Sie et al. (1992) and Silferskiold & Waters (1991), included participants with tetraplegia and paraplegia; 57% tetraplegia, 43% paraplegia and 66.6% tetraplegia and 33.3% paraplegia respectively.

Ballinger et al. (2000) and Eriks-Hoogland et al. (2016) both reported level of injury using a combination of the terms high/low paraplegia/tetraplegia and the American Spinal Injury Association (ASIA) Impairment Scale (AIS) levels A-D. Ballinger et al. (2000) range included; 5% high tetraplegia, 39% low tetraplegia, 45% paraplegia, 11% ASIA class D. Eriks-Hoogland et al. (2016) included 34.1% tetraplegia and AIS class A or B. Escobedo et al. (1997) and van Drongelen et al. (2006) both list level of injury as ranges; T3-L2 and C2-S5 respectively. The remaining five studies also list level of injury as ranges however provide further details on the percentage of participants within each range.

Dalyan et al. (1999) provided the most in-depth detail regarding level of injury; C2-C4 = 14.5%, C5-C8 = 35.5%, T1-5 = 7.9%, T6-T10 = 19.7%, T11-L2 = 21.1% and L3-L4 = 1.3%. Gironde et al. (2004) grouped participant level of injury into three ranges; T2-T6 = 34%, T7-T12 = 56.1% and L1-L2 = 9.9%. Similarly, Pentland & Twomey (1994 & 1991) used three ranges, however ranges differ by one level of injury within their groups. In 1991, they reported level of injury as; T1-T5 = 9%, T6-T10 = 18% and T11-L3 = 73%. In 1994, injury level was reported as; T2-T5 = 20%, T6-T10 = 40% and T11-L2 = 40%. Finally, Subbarao et al. (1994) grouped the reporting of level of injury into four ranges; C1-C4 = 9.2%, C5 – T1 =

34.6%, T12-L1 = 37.9% and L2 and below = 13.1%. The full range of reporting measures for level of injury can be found below in Table 2.2.

Table 2.2: Reporting measures for level of injury

Author (year)	Level of SCI
Aljure et al. (1985), Boninger et al. (2001) El-Essi et al. (2012) Samuelsson et al. (2004)	<i>All participants with paraplegia</i>
Sie et al. (1992)	57% tetraplegia, 43% paraplegia
Silfverskiold et al. (1986)	66.6% tetraplegia and 33.3% paraplegia
Ballinger et al. (2000)	5% high tetraplegia, 39% low tetraplegia, 45% paraplegia, 11% ASIA class D
Eriks-Hogland et al. (2016)	34.1% tetraplegia and AIS class A or B
Escobedo et al. (1997)	T3-L2
van Drongelen et al. (2006)	C2-S5
Dalyan et al. (1999)	C2-C4 = 14.5%, C5-C8 = 35.5%, T1-5 = 7.9%, T6-T10 = 19.7%, T11-L2 = 21.1% and L3-L4 = 1.3%
Gironda et al. (2004)	T2-T6 = 34%, T7-T12 = 56.1% and L1-L2 = 9.9%
Pentland & Twomey (1991)	T1-T5 = 9%, T6-T10 = 18% and T11-L3 = 73%
Pentland & Twomey (1994)	T2-T5 = 20%, T6-T10 = 40% and T11-L2 = 40%
Subbarao et al. (1994)	C1-C4 = 9.2%, C5 – T1 = 34.6%, T12-L1 = 37.9% and L2 and below = 13.1%

Time since injury

Time since injury was reported either as the mean years since injury or the range of years since injury. One study only (Ballinger et al. 2000), reported time since injury as the age that SCI occurred; mean = 27 years, range = 14-68 years. Four studies reported time since injury as the mean number of years since injury only; Boninger et al. (2001) mean = 11.5 years, Dalyan et al. (1999) mean = 11.8 years \pm 8.5 years, Escobedo et al. (1997) mean = 26 years, Gironda et al. (2004) mean = 20.3 years \pm 11.1. Three studies included time since injury as range only; Aljure et al. (1985) range = 3 months – 42 years. Silfverskiold & Waters (1991) and van Drongelen et al. (2006) both reported ranges of 6 -18 months' post SCI. Four studies included both range and mean time since injury; Pentland & Twomey (1994) range = 1-45 years, mean = 17.4, Pentland & Twomey (1991) range = 5-21 years, mean = 15.2, Sie et al. (1992) range = 1-42 years, mean = 12.1 and Subbarao et al. (1994) range = 21-77 years,

mean = 22.8. Two studies did not report any details regarding time since injury (El Essi et al. 2012 and Eriks-Hoogland et al. 2016).

Area of upper limb pain

The most common site of pain investigated was the shoulder alone (n= 7). Of these, Boninger et al. (2001) aimed to gain insight into the prevalence of shoulder injuries, however the study was primarily focused on identifying rotator cuff tears in patients with paraplegia. Six studies investigated the prevalence of pain on all the upper extremities; Dalyan et al. (1999), Gironde et al. (2004), Pentland & Twomey (1994 & 1991), Sie et al. (1992) and van Drongelen et al. (2006), while Subbarao et al. (1994) investigated pain at both the shoulder and wrists. Both Aljure et al. (1985) and Escobedo et al. (1997) were distinctive in that they investigated the occurrence of an injury rather than a pain site alone. Aljure et al. (1985) investigated the prevalence of carpal tunnel syndrome (CTS), while Escobedo et al. (1997) investigated the prevalence of RCTs in patients with paraplegia.

2.3.2 Outcome measures

The primary outcome measure used in all studies was a self-reported questionnaire establishing prevalence and location of pain (n=11). Interviews were utilised in six studies, either by telephone or face to face, to gather demographic data and data relating to prevalence of upper limb pain and injury. Eleven studies also conducted physical exams to establish prevalence and location of pain. Postal questionnaires were utilised in five studies (Dalyan et al. 1999, El-Essi et al. 2012, Gironde et al. 2004, Samuelsson et al. 2004, Subbarao et al. 1994). Of these, Samuelsson et al. (2004) and Subbarao et al. (1994) used postal questionnaires as an identification method to invite participants to attend a physical exam to further investigate upper limb pain. Nine studies formulated their own questionnaire; four studies used these to collect data relating to prevalence and location of pain (Boninger et al. 2001, Dalyan et al. 1999, Eriks-Hoogland et al. 2016, Gironde et al. 2004) and five studies used these to collect demographic data (Pentland & Twomey 1991 & 1994, Sie et al. 1992, Subbarao et al. 1994, van Drongelen et al. 2006). No standardised outcome measures were used solely to report prevalence of pain.

Functional Outcome Measures

The relationship between upper limb pain and functional limitations was formally assessed in eleven studies (Ballinger et al. 2000, Dalyan et al. 1999, El-Essi et al. 2012, Eriks-Hoogland et al. 2016, Gironde et al. 2004, Pentland & Twomey 1991 & 1994, Samuelsson et al. 2004, Silfverskiold & Waters 1991, Subbarao et al. 1994, van Drongelen et al. 2006). Of these, six studies used standardised outcome measures to report functional limitations (Ballinger et al. 2000, El-Essi et al. 2012, Eriks-Hoogland et al. 2016, Gironde et al. 2004, Samuelsson et al. 2004, van Drongelen et al. 2006). An additional two studies formulated their own functional questionnaire based on standardised outcome measures and pilot tested these with steering groups to ensure content and consensual validity was reached (Pentland & Twomey 1994 and Subbarao et al. 1994). The most commonly used measures were the Functional Impact Measure (FIM) (n=3), and the Wheelchair User Shoulder Pain Index (WUSPI) (n=3); both are reliable and valid tools (Kidd et al. 1995, Curtis et al. 1995). The FIM is an 18-item questionnaire designed to assess level of disability and patient's change in health status in response to further disability such as pain or medical intervention. The FIM is a well-documented assessment of functional ability and has been used across a wide range of disability cohorts. In comparison, the WUSPI has been designed specifically for the wheelchair using population, however is only specific to shoulder pain, not the upper extremity in its entirety.

A wide variety of additional standardised outcome measures were used across all studies including; the Craig Handicap Assessment and Reporting Technique (CHART) (n=1), the Shoulder Rating Questionnaire (SRQ) (n=1), the Sickness Impact Profile 68 (SIP68) (n=1), the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) (n=1), the Klein and Bell Activities of Daily Living Scale (n=1), the Canadian Occupational Performance Measure (COPM) (n=1), and the Constant Murley Scale (n=1). Of these, the SRQ and Constant Murley Scale are both specific to shoulder pain, while the remainder are generic tools assessing functional tasks. None of the standardised outcome measures are specifically designed for use with patients with an SCI.

Physical assessments

Physical assessments of dysfunction were utilised in twelve studies. Of these, eleven studies utilised a standardised method of assessment (Aljure et al. 1985, Ballinger et al. 2000, Boninger et al. 2000, Eriks-Hoogland et al. 2016, Escobedo et al. 1997, Pentland & Twomey, 1991, 1994, Sie et al. 1992, Silfverskiold & Waters 1991, van Drongelen et al. 2006).

Radiographic imaging was utilised in three studies (Ballinger et al. 2000, Boninger et al. 2001 and Escobedo et al. 1997). Radiographic images were taken following clinical protocols for identification of RCTs in Boninger et al. (2001) and Ballinger et al. (2000) studies. Shoulders were x-rayed in anteroposterior position only in Ballinger et al. (2000), while Boninger et al. (2001) used additional positions of scapular anteroposterior position and supraspinatus position.

Ballinger et al. (2000) also conducted a physical assessment of participants using manual muscle testing and range of movement (ROM). ROM was assessed in three additional studies (Eriks-Hoogland et al. 2016, Pentland & Twomey 1991, 1994). Eriks-Hoogland et al. (2016) assessed physical ROM via manual muscle testing and completion of the Wheelchair Skills Test. Biomechanical measures were taken using peak power output (PO_{peak}) requiring participants to complete a maximal wheelchair exercise test on a motor-driven treadmill. Transfers were also assessed using the FIM. Pentland & Twomey 1994, assessed ROM at both the shoulder and elbow. Bilateral upper limb function was assessed using concentric isokinetic torque using KinCom II isokinetic dynamometer and Smedley's hand held dynamometer, both which are valid and accurate tools for measuring muscle strength (Mayhew et al. 1994, Innes 1999). In comparison, van Drongelen et al. (2006) measured muscle strength subjectively as scored by the research assistant. Aljure et al. (1985) focused specifically on the incidence of CTS and assessed this by utilising electrophysiological studies of the median and ulnar nerves following a standardised protocol according to Johnson (1980).

2.3.3 Prevalence

All studies reported various areas and levels of upper limb pain or injury. Detailed prevalence rates by setting have been outlined in Table 2.3. The most common area of pain reported in the upper limb was the shoulder and the highest prevalence of shoulder pain

was reported by Dalyan et al. (1999) who reported 71% of participants with shoulder pain. Girona et al. (2004) reported the highest level of unspecified upper limb pain at 81%, however it is not aligned to any particular structure of the upper limb.

Dalyan et al. (1999), Ballinger et al. (2000), Eriks-Hoogland et al. (2016), and van Drongelen et al. (2006) all conducted prospective cohort studies and recorded their level of upper limb pain. Ballinger et al. 2000, reported an increase of shoulder pain over the 3-year study, and this was more prevalent in men who were older, reported poorer health and had acromioclavicular (AC) joint narrowing as determined by X-ray on first admission to rehabilitation. In contrast to this, van Drongelen et al. (2006) reported a decrease in shoulder pain (30%) at the second test point. Muscle strength was significantly inversely related to shoulder pain at the beginning of rehabilitation and body mass index (BMI) was a strong predictor for pain, one year after in-patient rehabilitation. Similar to Ballinger et al. (2000), Eriks-Hoogland et al. (2016) reported 32% of participants had limited shoulder ROM and 39% reported pain at the shoulder on discharge from rehabilitation.

Table 2.3: Prevalence of upper limb pain by setting

Setting*	Measure	Shoulder	Elbow	Wrist	Hand
Inpatient setting N= 2	<i>Median</i>	33%	N/A	N/A	N/A
	<i>Mean</i>	33%	N/A	N/A	N/A
	<i>Highest</i>	56.5%	N/A	N/A	N/A
	<i>Lowest</i>	39%	N/A	N/A	N/A
Outpatient setting N=4	<i>Median</i>	66%	25.5%	33.5%	28%
	<i>Mean</i>	61%	25.2%	33.5%	28%
	<i>Highest</i>	71%	35%	53%	43%
	<i>Lowest</i>	41%	15.5%	14%	13%
Community setting N=4	<i>Median</i>	39%	20%	40%	45%
	<i>Mean</i>	54.3%	20%	33.8%	45%
	<i>Highest</i>	73%	31%	55%	45%
	<i>Lowest</i>	35.6%	9%	6.6%	45%
Community and outpatient N=2	<i>Median</i>	31%	N/A	N/A	N/A
	<i>Mean</i>	31%	N/A	N/A	N/A
	<i>Highest</i>	32%	N/A	N/A	N/A
	<i>Lowest</i>	30%	N/A	N/A	N/A
Range and mean of combined prevalence estimates:		Shoulder Range = 35.6% - 73% Mean = 44.8%	Elbow Range = 9% -35% Mean = 22.6%	Wrist Range = 6.6% - 55% Mean = 33.6%	Hand Range = 13% - 45% Mean = 36.5%

* *Aljure et al. (1985) did not detail the setting of their study and no specific percentages of pain per area were reported in van Drongelen et al. (2006); both have therefore been excluded from this table.*

Aljure et al. (1985) and Escobedo et al. (1997) both investigated the prevalence of a specific injury, CTS and RCT respectively. Aljure et al. (1985) reported 63% of participants had electrical nerve abnormalities confirming the presence of CTS, while 44.7% also had ulnar nerve neuropathy. Escobedo et al. (1997) reported 70% of participants were symptomatic of RCT, with MRI imaging showing 62% full RCTs and 12% partial RCTs. Samuelsson et al. (2004) was the only study to associate pain with a diagnosis of a condition. Thirty seven percent of participants reported shoulder pain, with findings of muscular atrophy, pain, impingement and tendinopathy described. The estimated mean prevalence of upper limb pain by outcome measure has been detailed below in Table 2.4.

Table 2.4: Estimated mean prevalence of upper limb pain by outcome measure

	Questionnaire element N= 6	Physical Exam N= 3	Radiographic element N= 3	Electrophysiological element N= 1
Mean	52.6%	50.3%	50%	63%
Highest	71%%	73%	70%	63%
Lowest	35.6%	39%	30%	63%

2.3.4 Relationship of pain with participant characteristics

The relationship between pain and wheelchair user's characteristics was investigated in thirteen studies. Significant results were reported in nine of these studies. Time since injury was a significant factor in predisposing participants to the development of upper limb pain. More specifically, Gironda et al. 2004, Pentland & Twomey 1994, and Silfverskiold & Waters 1991, reported the development of unspecified upper limb pain was significantly associated with length of time since injury and Aljure et al. (1985) reported significant incidence of CTS increased with length of time since injury. Level of SCI was significantly related to upper limb pain in two studies (Pentland & Twomey 1991, van Drongelen et al. 2006). Pentland & Twomey (1991) reported pain is significantly associated with participants with paraplegia compared to the able-bodied population, while van Drongelen et al. (2006) reported participants with tetraplegia are significantly predisposed to developing upper limb pain compared to participants with paraplegia.

Two studies reported significant relationships between upper limb pain and age (Dalyan et al. 1999 and Escobedo et al. 1997) although this contradicts findings from three studies who reported no significant correlation between pain and age (Pentland & Twomey 1994, Samuelsson et al. 2004, Subbarao et al. 1994). Additionally, radiographic results from Boninger et al. (2001) found a significant relationship between imaging abnormalities and Body Mass Index (BMI), but not pain.

2.3.5 Relationship of pain with functional activities

Of the studies reviewed, eight assessed the impact of upper limb pain on functional activities. Dalyan et al. (1999), reported the highest level of pain was associated with pressure relieving, transfers and wheelchair mobility. Gironda et al. (2004) similarly to

Dalyan et al. (1999), reported wheelchair mobility and transportation as the activities resulting in the greatest amount of pain in the upper limb. Further to this, El Essi et al. (2012) examined wheelchair mobility to include pushing a wheelchair, propulsion up ramps and outdoor inclines as the primary contributors to upper limb pain. Seventy-four percent reported no limitation during recreational or athletic activities, while the remainder agreed that pain had limited function to varying degrees. Few participants reported seeking treatment for this issue, only 23-35% made changes to their routines and 6-16% had sought assistance from a carer or friend with ADLs due to upper limb pain.

Samuellsen et al. (2004), used the Canadian Occupational Performance Measure (COPM) to assess the impact on ADLs. From this, issues in 52 areas of occupational performance were associated with upper limb pain, with 54% of these related to self-care. Furthermore, van Drongelen et al. (2006) found upper limb pain to be significantly inversely related to functional outcome. Eriks-Hoogland et al. (2016) reported limitations of shoulder ROM were significantly associated with the ability to transfer, FIM motor scores and participants returning to work. Pentland & Twomey (1994) devised their own questionnaire based on the Barthel Index. Although functional limitations were not formally assessed, participants with pain reported tasks most impeded by pain included work/school, sleep, wheelchair transfers, outdoor wheeling and driving.

One study included a female only sample (Pentland & Twomey 1991). Participants reported outdoor wheeling as the most difficult task to complete while experiencing pain.

Additionally, Ballinger et al. (2000) reported men with shoulder pain scored lower CHART and FIM scores, however, this was not statistically significant.

2.3.6 Study quality appraisal

Appendix 2 provides details on the quality of the studies. There were four cohort studies and eleven cross-sectional studies. The cohort studies scored moderately well on the checklist with all scoring positively on over half of the criteria (Dalyan et al. 1999, Eriks-Hoogland et al. 2016, Silfverskiold & Waters 1991, van Drongelen et al. 2006). The remaining cross-sectional studies scored lower overall due to a number of biases relating to study design and analysis of data. In relation to the studies composed of a radiographic element,

only one study blinded the reporting radiographer to participants (Boninger et al. 2001). Escobedo et al. (1997) stated three observers interpreted the MRI results however it is unclear if they were blinded or what level of expertise they held. Four studies did not include any standardised outcome measures therefore questioning the validity and reliability of their results (Dalyan et al. 1999, Pentland & Twomey 1991, Pentland & Twomey 1994, Sie et al. 1992). Self-reporting questionnaires are also a limitation as they are likely to present an over endorsement bias, where participants answer questions relating to their health in an enthusiastic manner, often over reporting the extent of their pain or injury (Kroenke 2001).

Physical assessments were conducted in twelve studies with five of these studies following standard protocols for the reporting of muscle strength and ROM (Aljure et al. 1985, Samuelsson et al. 2004, Silfverskiold & Waters 1991, Subbarao et al. 1994, van Drongelen et al. 2006). Although van Drongelen et al. (2006) used a standardised protocol to conduct manual muscle testing, muscle force was subjectively measured by the research assistant therefore impacting the quality and objectivity of results reported. Pentland & Twomey (1991 and 1994), were the only two studies to use mechanical devices to measure muscle strength via use of a dynamometer. Dynamometers are well documented as accurate devices in reporting grip strength and therefore add to the methodological quality of these studies (Stark et al. 2011).

Sample size varied greatly across all studies. A larger sample size increases the validity of results as it reduces the chance of error that results occurred because of another reason and not the hypothesis in question. Four sample sizes included over one hundred participants however it was unclear if power calculations were conducted to ensure generalisability of results. The smallest sample sizes were observed in Pentland & Twomey (1991) and Boninger et al. (2001) who included samples of 11 and 28 participants respectively. A smaller sample size increases the risk of error in applying results to the wider SCI population and therefore these results should be interpreted with caution.

Recruitment bias refers to the methods utilised by studies for inclusion of participants. Several studies recruited participants from specific hospitals catering for different diseases

or conditions. Five studies recruited participants from Veteran Affairs Hospitals (Ballinger et al. 2000, Boninger et al. 2001, Escobedo et al. 1997, Gironda et al. 2004, Subbarao et al. 1994) who provide care specifically to Veterans and their families. Recruitment bias may exist where participants may not be an accurate representation of the wider SCI population or it may result in an uneven representation of the wider population as the hospital caters to a specific population of SCI patients.

2.3.7 Causation of secondary Musculoskeletal (MSK) injuries

The aetiology of upper limb pain was primarily attributed to the overuse of the upper limb during wheelchair propulsion and transfers in twelve studies. Functional activities which exacerbated pain the most included outdoor wheeling, ramps/inclines, wheelchair transfers and domestic ADLs (DADLs). Gironda et al. (2004) concluded that although the overuse of the upper limb contributed to injury or pain, it was not sufficient in explaining the development of pain itself. They stated the development, persistence and exacerbation of pain is further aggravated by functional activities, however injuries would be best understood in the context of a theoretical model to understand the person as a whole. Similarly, Subbarao et al. (1994), reported that not all pain can be attributed to the overuse of the upper limb alone. They reported that acute trauma to a joint or structure in the upper limb could cause early pain, while cumulative trauma may result in late onset of injuries. Incorrect loading of joints or abnormal movement patterns were viewed as the primary causation factors of upper limb pain in two studies (Samuelsson et al. 2004, Silfverskiold & Waters 1991).

Samuelsson et al. (2004) discussed the anatomical positioning of wheelchair users during wheelchair propulsion. He concluded the kyphotic position wheelchair users adopt while propelling places further strain on the shoulder joint, depressing the acromial process and changing the facing of the glenoid fossa, thus resulting in pain and injury. Similarly, Silfverskiold & Waters (1991) attributed the causation of injury to abnormal glenohumeral motion during active or passive ROM of the shoulder joint. Boninger et al. (2001) was the only study to attribute the causation of pain to increased BMI in SCI participants. They

reported an increased BMI resulted in increased weight for participants during wheelchair propulsion and transfers, thus placing further strain on the upper limb joints and structures.

Distinctly, only two studies attempted to distinguish the type of pain experienced by participants. Neuropathic pain is a common occurrence in the SCI population where pain occurs below or surrounding the level of injury. Both Eriks-Hoogland et al. (2016) and van Drongelen et al. (2006) attempted to distinguish between neuropathic pain and upper limb pain. Both used self-reporting questionnaires advising participants to report only pain they experienced as a result of trauma or injury, not directly related to their injury. It is not always possible to distinguish between both types of pain and the use of self-reported questionnaires placed the onus on participants to decipher this individually. It is therefore difficult to confirm if pain that was neuropathic in origin was included in their analysis.

2.3.8 Treatments sought

Only four studies reported on treatments availed of by participants experiencing upper limb pain (Dalyan et al. 1999, Gironde et al. 2004, Pentland & Twomey 1994, Sie et al. 1992). Dalyan et al. (1999) provided the most in-depth detail relating to treatments, stating 63% sought medical intervention on experiencing pain. Of this, 90% received either physiotherapy, pharmacological treatment or massage, and home modifications or joint protection education was sought by 27% of participants. Joint protection education was reported to be most beneficial by 63.3% of participants, however it is unclear when, or who delivered this. Twenty-six percent of participants also found home modifications useful. Both Gironde et al. (2004) and Sie et al. (1992) detailed how 43% and 30% of participants respectively used opiate medications on a daily basis, which provided only moderate relief. Pentland & Twomey (1994) discussed treatment options availed of by participants and found that many participants were fearful of seeking treatments such as steroid injections, surgery or hospital admission due to the invasive nature of such. The final treatment option which was discussed was that of resting the upper limb, however participants felt this was unachievable.

2.4 Discussion

The results from this systematic literature review highlight varying prevalence rates of upper limb pain across 15 studies. The shoulder was the primary pain site investigated by studies, with three studies investigating prevalence of pain of the upper limb in its entirety.

Prevalence rates ranged from 11%-81% and differed by reporting measures, outcome measures utilised, recruitment methods, level of injury of participants, time since injury and age. Little is currently known regarding prevalence rates of upper limb pain in SCI, however it is anticipated this review will highlight the variety of research undertaken and gaps in knowledge relating to upper limb pain in the SCI population.

There was considerable variation in the method of data collection across all studies. The heterogeneity of studies implies difficulty in drawing overall conclusions from the studies included (Higgins & Thompson 2002). The reported pain values vary from 11% -81%; no clustering of prevalence rates was noted suggesting the samples are heterogeneous. The varying levels of SCI were not consistently recorded. Some studies used the ASIA scale, some studies stated either participants with tetraplegia or paraplegia, and some studies stratified participants based on the medical level of injury reported. The lack of standard criteria defining level of injury in each study offers minimal help in explaining between-sample differences thus making it difficult to report results applicable to the wider SCI population.

The use of self-reported questionnaires was the most prevalent methodology utilised on the basis that they are cost effective and easy to administer. Self-reported questionnaires have been used widely across healthcare research to obtain prevalence rates, health status and health services accessed (Bhandari & Wagner 2002). Self-reported questionnaires are useful when the data required is not normally collected via audits or medical practice or when database analysis is deemed too expensive or time consuming to conduct (Short et al. 2009). Despite the widespread use of these, there is little consensus regarding the accuracy of information reported and the validity of findings (Chan 2009). Potential bias lies in the over or under-reporting by participants such as recall timeframe where participants may suffer memory decay. Literature shows an increased number of hospital or healthcare visits results in an under-reporting of the number of visits; the more often they occur, the less memorable they are to participants (Ritter et al. 2001, Roberts et al. 1996, Cleary & Jette

1984). Over endorsement bias may also exist where participants may under or over-report pain to please their healthcare professional or as an incentive to be included in a research study. Although this questions the validity of results, self-reported questionnaires are often the only option to obtain data when it is not recorded elsewhere.

A systematic review conducted by van den Beuken-van Everdingen et al. (2007) investigated prevalence of pain in cancer patients. They found the use of self-reported measures were more reliable than medically documented symptoms, as pain was only recorded by 10% of oncologists, resulting in the underestimation of the prevalence of pain. This is in part due to the complex nature of cancer where pain may not have been a priority for the physician to assess. It is reasonable to draw comparisons between the recording of pain in cancer populations and SCI populations as both conditions are complex in nature and potentially have more critical issues associated with their condition to report. Individuals who are diagnosed with a condition or illness are also less likely to report abnormal sensations or health related issues as they attribute these to the disease itself (Garber et al. 2004).

Muhajarine et al. (1997) conducted a study on individuals with hypertension and compared the efficacy of self-reporting questionnaires to that of an able-bodied population. They reported that participants with hypertension were less likely to report abnormal issues via use of a self-reported questionnaire in comparison to attending a physical assessment by a healthcare professional. Similarly to patients with an SCI, it could be argued that they felt this complaint was not significant enough to formally report in a questionnaire, however a face-to-face consultation may identify pain via a physical assessment or may allow healthcare professionals to probe further during consultations.

Within this current review, three studies utilised radiographic imaging to explore the pathology of pain and three studies also invited participants to attend for a physical assessment of their pain. The variance in methodology may have contributed to the variance in prevalence rates reported. A physical exam by a trained healthcare professional may provide objective reporting of injuries however a lack of standardised outcome measures utilised by studies resulted in data lacking validity and reliability.

Physical assessments of pain may also be deemed as invasive for participants who experience pain, and an additional burden lies on the participant in attending appointments and undergoing tests for the purpose of a research study. For the research team, both the use of physical assessments and radiographic imaging are time consuming and require expert knowledge and a number of assessors in order to ensure reliability and validity of results. Taking all of the above literature into account, the use of a self-reported questionnaire in the SCI population is feasible and cost effective, however may not be sufficient in accurately reporting the prevalence of pain or treatments availed of. Therefore, it could be argued that participant reported prevalence rates could be confirmed by accessing patient medical notes to determine specifically what pain they reported, how often it was reported, and treatments prescribed for the management of their pain.

The reporting of pain may also lead to questions around the validity of results in this review. Research evidence shows that of those with SCI who have experienced chronic pain, 40% of patient's pain is neuropathic in origin (Siddall & Loeser 2001). Neuropathic pain (NP) can occur above, at, or below the level of SCI and is commonly described as sensations of "burning", "stabbing", or "electric shock like" (Siddall et al. 1997, Sezer et al. 2015). Given the expressed unsettling and untreatable nature of the pain by the patients themselves, it is not surprising that NP is one of the most frequently reported and most difficult to treat secondary health conditions associated with SCI (Lindeman et al. 2013). The chronicity and prevalence of pain is strongly associated with an increase in hospital visits and utilisation of medical services (Burke et al. 2016, O'Connor 2009). NP is also quite difficult to distinguish from musculoskeletal pain. NP can occur at or below the level of injury, however in incomplete SCI, MSK pain can also occur at these sites thus making it difficult to determine the origin of pain.

Within this review, only two studies defined the origin of the type of pain experienced. Although some studies linked pain experience to functional activities, it is difficult to decipher whether the pain experienced is related to the level of injury or whether the pain is from functional activity alone (Finnerup & Bastrup 2012). The use of self-reported outcome measures further confounds this, putting the onus on participants themselves to make this distinction, which may prove difficult.

The causation of pain was attributed to the overuse of the upper limb in twelve studies. Wheelchair users rely on the upper limb for mobilising on a daily basis so it is unsurprising that this plays a role in the development of pain. Two studies referred to the development of pain stemming from anatomical positions adopted during specific wheelchair related activities. With such a small number of studies reporting this, it is difficult to determine if this is the sole source of pain or if there are other variables involved. Further research relating to the biomechanical movement patterns of wheelchair use may help explore the aetiology of injuries. Furthermore, wheelchair skills training could play a role in educating patients on joint protection during activities as reported by Subbarao et al. (1994).

Pain was most exacerbated by outdoor wheeling, propelling up ramps or inclines and wheelchair transfers. Education around energy efficient propulsion techniques or use of assistive technology to aid transfers may prove beneficial, however there is little literature to confirm this. Only four studies discussed the type of treatments the participants availed of. Only one study (Pentland & Twomey 1994) further investigated the use of treatments and found participants were fearful of seeking invasive treatments for relief, and rest was deemed unachievable. The question remains, what treatments are available, what are the advantages/disadvantages of each and how effective are they at relieving pain? Further research is also required to understand the implications of pain for participants. How does pain affect their day to day lives with work/school activities, sleep, personal care tasks, domestic ADLs, childcare or other psychosocial elements of their lives.

To the author's knowledge, only one study from the United Kingdom (UK) has addressed the prevalence of upper limb pain in the SCI population. Nichols et al. (1979) was one of the earliest studies to document the phenomenon of overuse injuries in the SCI population, however was excluded from this review on the basis that powered wheelchair users were included in the sample. Statistics relating to wheelchair use in Northern Ireland are limited, with the most recent figures estimating approximately 30,000 of the 1.8 million population of Northern Ireland classified as wheelchair users (DHSSPS 2008). This equates to 1.3% of the Northern Ireland population which is below the UK National average of 2%. It is not clear how accurate the regional figures are and they may not reflect the true situation. Northern Ireland has a strong history of conflict, most noticeably "*The Troubles*" which

lasted from 1960-1998, resulting in over 47,000 individuals injured and 500 severely injured (Moffett 2016).

Indeed, a similar country with a history of conflict (but on a greater scale) took place in the Gaza Strip, Israel, where El-Essi et al. (2012) undertook research. They hypothesised that the number of persons with an SCI in the Gaza Strip increased due to the conflict during the Al Asqa Intifada (2000-2005). Excessive force and the use of explosive devices was prevalent in war torn areas resulting in widespread casualties. Similar to El-Essi et al. (2012), it is reasonable to argue that the number of wheelchair users or those with an SCI is potentially under-reported in Northern Ireland. From 1960-1998 there were 36,923 shootings, 16,209 bombings and approximately 47,541 people were injured in Northern Ireland (Conflict Archive on the Internet last modified 1/02/18). Those who may have been injured during the troubles 10-50 years ago are now long-term wheelchair users. With length of time since injury significantly associated with the development of upper limb pain, and a potential greater sample of wheelchair users in Northern Ireland as a result of The Troubles, it is reasonable to hypothesise that Northern Ireland will have a higher SCI population and specifically a higher percentage of upper limb pain as documented in long-term wheelchair users. There is currently no literature documenting the prevalence of upper limb pain in the SCI population of Northern Ireland, a significant gap in knowledge considering the history of the country.

2.4.1 Review limitations

This review was limited in that only studies specifically referring to upper limb pain were included. Studies reporting on generalised pain in the SCI population were excluded as they were not directly relevant to the research question. Other limitations of the study were due to the exclusion of studies not written in the English language. Studies specifically focused on wheelchair athletes were also excluded as this population experience a higher level of physical activity and the potential for sporting injuries may skew results rather than reporting of injuries sustained by manual wheelchair use alone.

2.5 Conclusion

The increasing number of people with an SCI living longer and healthier lives comes with a consequence of secondary musculoskeletal impairments. The most common site of pain investigated was the shoulder. Varying reporting measures of age, time since injury, level of injury and standardised outcome measures hampered the comparison of the overall prevalence rates of upper limb pain. Little is currently known of the aetiology of upper limb pain, treatments available for upper limb pain or how pain affects sufferers on a daily basis. A uniform measurement of upper limb pain specific to the SCI population would be useful in comparing prevalence rates, however none currently exist. A basic pain data set (International Spinal Cord Injury Basic Pain Data Set, ISCIPDS) has been developed within the framework of the International Spinal Cord Injury data sets with the purpose of facilitating consistent collection and reporting of pain in the SCI population (Widerstrom Noga et al. 2008) however, it is not specific to the reporting of upper limb pain. Future research should focus on what treatments are available and most effective at treating upper limb pain in SCI, specifically in Northern Ireland where an underestimated population of long-term wheelchair users may exist.

CHAPTER 3:

A MIXED METHODS EXPLORATORY
STUDY OF THE LONG-TERM
CONSEQUENCES OF SUSTAINED
MANUAL WHEELCHAIR USE IN THE
SPINAL CORD INJURED (SCI)
POPULATION

Abstract

Introduction: Chapter 2 highlighted the prevalence of upper limb injuries in patients with a spinal cord injury. Limitations from the review outlined a lack of evidence relating to the most effective management of treatment of upper limb pain. Management of an upper limb pain may prove difficult due to the nature of the treatment. Relative rest is required in order for the upper limb to recover; this may prove problematic as the upper extremity is used for mobility on a daily basis. There currently is no literature directly related to the patient perspective of how upper limb pain affects their day-to-day lives. The patient perspective is therefore crucial in understanding the condition and the objective and subjective symptoms in order to provide true patient centred care in treatment of these injuries.

Aim: To explore the prevalence and nature of secondary upper limb injuries experienced by individual's living with spinal cord injury and the medical and rehabilitation approaches to treatment

Methods: 3-phase study; postal survey, audit of medical notes and qualitative exploration of individual's perspective of upper limb pain

Results: Two hundred and twenty information packs were distributed to SCI patients who previously attended the RSCI centre. Forty-one consent forms were returned for inclusion in the study (response rate = 18.6%). Seven participants who met the study criteria were included in the questionnaire analysis, and six participants consented to interview. The mean age of participants was 53.2 years (± 7.2), type of injury; complete SCI = 66.6%; incomplete SCI = 33.3%. Years as a wheelchair user ranged from 10-40 years, mean = 28.6 years (± 11.6). Shoulder pain was again the most prevalent site of pain reported, followed by neck, back, elbow, hand and finger pain. Prevalence of pain was poorly reported in the medical notes, with little to no information regarding any treatments availed of by participants documented. Pain primarily influenced participant's ability to complete physical activity (88.9%), washing and dressing (55%), work, and volunteering (55%). During one-to-one interviews, participants reported that pain affected them in all aspects of daily life and this was reflected in that 24/32 domains of the "ICF core set for SCI: chronic setting" were referenced during interviews. Five key themes emerged from the qualitative analysis; 1)

consequences of pain, 2) medical and rehabilitation input, 3) coping with pain and self-management, 4) resilience and pride, and 5) looking towards the future. In relation to treatment, participants primarily reported self-managing their pain. Participants reported a lack of specialised services in the community equipped with relevant knowledge in relation to management of their SCI. Participants reported good benefits from attending allied health services such as physiotherapy and occupational therapy, unfortunately they reported only short term relief from treatments available overall.

Conclusion: More specialised SCI services in the community, education of patients and signposting to relevant bodies may prove beneficial in educating patients to understand their condition and facilitate early identification of their injuries prior to pain becoming life limiting and chronic in nature. Clear identification of the treatment pathway and more structured services in relation to reporting of upper limb pain should be considered to facilitate early identification of injuries. Additionally, equipping SCI patients with knowledge regarding joint protection and energy conservation can assist them in living independent lives.

3.0 Introduction

For individuals with lower level paralysis (C6-S1) of the spinal cord, manual wheelchairs are an assistive device that can be utilised to improve functional mobility and independence. The use of manual wheelchairs can be key to maximising social and environmental exploration, Activities of Daily Living (ADLs), and providing a strong foundation for maintaining independent functional mobility to maximize quality of life (Requejo et al. 2015). As outlined in Chapter 2, although manual wheelchair use provides a level of independence, it is not without its consequences and requires significant patient support structures in place; the absence of which may lead to user dissatisfaction and sub-optimal use of these devices (Visagie et al. 2016).

Manual wheelchair use can expose the upper limb to significant strain due to the load and repetition of the mechanical movements required to propel the wheelchair (Medola et al. 2014). Functional mobility of wheelchair use primarily consists of manually propelling the wheelchair and transferring both in and out of the wheelchair. Propulsion requires the use of the upper limb to apply force to the hand-rim in the push phase to move forward, followed by the pull phase to stop (Van der Woude et al. 1995). The movement pattern of the push and pull phases requires the brachial biceps and triceps, anterior deltoid, posterior deltoid, trapezius muscles and pectoralis major muscles to undergo significant loading in order to exert force on the hand-rim (Schantz et al. 1999).

Similarly, transfers involve excess strain on the upper limb where the shoulder is often expected to take the weight of the individual while moving to another surface. The positioning of the shoulder during transfers is that of flexion and internal rotation, which brings the glenohumeral head in contact with the acromion, causing significant posterior forces at the shoulder joint (Morrow et al. 2011). The repetitive nature of this movement has been associated with shoulder impingement, instability, capsulitis, and tendinitis (Tsai et al. 2014, Gagnon et al. 2008, Gagnon et al. 2009). These injuries may also predispose individuals to a greater risk of developing rotator cuff tears (Dalyan et al. 1999, Gellman et al. 1988, Curtis et al. 1995, Boninger et al. 2005). Full time manual wheelchair users, such as those with a Spinal Cord Injury (SCI), perform as many as 14 to 18 transfers on an average day (Finley et al. 2005), highlighting the strain the shoulder joint withstands on a daily basis.

Over time, the repetitive nature of these activities may result in secondary upper limb injuries.

As highlighted in Chapter 2, the aetiology of upper limb injuries is still unclear, however several authors (Pentland & Twomey 1994, Alm et al. 2008 and Requejo et al. 2008) all highlight the repetitive nature of propulsion and transferring as the primary contributing factors of upper limb pain in the SCI population. Pain by nature is troublesome and unsettling and impacts on everyday activities even in the able-bodied population. This is further magnified for the manual wheelchair using population where they rely on the upper limb for mobility on a daily basis. The associated pain and decreased range of movement, may contribute to an overall reduction in performance in ADLs which are key to independent living (Boninger et al. 2004).

Dalyan et al. (1999) determined that of SCI patients experiencing upper limb pain, 26% required additional help with functional activities and 28% reported limitations of independence. Between 49% and 73% of SCI manual wheelchair users develop carpal tunnel syndrome and between 31% and 71% report shoulder pain (Toosi et al. 2010). This may have serious implications for functional mobility, sleep and living life independently (Widerstrom-Noga et al. 2001). Research literature highlights that these injuries occur throughout the life span of wheelchair users, particularly in those whose wheelchair use has spanned decades (Asheghan et al. 2015); with increased life expectancy, this is likely to be a more common occurrence in this population if power assist add-ons are not sought.

There is a substantial amount of literature in the area documenting the prevalence of these conditions. Injuries such as shoulder, neck and back pain resulting from poor wheeling practice in the long-term are documented in both those who began wheeling as adults or as children (van Drongelen et al. 2006, Kennedy et al. 2006, Rice et al. 2009). In February 2016, The National Institute for Health and Care (NICE) published guidance on spinal injury assessment and early management, however there are currently no evidence based-practice guidelines relating to the *treatment* of upper limb injuries associated with SCI. Rice et al. (2013), investigated a strict protocol – “Preservation of Upper Limb Function Following Spinal Cord Injury (2005)”, addressing the impact of an education protocol on transfer skills

and wheelchair propulsion in the SCI population. Recommendations from the report highlighted a lack of research in the area of upper limb injury and a need for further research to understand the basic mechanisms of musculoskeletal upper limb injuries in SCI and investigation into the benefits of management (Connolly et al. 2014).

Unfortunately, there is no literature directly related to the client's perspective of how the injury affects their day-to-day lives. Management of an upper limb injury may prove difficult due to the nature of the treatment. Relative rest is required in order for the upper limb to recover, both in relation to initial injury and treatments prescribed. This may prove problematic as the upper extremity is used for mobility on a daily basis (Alm et al. 2008). The patient perspective is crucial in understanding the condition, and aligns the objective symptoms with their subjective responses in order to encompass a holistic approach of how the client and their disease/injury interact together. The objective measurement of health is no longer satisfactory in assessing patients' needs as a whole (Sullivan 2003).

The International Classification of Functioning, Disability and Health, also known as ICF (WHO & World Health Organisation 2007), is a classification of the health components of functioning and disability, giving consideration to activity, participation and the environment. A client centred approach was central to this study using the ICF as a framework to establish how the upper limb injury affects SCI participants and to identify the occupational and social barriers experienced by SCI participants (Van der Woude et al. 2006). The ICF framework is used in this study as an approach to highlight the importance of understanding the person as a whole – encompassing leisure activities, ADLs and environmental factors. It is the patient who has the authority to judge their quality of life, therefore the patient's role in communicating their experience with the injury is critical (Robinson et al. 2008). The purpose of this study was to combine objective reporting of injuries from medical notes with the perspective of the patient, to understand the overall impact of upper limb injuries sustained, specifically from manual wheelchair use.

3.1 Aim and Objectives:

The aim of this study was to explore the impact of upper limb musculoskeletal injuries sustained from long term manual wheelchair use in the spinal cord injured population.

Objectives:

- To carry out a mixed method (quantitative and qualitative) study to determine the rate of occurrence and time-line after SCI of upper limb injury
- To explore the prevalence and nature of secondary upper limb injuries experienced by people living with spinal cord injury
- To identify the medical and rehabilitation approaches to the management of upper limb injuries in the population
- To conduct a qualitative exploration of SCI manual wheelchair users' experience of secondary upper limb injuries relating to the injury and treatment

3.2 Methods

3.2.1 Study Development

Following a systematic review of literature (Chapter 2), significant gaps in knowledge were identified in relation to the prevalence of upper limb pain in patients with an SCI, how pain impacts on the lives of this population, what treatments or services are available to manage pain and how patients can be further supported. The study was designed to address these discrepancies and encompassed a mixed method design to investigate the perceived long term effects of these injuries. A steering committee was devised of SCI manual wheelchair users who peer reviewed the study documentation and provided feedback on the wording and content of each. Amendments were subsequently made to reflect their recommendations. Recommendations highlighted the need to include functional transfers such as in/out of car, and the use of a roof-box for storage of their wheelchair. Further comments outlined it would be useful to record the number of people who are in employment and whether this is part/full time employment as this may influence how active someone may be, which in turn could potentially increase/decrease their risk of developing upper limb pain.

3.2.2 Study design

The study consisted of three phases; Phase A consisted of a postal survey posted to participants to self-record their level of upper limb pain and treatments they availed of. Phase B consisted of the researcher accessing participant's medical notes to record and identify the number and type of procedures (both surgical and conservative management) of their reported upper limb injury. Phase C consisted of a qualitative exploration of participant's experience of their upper limb pain via one-to-one interviews.

3.2.3 Study Setting

The study took place onsite in the Regional Spinal Cord Injury Centre (RSCI) between June and November 2017. Ethical approval was obtained from the Institute of Nursing and Health Research Governance Filter Committee, Ulster University; Office of Research Ethics NI and the Belfast HSC Trust, rec reference: 17/NI/0062. Further in-depth information is available via the study protocol and ethical approval documentation (Appendix 3). On receiving a placement contract with Belfast HSC, the researcher underwent training in relation to Trust procedures and policies in accessing patient notes. Patient notes were accessed on site at the RSCI centre and were examined in line with ethical permission; data was only recorded if it was specific to the research aims and objectives. No patient notes were removed from the centre. All participants were allocated a participant identifier number so as their details were anonymised. All research team members completed Good Clinical Practice (GCP) training in line with Trust policy.

3.2.4 Participants

Participants were eligible for inclusion in the study if they had a traumatic SCI, were aged 18 years or older, were a minimum of 6 months post initial SCI, used a manual wheelchair for mobility purposes and had previously attended the Regional Spinal Cord Injury Centre (RSCI) Northern Ireland for treatment of their SCI. Participants were excluded if they were life time powered wheelchair users, had a cognitive impairment, pre-existing comorbidity or taking medication that would prevent them from participating in a one-to-one interview with the researcher.

3.2.5 Phase A- Questionnaire with SCI participants and identification process

Information packs were posted to two-hundred and twenty patients who were attending, or had previously attended the RSCI centre for medical treatment of their SCI. The pack included an invitation letter, participant information sheet (PIS), consent form and a questionnaire with a stamped addressed envelope to be returned to the researcher (AMC) (Appendix 4). Information was provided on the follow-on stages of the study and it was explained explicitly that the researcher was requesting permission to access their medical notes under the guidance of the clinical lead (SM). Participants were invited to consent to completing the questionnaire and explicitly to provide consent for the researcher to access their medical notes on site at the RSCI centre. Potential participants were invited to answer a series of questions to ensure they met the study criteria, see Table 3.1.

Table 3.1: Eligibility screening criteria

	Criteria
1	Do you have a spinal cord injury?
2	Are you minimum 6 months' post SCI?
3	Do you use a manually propelled wheelchair or have you used a manual wheelchair in the past but changed due to the strenuous requirements of a manual wheelchair?
4	Did you undergo treatment at the Regional SCI centre?

Following a lower than anticipated response rate and approval from relevant ethical committees, a poster was sent to UK charities associated with physical disability (WAVE, Back Up Trust, Disability Sports NI, Ulster Barbarians, Knights Basketball club, Spokes in motion) to advertise the study on their websites and via social media channels. The researcher also contacted 17 local wheelchair sports clubs via email and attended training sessions in person of the agreeable clubs. Twenty information packs were distributed in person via various wheelchair sports clubs and advised potential participants to contact the researcher should they wish to be included in the study. Participants signalled their intent to be included in the study by returning the signed consent form together with the completed questionnaire included in the pack to the researcher (AMC). A cooling off period of two weeks was enforced to allow time for participants to make an informed decision.

3.2.6 Phase B: Audit of medical notes

On completion of Phase A, participants who had consented to the researcher reviewing their medical notes, moved into Phase B. The medical notes were accessed by a member of the RSCI medical team and passed to the researcher. Notes were screened on site at RSCI centre using a specifically designed data extraction form (Appendix 5) to record relevant details such as type of upper limb injury, how the injury was sustained, medical intervention required, number of referrals to Occupational Therapy/Physiotherapy, medication prescribed, improvement in symptoms reported.

3.2.7 Phase C: One-to-one interviews

Qualitative methods of investigation have been found to be especially useful during the discovery phase of research, where questions are explored and hypotheses created (Morgan 1998, Litosseliti 2003, Barbour 2008). Interviews were the chosen method for data collection due to a number of factors. Interviews adopt a structured, semi-structured or unstructured process in which data can be obtained. Semi-structured interviews were chosen for the purpose of this study as this type of interview provides the researcher with a degree of flexibility while still maintaining the focus to the pre-determined research questions (King and Horrocks 2010).

On completion of Phase B, participants who had consented to taking part in a one-to-one interview were contacted to participate in Phase C. The researcher (AMC) phoned participants and explained the follow-on study. Participants were asked again, if they would like to be included in a one-to-one interview and were posted or e-mailed (dependent on preference) a further participant information sheet. On accepting to take part in the study, participants were given the option to conduct the interview via telephone/skype or attend Ulster University Jordanstown, at a date and time that was convenient. A topic guide (Appendix 6) was used to ensure the interview flowed and stayed relevant to the research question.

The topic guide was designed to address the components of the ICF: Body Functions, Body Structures, Activities and Participation, and the contextual factors - Environmental and Personal Factors, in relation to upper limb pain and its consequences. The topic guide had

been previously reviewed by a steering committee made up of two manual wheelchair users with an SCI. Amendments were made to all study documentation to reflect their comments and recommendations. The topic guide informed the direction of each interview with participants free to discuss any relevant issues. At each interview, the researcher outlined the aims of the study, the proposed length of the interview and the participant's right not to answer any questions should they not feel comfortable doing so. Confidentiality was explained and that participants would be assigned a unique identifier number so as they would not be identifiable. Interviews were audio recorded and transcribed verbatim following informed consent.

3.2.8 Data Collection

Data for all elements of the study were stored and protected in line with Ulster University's data protection regulations. All research project data was stored on encrypted computers and hard copies, such as consent forms, were stored in a locked data storage room on site at Ulster University. Interviews were recorded using a *Roland Edirol R-09 Digital Voice Recorder 24-bit WAVE/MP3* and downloaded on to an encrypted computer. Interviews were transcribed verbatim by the researcher and provided an opportunity for the researcher to become immersed in the data. Repeated listening ensured accurate transcriptions of the audio files. Interviews were transcribed almost immediately after the interview had taken place and allowed initial preliminary analysis to be conducted. New topics or emerging themes not listed on the topic guide were added prior to the next interview to ensure an iterative process took place. The transcription process allowed the researcher to anonymise all data with unique identifier numbers and any identifiable information removed to ensure anonymity. All audio files were deleted once transcription had been completed and cross-checked.

3.2.9 Data analysis

Quantitative data obtained from the questionnaire and review of medical notes was entered into Microsoft Excel under participant identifier numbers. Data was then exported from Excel to SPSS (Version 22) and analysed using inferential and descriptive statistics and presented in tabular form. Ritchie and Spencer (2002), state the purpose of qualitative research is to define, categorise, theorise explain and explore map findings. A deductive

approach was undertaken to conduct initial thematic analysis using Braun and Clarke's Thematic Analysis (TA) framework (2006). The codes and themes expressed by participants were then mapped to the ICF framework to obtain a wider perspective of upper limb pain in the SCI population. The ICF framework recognises the importance of personal and environmental factors in facilitating holistic transition planning and service delivery for persons with chronic health conditions (Nguyen et al. 2018). By using this approach, a wider perspective and a broader understanding of the impact of upper limb pain in the SCI population was obtained. In the final step, the researcher's supervisory team reviewed the entire analysis to validate the findings and to ensure no aspects were missed. The data has been presented in the form of comparative case studies due to the small sample size. Quantitative data from the audit of medical notes has been incorporated to strengthen the results.

3.2.10 Research Rigour

The researcher adhered to strict rigour to ensure credibility and validity of the research findings. Bracketing was incorporated throughout the data collection and analysis phase to ensure validity (Tufford & Newman 2012). Bracketing is a process used to eliminate bias in research where researchers outline and state their prior experiences/views of SCI or working with those with an SCI. Bracketing occurred throughout the data collection and analysis phase and was recorded via use of a reflective journal. The reflective journal was used by the researcher (AMC) conducting the interviews to ensure any preconceived ideas of those with an SCI were left aside and to ensure the study was conducted in an ethical and fair manner (Lea & Peter 2012). Rich and thick verbatim descriptions of participants' accounts were used to support findings and meticulous record keeping and demonstrating a clear decision trail ensured interpretations of data were consistent and transparent. Analysis was conducted independently by the researcher (AMC) initially and consultation with the researcher's supervisory team to confirm coding and thematic analysis was subsequently completed.

3.2.11 Case Studies

Case studies were the chosen method to present the findings of the study as it allowed the researcher to provide an overall perspective of how upper limb pain impacted each

participant individually. A case study is a research method to examine a “*contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident*” (Yin 1994 pg 13). This study used a series of multiple case studies to demonstrate the individual nature of all participant’s needs and to compare common themes observed during the thematic analysis stage.

3.3 Results

A total of 32 responses were received from the postal questionnaire with a further 9 responses from the various sports clubs (response rate = 18.6%). Thirty-five participants were excluded as they did not meet the inclusion criteria and are outlined below in Table 3.2; no participants were excluded based on pre-existing comorbidities or cognitive issues. Seven participants completed the questionnaire with six participants consenting to complete a one-to-one interview with the researcher.

Table 3.2: Reason and Number of Participants Excluded from Study

Reason for Exclusion	Total <i>n</i> = 35
Not a wheelchair user	<i>9</i>
No upper limb pain	<i>10</i>
Pain not from wheelchair use	<i>2</i>
Spina bifida	<i>1</i>
Amputee	<i>1</i>
Deceased	<i>1</i>
Questionnaire returned no reason	<i>9</i>

3.3.1 Demographic results

Demographic data was recorded for 6 participants and is detailed below in Table 3.3. The mean age of participants was 53.22 ± 7.27 with a predominantly male sample (77.7%). The most commonly reported pain site was shoulder pain (87.5%), followed by neck, back and wrist, all (50%), elbow (37.5%) and finger pain (25%).

Table 3.3: Demographic data of study participants

Demographic Data		
Age	<i>Range</i>	40-64 years
	<i>Mean</i>	53.22 ± 7.27
Years in wheelchair	<i>Range</i>	10-40 years
	<i>Mean</i>	28.67 ± 11.63
Gender	<i>Male</i>	77.7%
	<i>Female</i>	22.2%
Type of SCI	<i>Complete</i>	66.6%
	<i>Incomplete</i>	33.3%
Level of SCI	<i>L1/L2</i>	incomplete
	<i>T12/L1</i>	incomplete
	<i>T9/T10</i>	complete
	<i>T4/T5</i>	complete
	<i>T3/T4</i>	complete
	<i>T2/T3</i>	complete
	<i>C5/C6</i>	incomplete

3.3.2 Visual Analogue Scale for Pain (VAS) Results

VAS results obtained from the survey describing the level of pain experienced during the various activities are as follows: ADLs: (range 0-7; mean, 4.63 ± 2.38); Mood: (range = 0-7; mean 3.63± 2.50); Sleep: (range 1-9; mean = 4.75 ± 2.44); weekly pain intensity: (range = 1-7; mean = 4.75 ± 2.05). These statistics relate to data from six participants and therefore should be interpreted with care due to the small sample size.

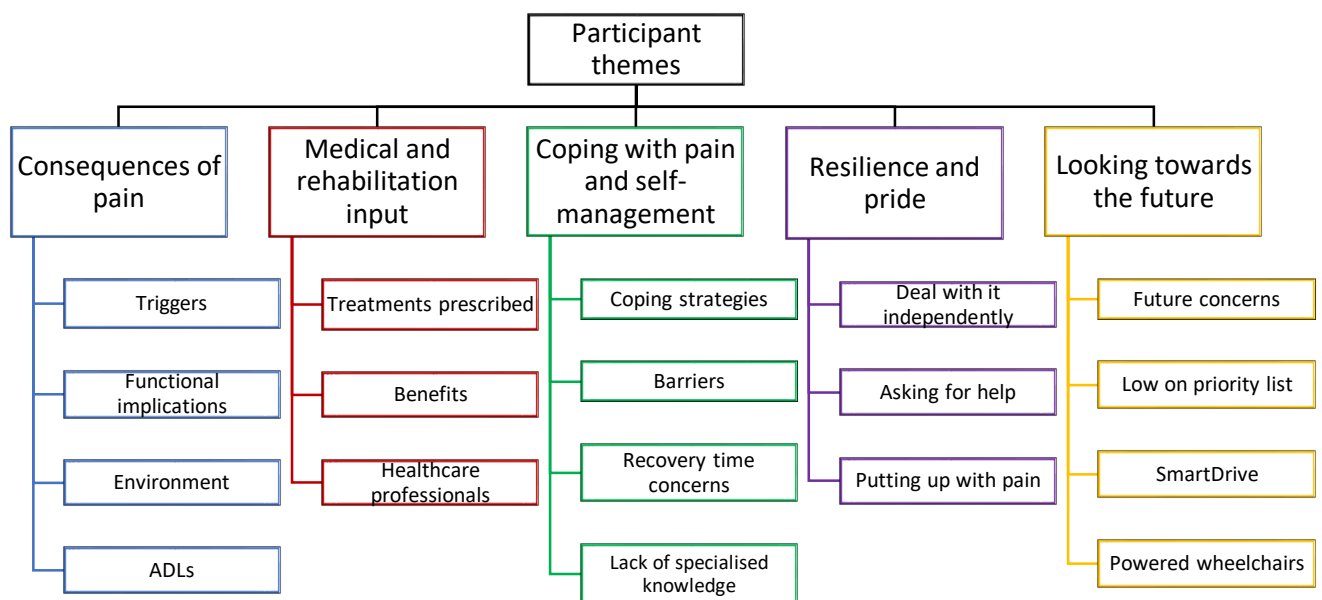
Fifty-five percent of participants reported pain with washing and dressing, 44.4% reported minimal to moderate pain with domestic tasks, 88.9% reported pain with physical activity, 33.3% reported pain prevents them from participating in social activities, 55.5% reported pain while working/volunteering and 55.6% reported pain while driving.

The relationship between participants who reported pain and those who did not was investigated together with demographics using the Fisher's exact test for gender and Kruskal-Wallis H test for injury level. Both returned insignificant results; (p=0.183) for gender; (p=0.73) for level of injury.

3.3.3 Thematic analysis

The one-to-one interview data was transcribed verbatim and coded by the researcher initially. Codes were grouped into themes to reflect the content of participant's views. The themes and codes extracted from the data have been outlined below in Figure 3.1. Data was grouped into five themes; 1) consequences of pain, 2) medical and rehabilitation input, 3) coping with pain and self-management, 4) resilience and pride, and 5) looking towards the future.

Figure 3.1 Participant themes and codes



3.3.4 Mapping to ICF framework

The ICF contains a detailed categorisation of body functions and structures, activities and participation, and environmental factors. The ICF has condition specific categories, namely ICF core-sets aimed at transforming information regarding function to a common language; the ICF language. The “ICF Core Set for Spinal Cord Injury - Chronic Situation” describes the typical spectrum of functional issues encountered by participants with an SCI and was used in this case to map the themes from the thematic analysis to understand the broader patient perspective of upper limb pain in the SCI population. The mapping of themes is

shown in Appendix 7: Overview of thematic analysis aligned with the “Comprehensive ICF Core Set for Spinal Cord Injury – Chronic Situation”. All three domains of the ICF framework are represented across participants’ responses in relation to how upper limb pain affects their lives. Pain is not only a physical symptom, but has consequences on patients’ psychological well-being, relationships, vocational activities, leisure activities and environments. By presenting the complexity of upper limb pain experienced in relation to ICF components, it is clear participants’ upper limb pain poses a daily challenge to persons with an SCI and has the potential to affect their lives in a negative way.

Theme 1: Consequences of pain

The consequences of pain as highlighted from the initial thematic analysis are primarily interpreted as having negative impacts on aspects of life as classified by the ICF. All participants reported pain of the upper limb, with pain being described as “sickening” and compared to that of a “tooth ache” when attempting to sleep. Participants reported pain with all aspects of ADLs such as personal care, domestic tasks and leisure activities. At times participants reported how their upper limb pain acted as a barrier to attending social activities and would use their own coping strategies to manage the pain themselves, rather than seek treatment.

Theme 2: Medical and rehabilitation input

Participants feelings towards the treatment they received to date has been mixed. Some participants reported relief from certain interventions however, several participants reported being unhappy with the level of care they received from the RSCI centre. Participants were not followed up regularly and on attendance they felt it was a “tick-box” exercise from the consultants involved in their care. Participants reported greater satisfaction from attending Allied Health Professional (AHP) services such as Physiotherapy and Occupational Therapy. The majority of participants sought this treatment privately or attended their GP for a referral rather than having their consultant review their upper limb pain. Participants reported having being advised previously that this upper limb pain was inevitable and that little could be done to treat their symptoms.

Theme 3: Coping with pain and self-management

Participants primarily reported self-managing their pain and were reluctant to seek treatment. Barriers to treatment included concerns over recovery time, lack of specialised knowledge and short-term relief from medication. All participants reported having good support networks to call on family members or friends to assist when needed, however the general attitude of participants was to deal with the pain independently.

Theme 4: Resilience and pride

Participants' responses varied in relation to their attitude to pain. Participants were keen to manage their day-to-day lives and manage pain independently. Participants did not like to let pain stop them from completing ADLs, participating in leisure activities or social engagements. Pride was a key factor, particularly in relation to male participants. Men reported feeling obliged to complete the "manly tasks" and did not like to burden their families with tasks deemed more appropriate for men, such as heavy lifting or mowing the grass. Some participants did not like to ask for help, they would rather find a way to do it themselves. Other participants had no problem asking for assistance and would do so regularly, particularly in the case of environmental obstacles during work related activities or with transfers.

Theme 5: Looking towards the future

All participants expressed concerns over what the future may hold. Participants reported they are managing to live independent lives but particularly in recent years, their upper limb pain has become more apparent. The nature of pain and the uncertainty as to how long the pain will last was a concern, as it is difficult to plan or manage daily activities not knowing if their independence will be limited. The discussion around powered mobility made it clear participants were keen to keep the level of independence they have; adaptations would need to be made in the future in terms of their home environment, their cars and their workplaces, all incurring a financial cost. Participants felt powered mobility would be a last resort in some cases and would refrain from considering it as an option to ensure they do not lose their current level of independence.

3.4 Case Studies

3.4.1 Case Study A

Participant A was a 58-year-old T3/T4 paraplegic male. He has been a manual wheelchair user for 36 years. He lived alone and worked full time in the Higher Education sector. His pain was located primarily in the shoulder region and he described it as “throbbing” in nature. His pain was initially worse in the mornings highlighting issues with transfers particularly, and eased as the day went on. His pain tended to interfere more so with sleep; he scored his pain in relation to sleep on the Visual Analogue Scale as 5/10. He reported difficulty with getting to sleep and compared the pain to that of a toothache.

“...when I go to sleep, I sleep on my side and when I wake, because I don’t move through my paralysis, most people move during the night automatically, I would turn myself from side to side and it’s when I’m lying on my shoulders again you can get that throb of pain you know, more like an ache you know, when you’re trying to get to sleep again it’s like trying to get to sleep when you’ve a tooth ache or any pain, it becomes much more obvious”

As he lived alone, pain had a significant impact on his ability to complete ADLs and domestic tasks. He reported in the case he did have a flare up; he would need to “curtail” what he could do so as not to exacerbate the pain. He reported difficulty with meal preparation, particularly if he wanted to cook something in the oven, the combined balance and muscle strength required to lift food out of the oven would cause significant issues as he stated:

“you can’t hold stuff and move at the same time”

He reported great benefit from physical activity, “as long as you’re not exceeding certain limitations”, and felt it was important to keep moving. He reported using medication when pain was at its worst but felt relief was “very temporary”. He reported a positive experience from having previously attended Occupational Therapy for wheelchair and cushion related queries. Overall, he felt there was limited medical treatment options available to him, reporting how he was commonly advised to “rest”, something he felt was difficult to do as a wheelchair user.

"If you went to go and see your doctor he'd just tell you to rest it. I'm afraid I can't because you know I have to get to work, you know I have to do daily routine."

He was unaware of any treatment options available through the RSCI Centre and reported a lack of contact from his consultant, having not been called for review in ten years.

"It must be 10 maybe plus years since I've seen her. I left hospital, let's see, I left hospital in 1982, and every year there used to be a letter in from (name of hospital) to go and see the consultant and that would be near enough a check up on how you were, but also to have a kidney scan to see if your kidneys...basically your kidneys, bladder, your water works, you know, how they were functioning. And that over the years has dwindled away and now it doesn't happen and now, unless I did something myself, it wouldn't"

He reported having a good support network of family and friends, and having "people he could call on" in the case he required some assistance. He enjoyed socialising with friends and would be comfortable with them assisting him while out and about, at times he was dependent on them due to environmental factors. Pain had previously impacted negatively on social aspects of his life at times preventing him from going out.

"I wouldn't have went out unless I had, there was a couple of other people there who help. There's a step in to a restaurant, I couldn't have done that on my own plus there was a steep hill up to the pub, I needed help up that. I could have done it but it's very sore on the arms and the shoulders...You know, certainly about 6 weeks ago when I did something to my shoulder I wouldn't have been able to go out"

For participant A, his pain was not a daily occurrence and felt he was managing quite well. In the future however, he had concerns regarding his pain as he aged and a level of uncertainty as to how it would develop over the coming years. He felt he was quite independent and his pain occasionally bothered him, but was not a pressing issue.

“Leading to a certain amount of concern on my behalf that, you know, as I get older, will this get worse...there’s the more gradual one (pain) that seems to be coming from, I don’t know whether from age or wear and tear, but this is the one that kind of I’m keeping an eye on at the minute, lifting myself. I think I’m weaker as I’m getting older but lifting myself from the bed on to the wheelchair, in and out of the car...it’s that one I’m keeping an eye on to see, over the next few years how that develops”

3.4.2 Case Study B

Participant B was a 40-year-old T2/T3 complete paraplegic male. He had been a manual wheelchair user for twelve years and lived with his wife and three young children. He worked part time in an office setting and the remainder of the week he volunteered for a charity in the health sector. His work took him all over the country and he had a lengthy daily commute consisting of 1.5 hours each way, something he felt exacerbated the pain by the amount of driving he completes on a weekly basis. His primary pain was his left shoulder which he described as similar to that of a “bee sting”. He tended to manage his pain independently but often he would attempt to reduce his driving hours which could impact on his weekly work schedule:

“if I’m doing too much driving, so if I’m driving down south maybe all over the place I would maybe get it you know...if it was constant and it was annoying I would try and cut down on the driving. I would just take it easy around the house. I suppose it is having an impact when I’m needing to go I would avoid going and try and stay at home more, until it eases off”

In terms of treatment, Participant B was quite keen to stay active and discussed the positive aspects of physical activity although warned of the consequences of doing too much. He previously attended his GP regarding his shoulder pain and he referred him to a gym programme of which he felt benefitted him. He had a good relationship with the health professionals involved in his care and feels his needs have been met, although many of the interventions only provided short term relief.

“when I went to the gym and built up the muscles the other muscles in my left shoulder then that really kept the pain away for a good few months, that was it worked, it kept the pain away for longer than the acupuncture. But then again just getting to the gym it was difficult with family life. Also, one time I went to the gym and actually did too much and actually gave myself a sore neck, a sore back, I pushed myself too much”

As a family man, his wife and children were his priority and he would not allow his shoulder pain impact on his interactions with them. He recently was away on a family holiday and was keen not to let his pain impact on their experience or with social activities in general.

“I was over in France there for a few days and it was tough. Em that and the bit of pain came back and that was annoying, but I’d no choice, was pushing myself all day...so it was quite a lot of pushing about...I have the heart of a lion really (laughs). If I, I wouldn’t let something like that there stop me going places or to some sort of event so I’m lucky it’s not an extreme pain. At times it’s ridiculous pain. It can be annoying over long periods of time but it wouldn’t stop me from going out”

His upper limb pain, similarly to participant A, was not a constant daily pain. He stated he had not reported it to his consultant however, he had sought private physiotherapy for treatment. In terms of his priorities, his pain was not something he was actively concerned about and he tried to live his life as independently as he could.

“I didn’t really have this problem high on the list...maybe it’s because, there’s stuff more serious like IVF and that”

3.4.3 Case Study C

Participant C was a 57-year-old T4/T5 complete paraplegic male. He was a manual wheelchair user for 40 years and lived with his elderly father in their shared home. His mother had recently passed away from Parkinson’s Disease and until recently he had been managing his daily routine with caring responsibilities for her. He was also diagnosed with orbital cancer of his left eye and underwent chemotherapy and radiotherapy several years ago. He was in remission for five years with what he described as no “real lasting effects”

aside from issues with his sight and secondary issues with his throat as a result of the chemotherapy. He reported pain in his shoulders, neck, back, elbows and wrists from what he felt stemmed from a very active career in wheelchair sports.

“I’ve had an awful lot of injuries and a lot of them, because of the active lifestyle I chose to follow and the sport, and I did quite a bit of weight training, so that took its toll as well and so I have particular problems with shoulders, elbows and wrists and hands even”

Compared to the other participants, he had a very real issue with constant upper limb pain, particularly transfers, which limited his ability to mobilise. He reported his upper limb pain would strongly influence his decision whether or not to leave the house on occasion, let alone participate in social activities.

“well I’m not as good at transfers than I used to be and I’m generally slower, I’m quite a bit slower at everything including getting dressed in the mornings so it all takes a bit longer than it used to. And I need to be a wee bit more careful with transfers even putting brakes on the chair occasionally which I never used to do at all, there was no need to”

“there are there have been occasions when there’s been nothing for it only to stay around the house only because I couldn’t really trust myself to do safe transfer, but really so far that has really been a matter of giving what the particular problem was a bit of time until it recovers reasonably”

In terms of medical treatments experienced, he attended physiotherapy, occupational therapy, underwent surgical intervention and steroid injections for a number of upper limb injuries with mixed feelings to the relief provided. Physiotherapy provided relief initially however, he felt this was on a short-term basis. He underwent surgery for a tendon repair some years ago and was satisfied with the dynamic splint provided by OT and felt the rehabilitation treatment provided by physiotherapy staff was excellent. His experience of attending his GP and receiving steroid injections below demonstrates how difficult it is for a manual wheelchair user to “rest”; as such this treatment was not beneficial as he was

unable to rest. He also showed apprehension should he wish to undergo surgical procedures again.

“You know when you go to the doctor they say well rest is the only thing for it but it’s virtually impossible to rest upper limb joints if you’re in a wheelchair. You always have to put them under stress but just trying to limit it as much as possible”

“yeah I have tried on occasion with a low dose but limited success. The last basketball tournament I went to was in Barcelona...I took the last minute desperate measure of having steroid injections and ideally to get them to work you would rest, complete rest for a couple of days, so the whole thing which I couldn’t do of course (rest), so as a result they weren’t very successful and I ended up playing only 17 minutes in the whole tournament”

“I had pulled the triceps tendon in this arm about 1989 or so and at that time this brace hinged thing wasn’t available and it was in plaster from wrist to there. All the time. It was very awkward plus when they took the plaster off finally, I nearly passed out because of the weight of the arm, but at the same time the arm was just skin and bone it was completely wasted away”

He found great pleasure in being involved with sports clubs and used to run the administration side of the wheelchair basketball club when he found it difficult to gain employment due to his disability. He reported finding satisfaction in both the physical activity and social interaction from being involved in the club.

“Absolutely I’d be lost without it. That was very much part and parcel of things. We got great satisfaction from the sports side of it but the social side of it and the rehabilitation side of it which was entirely incidental as far as I was concerned, was massive. It really did make quite a difference to quite a few people”

As a long term wheelchair user, Participant C had mixed experiences of health professionals, a particularly negative perspective of the RSCI centre. He felt it was “impossible” to be

examined by anyone and felt there was a lack of specialized knowledge of healthcare professionals outside the RSCI Centre.

“I’m supposed to see her (consultant) once a year and the last time I was with her I was having a few problems and she said she would need to see me back in 6 months but that was getting on toward 18 months ago now I would say. I don’t know whether it’s the consultant or whether it’s the secretary, but appointments are like gold dust in that place in the spinal injury centre they’re really hard to see anybody at all”

“I was told that if I had any problems at all regardless of what it is don’t go to the GP, don’t go to A&E, go straight to the spinal injury which I did and they were more than helpful on many occasions. But the last few years there that policy has completely changed and now it’s nearly impossible for a former patient to get in to the spinal unit. Now I don’t know what the setup is in the UK whether they’re using the same system or not but I find it hard to believe that they would actually, because when you go to any other department they haven’t got the first idea how to look after a paraplegic, they really don’t”

“no there’s no point in trying to get an appointment in (hospital name) I’ve given it up years ago”

In terms of looking towards the future, Participant C’s main concern was the possibility of transition to a powered chair. This, in his opinion, was not feasible or practical, solidifying his desire to remain as independent as possible.

“it’s not that practical or desirable to be honest because you are kind of giving a degree of your independence because you’re going to have to look at an entirely other way at getting in and out of a car because you’re not going to lift up one of those things and put it in the back seat”

3.4.4 Case Study D

Participant D was a 53-year-old L1/L2 incomplete paraplegic female. She lived with her 25-year-old son who was her primary carer. She reported pain in her lower back however her main concern was the pain she experienced in her legs. She suffered with neuropathic pain below her level of injury and foraminal stenosis (narrowing of the cervical disc space caused by enlargement of a joint) and was receiving ongoing treatment for this.

“During the day I have pain in my lower back and have leg pain in my legs. At night time I have pain in my leg and my leg would go like, one would be burning and would, would be cold or both would be burning or both would be really cold. But whenever they’re you know really warm both would go red so”

Her main issue with pain was the impact it had on her sleep. She scored her pain on the VAS as 9/10 and recorded it as “unbearable pain”. She took strong painkillers to manage the pain but again this was more in relation to the neuropathic leg pain rather than the back pain she experienced.

“yes. Lyrica and Amitriptyline...no still have the pain but if I don’t take them I wouldn’t even get 5 minutes of sleep, I wouldn’t even try...I really don’t have much in the legs but it’s at night time I find it would really annoy you”

The difficulty she experienced with sleep had a knock-on effect on her mood, scoring it as a 6/10 on the VAS scale. Her ability to complete ADLs had also suffered as a consequence; she scored pain that interferes with ADLs as 6/10 and stated she would be “limited” in terms of mobilizing both indoors and outdoors on a daily basis.

“out and about and when I’m pushing. Trying to push there’s hills I’d get bad pain in my shoulders”

In terms of treatment, participant D had a good relationship with the healthcare professionals involved in her care. She was previously referred to a pain clinic from which she found of limited benefit; describing it as “like mind control”. She did not enjoy physical

activity stating it was *“too sore and it’s not worth the hassle to be honest”* however she did go to the pool once a week and found the water provided relief of sorts.

“it’s good yes... whenever I get in my legs feel very, very stiff you know. It’s funny like”

She saw her consultant regularly every 6 months and received injections to manage the pain every five months. Unfortunately, the relief was short lived stating; *“about 4 months they just wear off you know slightly”*. She had a good understanding of her pain and stated she would ask for help whenever she experienced a flare up. She had good family support from her son however she was reliant on him for many tasks, particularly around the home. She also received assistance from carers three times a week to help her with washing and dressing tasks.

“Well my son would help me. Things whether they need done or not I just can’t do them...cleaning windows and things”

Overall her pain was primarily managed by medication and regular follow up by her consultant; she was satisfied with the services she availed of to date. Similarly, to participants A and C, her upper limb pain was not a pressing issue due to the extent of the neuropathic pain in her legs. For her, she understood she would always be reliant on her carers and son and may never return to her full level of independence as she was prior to her injury. Hence her goal was to manage her neuropathic pain as effectively as she could while remaining at her most independent level.

“I think the back and shoulder pain it is discomfort but not bothering when you’re trying to sleep”

3.4.5 Case Study E

Participant E was a 57-year-old C5/C6 incomplete paraplegic. He worked full time in the legal sector and lived with his wife and teenage daughter. He reported his primary source of pain was his neck but he also experienced pain in his back, neck, shoulder, elbow and wrist of which he attributed to quite an active lifestyle, but also to his level of injury.

“I’ve quite limited movement sideways and up and down. Now, there may be an element of that is obviously down to the injury and I have a spinal fusion at C5/6 but it didn’t really bother me and now I wasn’t aware of this until maybe the last couple of years”

Participant E felt he was quite capable of mobilising independently however in recent years had noticed a decrease in his ability and had resorted to the use of sliding boards for transfers. He stated he had a good support network in his wife however, had become more reliant on her for assistance over the years. At times, his upper limb pain had impacted his ability to leave the house, complete leisure and social activities, limiting his day to day life and work activities.

“I started using sliding boards maybe about 4/5 years ago because I was finding it at times you know I was having real difficulty managing in/out of the car and even once or twice just going somewhere because I couldn’t get in to the car”

“like that and in the past when I have had these pains that led to me using the sliding board I did find that they could last for a few days and then go away most days as mysterious as they came”

“well for example until recent years I would have happily gone off to England on my own or somewhere you know getting on a plane and going somewhere. I’ll probably not do that anymore”

He reported further difficulty with environmental barriers. For someone who travelled quite regularly, this was an issue as he could never prepare for the type of facilities he might encounter. He felt being able to rely on his wife was a great help, however it was not practical for when he was away with work and he would have to think carefully about his level of pain and dependence prior to agreeing to travel for work.

“well you get out of the way of lifting your body and shifting so I undoubtedly found that much hard to on/off for example toilets, much more bothersome if they’re not on the right level. Or I’ve also found the positioning of the grab rail can be a real difficulty if it’s not

where I would normally have it at home and I think the standard is down in building control regulations they like to have a gap between the toilet and the wall and I found that I'm now, that puts the bar on the wall too far away for me to get much use of it sometimes, real difficulty if you're not at home, trying to use a hotel or"

Upper limb pain had an impact on his sleep at times; particularly trying to fall asleep in the first instance. He felt he was lucky to have a sister who was a physiotherapist and she was able to recommend appropriate medication when pain was at its worst and pillows to help ease his neck pain.

"well certainly it prevents you getting over to sleep for some time, em again its very variable, as to how long I, my sister who's a physio got me a pillow... so I use that a lot. I can't honestly swear that I'm sure that it helps that much but I have it here in the bed and I got that because of this neck problem"

"there are one or two tablets that my sister recommended them, I'm trying to remember the name because I thankfully haven't had to take them. I think ibuprofen and Voltarol"

In relation to social activities, he felt pain would impact on his decision whether to leave the house or not. Overall, he would rather attend than not attend, managing his pain independently, but occasionally he had cancelled events due to the pain. His wife is his main carer and often assisted him with any toileting needs. She drove him to work and could take his wheelchair out of the car for him on arrival, something he felt eased the strain on the joints substantially.

"Occasionally I may have cancelled things but on the whole, you just try to sort of carry on. Usually we're not going to do anything very active. As long as you can get there, sit there quietly, take some sort of painkillers (laughs)...my wife, you may hear her in the background (laughs) I'm more reliant now on her mainly things like the getting on/off the loo just to make sure the chair doesn't move or getting me the board and helping me"

Participant E's feelings towards the medical treatment he had received to date was mixed. His experience of physiotherapy was positive; he previously attended and found it useful for relief of pain, albeit short term relief. Similarly, he found occupational therapy beneficial for wheelchair and cushion related queries. He reported little benefit of attending his GP for treatment; his GP prescribed rest although he found this difficult with living such an active life stating:

"rest is an attractive idea but not practical (laughs)"

The attitudes of his health professionals were that they would expect to see overuse injuries in wheelchair users and that not much could be done to treat his symptoms.

"You tend not to go to the GP a) because it's a real pain trying to go through the effort to get there, and the GPs don't understand anything really about spinal injury. You know there occasionally I have to rely on them but I wouldn't if I had a real problem that I thought was connected, I wouldn't go to my GP...I did have an MRI one time because of the combination of pain and a bit of sort of tingling in my arms but it didn't, it wasn't very conclusive, they didn't see anything that they didn't really expect"

His experience of the RSCI centre was limited due to the fact he has not been called for review in several years. He had attended previously in relation to a pressure sore however he felt again there was not many options available to him for treatment.

"it's sort of basic advice...other than you're doing alright than the length of time you're around (laughs)"

In terms of looking towards the future, Participant E reported real concerns as to how he will manage as he ages. He was dependent on his wife, but how much he could depend on her in the future was another concern as she aged also. He found great benefit from using the "SmartDrive" device, although it still caused some issues in relation to ease of attaching the device, limiting what he could do independently.

“Smart drive is the first thing I can sort of manage on my own but even for me it’s an awkward thing to get on and off. I can get it off quite easily, getting it on is more problematic but I can do it. And for me that immediately limits what is the practical range of choices you have and probably then you’d say I should just put up with the shoulder pain (laughs)”

On discussing powered mobility, he voiced his concerns around changes that would need to be made in order to facilitate this. He felt powered mobility would be giving up a level of independence and also pride; a powered wheelchair user may be perceived as more dependent than a manual wheelchair user, and would be more reliant on others for assistance.

“The real problem is overlaid on top of what are the best medical and health choices. You’ve got to actually balance that against what are the most practical of choices and for example that’s why I stay away from powered chairs. Apart from there’s a sense of pride in it also, they’re just not as transportable...all those things are expense, and also, they change the way you do things and probably for me, always the biggest goal is to maintain the flexibility and not to constrain my choice about where I go, when I go, you know not to have to be relying on people getting the chair in and out of the car”

In conclusion, he was managing independently but the combined issue of ageing, strength and pain has forced him to consider long term options; something he was not prepared to embrace just yet.

“I mean I’m 57 I do wonder whether I’ll be doing this in my sixties I don’t know. At the moment, I might take a moments breather after I’ve done all that because you’ve also got the palaver of getting the chair in the right place and then setting it back up again and stuff”

3.4.6 Case Study F

Participant F was a 45-year-old T9/10 complete paraplegic male. He lived with his wife on an extension to his parent's house and had no dependents. He primarily reported pain in his neck, back, shoulder and fingers, alongside visceral pain of the abdomen and leg/muscle spasms. His pain was not constant however he described it as dull, prickly and throbbing when apparent. His pain interfered with sleep and mood; he scored both as 7/10 on the VAS. He reported his pain could be triggered with transfers or when lifting an object, specifically when lifting and maneuvering.

“yeah it does it does sort of interfere at certain times of the day, mainly at night when I'm lying down and I'm trying to find a position to sort of, even in just the way I'm sort of lying keeping on my side or something...it would hurt whenever I'm lifting things a certain way. If I was lifting sort of straight up with my arms straight out, things you've to sort or manoeuvre a bit differently with different things”

He reported having good support at home from his wife and his parents, specifically in the morning time with washing and dressing. His wife completed most of the domestic tasks at home and they regularly went out for dinner or lunch as his working schedule allowed.

“so, I would get a lot of support from them for basically getting out of bed in the morning, getting into bed at night, getting a hand to dress the bottom part of my body you know after I got a shower and stuff giving me a hand with going to the toilet you know, so I'd be dependent on them, so they're all between themselves pretty hands on when it comes to looking after all those needs. Once I'm out and about and I'm on the chair I'm independent enough, but for those things I would still need their support, do you know what I mean, that way”

He did not like to let his pain limit him in any way and did not like to disappoint people. He frequently spoke about his injury to various educational institutes and organisations about the impact it had on his life and how he has overcome adversity. He had a “can-do” attitude and wanted to live as independently as he could.

“I’m always doing something do you know what I mean, so it’s very hard to let people down and you know when I am in pain I just get on with it, do you know what I mean. I think actually keeping busy helps dealing with the pain too you know, takes my mind off it”

Although he had limited interest in sport or physical activity, he felt it was important to stay active. He struggled with his daily pushing requirements due to work commitments and had encountered environmental obstacles in his new employment role. He was welcoming of anyone who could provide assistance and had no problem in asking for a helping hand when needs require.

“It’s a big ramp, there’s no rail at the minute so I’ve said look get a rail in, so they are going to get one in. But this past while it’s been going past and waiting for someone to walk past and give me a push up that ramp cause, do you know what I mean. I wouldn’t be afraid of asking, do you know what I mean, like I wouldn’t be embarrassed to ask say “jump on the back there mate give us a push up” so I’ll take the help where I can get it”

In relation to the medical treatment he’s undergone, similarly to the other participants, he had mixed experiences. In general, he preferred to manage pain independently, but at times it could be aggravating during his working day.

“Getting from a to b short distances is fine but, do you what I mean, there’s times I’d see myself up and down here and being wrecked by the time you get to where you’re going so rest that way yeah, and like if I’m sitting at the desk here, do you know what I mean, I would try and put the arm up a certain way to try and take the strain off or find a position that’s suitable even like a cushion on the desk so you know what I mean so”

He had mixed feelings about the RSCI centre which he felt stemmed from his previous experience at hospitals, not the health professionals themselves. He understood that he had a part to play in this however, in recent years he stated he had not been called for review in 10 years.

“It’s sort of, whenever I first came out of (hospital name) so that was ‘94, I’d a real sort of bad taste in my mouth I think, I just got disenchanted with hospitals and I don’t think I got on well with the previous consultant... Em it just sort of put me off going back and then (consultants name) came along and I went a couple of times, once a year type thing, whatever it was, and I don’t know what happened, whether I never got more letters to go or I just fell off the books or something. So, I haven’t, haven’t went in nearly 10 years maybe. Which is probably not a good thing but for me I was just getting on with it, do you know what I mean, and doing my own thing. Probably not the best way to go about things really”

He had previously attended private physiotherapy with mixed results. He felt he benefited from the treatment however the results were not long lasting. He recognised that the pain he had is ongoing and there may not be a “cure” as such, but he would still like to manage it as best he can.

“it was, just massage. I think it, the original couple of sessions, the first couple of sessions he’d stuck a machine on but that was only like once or twice but most of it was just a good, good rub, know what I mean. I think that helped a bit... it was more short term, sort of realised that the injury will probably be there, do you know what I mean, for the long term so it’s just a matter of managing it putting up with it really, that way”

Previous advice he had received from his GP he felt was not applicable; similarly, to the other participants, rest is not always a viable option for an active manual wheelchair user. As participant C mentioned above, in order for injections to take effect, a certain level of rest is required, it’s hard to understand how this may be achieved without potentially putting your life on hold for a few days.

“it’s hard to actually always rest it but if you can’t get the injection, you can’t rest it, you’re always using it... so yeah, so that’s yeah, catch 22 really. Do you lie in bed all day or do you get up and get on with it?”

In looking towards the future, Participant F had concerns over how his pain will affect him in the long term. He was dependent on friends and family but he feared he may become completely dependent, and as he stated below, he would be “stuck completely”.

“Down the future it could go and I could be stuck completely, I’d be stuck for help to get dressed even to help myself jumping on and off, transferring and stuff so there is a fear of that going and I’d be really stuck then do you know what I mean”

3.4.7 Case study G

Participant G was a 55-year-old T12/L1 incomplete paraplegic male. He worked part time in an office setting and lived with his wife and teenage daughters. He reported pain in his neck, shoulders, elbows and wrists. He described pain in his shoulders as a continuous “throbbing pain” and the pain comes and goes in his neck, elbows and wrists. He was a strong-willed gentleman and tended not to let his pain impact on his life however he did report a decrease in his strength and he no longer carried out physical tasks as before. Up until this year, he suffered with neuropathic pain; he underwent what he describes as “life changing surgery” and as a result his pain was much more manageable. His most prominent pain site was his shoulders which he described as a “sickening ache”, which he attributes to the nature of wheelchair propulsion – “because we’re kind of pushing the one way all the time”. Prior to his injury, he was an electrician by trade and lead a very active life. He was involved in wheelchair tennis and still regularly competed in international competitions, although pain had limited his involvement over the last few years. He was a very proud man and did not like to ask for assistance with daily tasks. His wife was supportive however he still liked to take tasks upon himself.

“well I have a wife and two daughters but I tend to do everything kind of by, you know all kinds of chores and things, I would do all by myself and I don’t normally ask for assistance you know. I mean my wife would do 99% of the cooking that sort of thing but the sort of manly chores around the place and what needs done around the house, I just get on and do that myself... I think they would if I asked them but I suppose a bit of male pride thing you just get on with it yourself... I mean anything that I couldn’t do would be too heavy for ladies anyway so I probably wouldn’t annoy them really”

His involvement in wheelchair sports had provided him with a great social outlet and thoroughly enjoyed both the social and physical aspects. His pain occasionally impacted on his ability to partake in both sporting and social activities although he was keen not to let it hold him back.

"I don't let any sort of discomfort or anything sort of stop me from doing anything and you know especially when I'm in company when I'm with my family or were going doing something we all go out and you know manual wheelchair, get it out of the car and just push it wherever you need to go. And obviously, I wouldn't go to restaurants maybe where there's a pile of steps or something you know so something fairly accessible, but you know you would notice even pushing around the town even slopes and curbs and things you do notice the shoulder discomfort, but as I've said, keep saying to you, you just have to get on with it you can't let it stop you or you do nothing"

In relation to treatment he underwent, similar to the other participants he had mixed feelings. He attended physiotherapy privately; he "just went privately for quickness" however the relief was short lived.

"massage, stretching, bit of manipulation of the thumbs at times, I mentioned ultrasound so that type of thing, maybe half a dozen times or up to 10 sessions which seemed to help things a bit but once you get going again and back into your usual sporting life, or whatever things you done, you know the shoulder pain does come back"

His neuropathic pain had primarily dominated in terms of his treatment goals and would have attended the RSCI centre for treatment of this, however his experience had not been positive.

"well you know (hospital name) I really dislike. I felt it was a formality, they asked you how you were doing, they ticked a few boxes and it was always the same right up until this year. "I know you've chronic neuropathic pain but I know you can do nothing about it" and that was it really. And if you said there was anything else wrong with you, I may have mentioned the shoulders, probably didn't, but as I said it was so insignificant compared to the

neuropathic pain you just went in, you got your boxes ticked and then you went out again...they're supposed to send for you once a year but sometimes it could be 2 or 3 years"

He has previously received steroid injections for treatment of his pain however like participant C, he had difficulty with the aspect of "rest" as required for the injections to take effect.

"I had tennis elbow a few years ago and I got a cortisone injection, I was heading off for a competition and I had my arm in a sling for 2 days and it was a nightmare. You know trying to transfer, trying to do all the things everybody else does in their everyday life was extremely difficult and I would be very independent, very proud so you know I don't like taking help with anything so like that there so no"

On discussing potential future surgical interventions, participant F had real concerns over the recovery time required for rehabilitation, a common theme throughout.

"You're talking about your arm in a sling for something like 12 weeks and that just makes life so difficult. I mean talk about running out of limbs you're going from 4 limbs down to 1 then you know (laughs), you'd end up just pushing around in circles you know, so unless it gets to the stage where I just have to have it, I'll probably just go with it and keep going because the thought of being down to one arm for a few weeks is just"

In conclusion, his shoulder pain was not a priority due to the intense pain levels he had experienced due to his neuropathic pain. He was keen to remain active and had an overwhelming sense of pride in relation to his work and private life.

"you do notice the shoulder discomfort but as I've said keep saying to you, you just have to get on with it you can't let it stop you or you do nothing... you do have to rise above it, I seldom let it stop me doing anything...I'm thinking later in life when I need to get around, but I also like the exercise as well you know, even if it does half kill me (laughs) you know but I still like the exercise and getting up and round and I think that... but you know 10 years' time how much pushing will be left in me I don't know (laughs)"

3.4.8 Summary of findings

In summary, participants highlighted the consequences of upper limb pain had negative impacts on all aspects of life as a manual wheelchair user. At times participants reported how their upper limb pain acted as a barrier to attending social activities and would use their own coping strategies to manage the pain themselves rather than seek treatment. This predominantly stems from the mixed feeling participants had about the efficacy of treatments received previously. Some participants reported relief from certain interventions however, several participants reported being unhappy with the level of care they received from the RSCI centre. Participants reported greater satisfaction from attending Allied Health Professional (AHP) services such as Physiotherapy and Occupational Therapy however, participants reported having been advised previously that this upper limb pain was inevitable and that little could be done to treat their symptoms. In looking towards the future, all participants expressed concerns over what the future may hold.

Participants reported they are managing to live independent lives, but particularly in recent years, their upper limb pain has become more apparent. Participants felt powered mobility would be a last resort in some cases as it portrays to society that a person is more dependent and the financial cost involved. Overall, participants felt more could be done to support them, however a lack of specialised knowledge specific to SCI may limit the effectiveness of these services.

3.5 Discussion

The study undertook a holistic view of the person, exploring their personal, social and vocational domains and the psychosocial impact this injury may, or may not, have had on their lives. In addition, this study sought to establish whether service users feel their needs are being met; the impact of day-to-day living in a wheelchair is having on their personal lives and what they feel can be done to better support them, this is reflected in the extracted themes and mapping framework.

The quantitative data collected in this study is in line with other research in the area of upper limb pain in SCI (Subbarao et al. 1994, Curtis et al. 1999, Ballinger et al. 2000), which reported shoulder pain prevalent in 30-72% of participants. More recently Bossuyt et al.

(2017) found shoulder injuries prevalent in 35.8% of participants. Shoulder pain in this study was prevalent in 87.5% of participants. Wrist, elbow and neck pain were the second most commonly reported pain site in this study, prevalent in 50% of participants. Kentar et al. (2018) reported wrist and elbow pain in 47% and 33% of participants respectively, Sie et al. (1992) also reported 66% of SCI participants reported more general upper extremity pain.

To the researcher's knowledge, no study to date has directly identified the exact time since injury that upper limb pain occurs, as no two participants will ever lead the same lifestyle, with too many confounding variables. Eriks-Hoogland et al. (2014) however, conducted a prospective cohort study in which 225 newly injured participants were recruited to identify potential risk factors that put them at an increased risk of developing upper limb injuries. He identified distinct trajectories for those who may experience high levels of pain. Participants with pre-existing known factors relating to their injury were at a greater risk of developing upper limb pain as a result. He concluded that participants with a higher-level injury and those with limited range of movement (ROM) prior to commencement of rehabilitation had a greater likelihood of developing upper limb pain. Contrarily, in this study, the participant with the lowest level injury but with what could be deemed as the highest level of pain, had undergone the greatest number of surgical procedures for treatment of their pain. This study did not account for previous baseline abilities or lifestyle factors therefore it is difficult to compare the study results. Both, however, concluded that SCI participants are at a greater risk of developing upper limb pain as a manual wheelchair user, compared to those without an SCI.

In terms of treatment, an interesting observation was that none of the participants reported experiencing any long term relief from treatments prescribed. Medication tended to manage the pain for a few hours, physiotherapy for several weeks at most, and two participants warned of the prerequisite of "rest" in order for steroid injections to take effect. The idea of rest was a commonly prescribed treatment but it was difficult for participants to fully "rest" as the upper limb is used for all aspects of wheelchair use. Even for participants who stated they could take it easy around the house, they still have several transfers to complete in the morning, getting washed and dressed, transferring to the couch; a day of complete rest seems almost impossible for a wheelchair user. Similarly,

surgical intervention would also require a period of “rest”, however, again the ability to mobilise independently or complete ADLs is hindered for a period of time, often up to 3 months in some cases.

Each patient is individual and therefore there is no one treatment that would fix all. A combination of treatments may prove beneficial, but in addressing this issue as a whole, perhaps prevention may be better than cure. It was clear pain affected participants daily, however they relied on their own resilience and their family and carers for support. Participants understandably expressed concern over what the future may hold. The assistance they receive currently is minimal and the concern is, that as they age, become weaker or lose muscle strength, how will they manage then? Will they still have the same support from family members? Their carers are also ageing and for some participants, it is the fear of the unknown, “*what will I do then?*”. Several participants discussed how, at their initial inpatient rehabilitation, they were warned of these injuries by their health professionals; the attitude appears to be that manual wheelchair users are just expected to “put up” with the pain, rather than being advised of potential risk factors or strategies to reduce or minimise the strain on the upper limb.

There is an element that these injuries are part of the ageing process as an active wheelchair user and the researcher acknowledges that they may not be entirely preventable, however, identifying these injuries at an earlier stage or implementing correct wheelchair techniques may delay or perhaps prevent, the onset of injuries. This would reduce the number of patients presenting with long-term injuries and therefore reduce waiting times in getting treatment for these injuries when they do manifest.

This study highlighted the importance of the patient voice in delivering client centred care specific to all individuals. The National Health Service (NHS) is currently under substantial strain yet healthcare professionals are still working tirelessly under these constraints to ensure the needs of their patients are met. Long-term conditions by nature act as a substantial challenge to the NHS in providing sustainable long-term care to patients. The increasing prevalence of long-term conditions is also associated with an increase in secondary complications resulting in further strain on the NHS and the patient themselves

(Barnett et al. 2012). Healthcare professionals are bound by clinical guidelines, national policies, staffing levels, increasing waiting lists and financial constraints of the service they work in, making it difficult to provide true patient centred care (Gillespie et al. 2004). Many healthcare professionals believe they already practice according to the needs of patients; however patient satisfaction surveys do not agree to the same extent (Coulter 2011).

In this study, several participants stated they had not been reviewed in over ten years. Eaton et al. (2015) reported that patients with long term conditions spend just a few hours a year in the care of healthcare professionals, and 99% of patients self-manage their condition. In addition to upper limb pain, other assessments of comorbidities associated with SCI which may be more life threatening, such as kidney and bladder function tests, were not followed up on a regular basis. Again, there are no set guidelines stating how often patients should be reviewed in relation to these issues specifically, however, guidelines published by the National Consortium for Spinal Cord Medicine (1998) recommend screening should take place annually. An annual review for people with an SCI would be beneficial in providing an opportunity for patients to discuss any medical issues they may be having with their consultant, to facilitate early identification of injuries.

SCI patient reviews are designed to highlight any issues patients may be experiencing, however it is not always feasible to conduct a full clinical assessment for every patient who is called for review. Limited consultation times and workload pressure are just some of the barriers to providing client centred care or exploring new methods of delivering care. It could be argued that patients are not receiving frequent reviews or adequate care, however an element of responsibility should lie with the patient also; patients have a responsibility in communicating issues they are experiencing to their healthcare provider. Several participants in this study stated they had yet to report their pain to their consultant. This may be attributed to several reasons, they may have built up a higher level of resistance to the pain, it may be the small sample size recruited, or perhaps participants with a longer standing history of manual wheelchair use would be more appropriate in future research.

Pride was an underlying theme in participants' attitude toward coping with pain. There is an overwhelming sense of dignity in being independent – this was particularly noticeable in the

male participants in the study who were reluctant to acknowledge they had pain. Addis & Mahilik (2003) accurately sum up the “masculine gender role socialisation” which may have played a role in the under-reporting of injuries to healthcare professionals. This follows the assumption that behaviours from cultural values, social norms and ideologies impress on society as to what it means to be “masculine”. Society has created a stereotype of men where they have always been portrayed as strong and independent – think action movies, social media, social norms. It is therefore not surprising that men are more reluctant to seek help from healthcare professionals compared to women. Men are less likely to visit their local GP, primary care providers or other healthcare professionals (Oliver et al. 2005, Smith et al. 2006, O’Brien et al. 2005). It could therefore be argued male participants may feel more comfortable in reporting pain in an anonymous questionnaire as implemented in this study, rather than speaking face to face with their healthcare professional about their experience of pain.

3.7 Limitations

Acknowledging biases in sampling and ongoing reflection of methods is critical to ensure sufficient depth and relevance of data collection and analysis. Due to the nature of the recruitment method that not all invitees accepted to participate in the study and the smaller than anticipated sample size, the researcher acknowledges that the results and findings of the study may not be an accurate reflection of the SCI population with upper limb pain. The sample size potentially could have been larger, an advertisement, which was posted out by a far-reaching organisation in SCI, was published in a quarterly newsletter after recruitment and data collection had ceased. On speaking with potential participants via local wheelchair sports clubs, it became apparent that potential participants were not keen to have their medical notes screened. SCI is a life changing event and there are many additional concerns such as bowel and bladder management, sexual function, home adaptations, etc. It is understandable for participants to be apprehensive for someone other than their healthcare professional to review their medical notes, particularly someone they had never met before.

The researcher had received requests from six other potential participants but as data collection had ceased, they were unable to be recruited in to the study. Questionnaires were posted in early July 2017 and received up until 9th November 2017. Any participants

who returned questionnaires after this point were not included in the analysis. This study was part of a PhD study and was therefore limited in terms of time constraints of the PhD student and her thesis submission deadline.

3.8 Conclusion and recommendations

In conclusion, this study offers insight on the perspective of living with upper limb pain as a long-term manual wheelchair user. Looking towards the future, patients with an SCI who use a manual wheelchair need to be more adequately supported in the community, especially important as there are no specialised outpatient SCI services. SCI patients' needs and abilities will change throughout their lifespan, whether that be from ageing, illness or pain. A specialised multidisciplinary team based in the community would be beneficial to provide follow up care, providing home exercise programmes, advise on home adaptations or grading of activities based on patients' abilities. Additionally, a clear pathway of how to access services when patient's experience pain or a flare up of an injury would facilitate early identification of injuries. Education plays a pivotal role in ensuring patients are aware of potential complications of their condition and allow them to take informed and proactive steps in addressing their injury. Coulter (2005) reported that approximately 40% of patients with long-term conditions have a poor understanding of their condition, lack confidence or find the complexity of their treatments overwhelming. In equipping these patients' with knowledge, we can educate them to self-manage their condition, thus taking further pressures off the NHS and its healthcare professionals.

CHAPTER 4:

SECONDARY UPPER LIMB INJURIES
IN THE SPINAL CORD INJURED (SCI)
POPULATION: A MIXED METHOD
INVESTIGATION OF HEALTHCARE
PROFESSIONALS' PERSPECTIVES

Abstract

Introduction: In taking an evidence based practice approach, the healthcare professional perspective is key in understanding how the service may be improved, what works well, and what has the potential to hinder patient care within the service. Chapter 3 described the spinal cord injured (SCI) patient's perceptions of upper limb pain and the treatments provided and availed of. Patient's highlighted a distinct lack of specialised care in the community and a feeling of unknown moving forward as they age with their upper limb injury or pain. To date, there is no literature relating to the experiences of healthcare professionals involved in the treatment of upper limb pain in the SCI population. Additionally, there is unclear evidence relating to the medical and rehabilitation pathway for obtaining treatment of upper limb pain for patients with an SCI. Given the limited data available relating to clinician's perspectives within the scope of upper limb injury in SCI, the aim of this study was to collect in-depth data from this population with first-hand experience of treating SCI patients with upper limb pain.

Aim: An investigation of healthcare professional's perspectives relating to the injury and treatment of secondary upper limb (UL) musculoskeletal injuries in the manual wheelchair using spinal cord injured (SCI) population.

Methods: A mixed methods study combining quantitative and qualitative data in the form of questionnaires and one-to-one interviews with healthcare professionals involved in the care of spinal cord injured patients. Open-ended questionnaires were distributed to the entire medical staff of the Regional Spinal Cord Injury (RSCI) centre. Participants were asked to complete the consent form and accompanying questionnaire and were asked to signal if they wished to be included in a one-to-one interview with the researcher. Semi-structured face-to-face interviews were utilised to further explore the medical perspective of the identification and treatment of upper limb injuries in the SCI population.

Results: Seven healthcare professionals completed the questionnaire (3 occupational therapists (OTs), 2 medical consultants, 2 physiotherapists), with the three OTs further consenting to completing a one-to-one interview. 100% of participants reported the overuse of the upper limb as the primary causation of upper limb pain. A variety of treatments were

recommended which were grouped under the following; 1) assistive technology, 2) adaptation of task, 3) manual therapy, 4) rest, 5) painkillers, 6) education. Four overarching themes that impacted treatment prescription for upper limb pain were proposed during the qualitative interviews: 1) patient priorities, 2) lack of outpatient service, 3) future concerns for upper limb injuries, 4) proposed method of improvement. Participants reported a distinct sense of responsibility in treating their patients as they were consciously aware that once they leave the Regional Spinal Cord Injury centre, they may never receive the same level of specialised treatment in the community. Participants felt that upper limb pain was not a priority for patients on leaving the RSCI. Participants were encouraged to set goals in the short and long term, however as an SCI is a life changing injury, often patients think of the immediate goals of returning home and adjusting to life.

Conclusion: This study is the first study, to the researcher's knowledge, exploring the perceptions of healthcare professionals involved in the care of the SCI patient, in relation to upper limb pain and injury. It has provided an insight into both the early phase of initial rehabilitation, and the adjustment process patients undergo throughout their stay. The findings of this study suggest that patients are not emotionally in a position to think long-term about the potential consequences of manual wheelchair use and upper limb injuries, and thus are not focused on preventative measures therapists initially educate them about during rehabilitation. Participants highlighted the need to follow up with patients post rehabilitation to ensure they receive the specialised care they require. The lack of an OT outpatient service was a common thread throughout the interviews in discussing the barriers to treatment of these injuries, however such a service would come at a cost to an already under pressure NHS. In addition, the findings of this study would need to be considered and further explored by service developers, managers and commissioners, to ensure adequate and cost-effective provision of care is implemented.

4.0 Introduction

Much of the literature relating to prevalence and impact of upper limb pain has previously been covered in Chapters 2 and 3, however, to the author's knowledge, no previous literature has reported the healthcare professional's perspective of delivering treatment for upper limb pain in SCI. Chapter 3 described the spinal cord injured (SCI) patient's perceptions of upper limb pain and the treatments provided and availed of. Patient's highlighted a distinct lack of specialised care in the community and a feeling of unknown moving forward as they age with their upper limb injury or pain. To date, there is no literature relating to the experiences of healthcare professionals involved in the treatment of upper limb pain in the SCI population, and there is unclear evidence relating to the medical and rehabilitation pathway for obtaining treatment of upper limb pain for SCI patients. Chapter 3 highlighted a range of treatments availed of by participants however, it is unclear how these are offered within the remit of the National Health Service (NHS) or the Regional Spinal Cord Injury (RSCI) centre, and which treatments may provide the best long-term outcomes for patients.

Evidence based practice is key in delivering client centred care, specifically improving the patient experience (Laschinger 2009). Evidence based practice in healthcare advocates the use of current best evidence in making decisions about care (Sackett et al. 1996). This approach not only includes the use of best available evidence but promotes the inclusion of clinical expertise and patient values (Schlegl et al. 2017). Previous NHS initiatives to improve patient care such as "Improving the Patient Experience" (2013) and NHS England's report "Staff Experience and Patient Outcomes: What do we Know?" (2014), highlighted the impact healthcare staff experience has on patient outcomes and quality of care. The reports outlined that increased staff satisfaction resulted in increased positive feedback from patients, however this was only achieved when staff felt they were well supported, received adequate training, and were actively involved in the decision-making process. In promoting positive staff morale and satisfaction, communication with staff is key in understanding how the service may be improved, what works well, and what has the potential to hinder progress of development, with the aim to improve patient care within the service.

Given the limited data available relating to clinician's perspectives within the scope of upper limb injury in SCI, the aim of this study was to collect in-depth data from this population with first-hand experience of treating SCI patients with upper limb pain.

4.1 Aim and Objectives

The aim of this study was to investigate healthcare professionals' perspectives relating to the injury and treatment of secondary upper limb musculoskeletal injuries, in the manual wheelchair using spinal cord injured (SCI) population.

Objectives:

To carry out a mixed method (quantitative and qualitative) study to identify:

- the causation and risk factors associated with the development of upper limb pain in SCI
- the medical and rehabilitation approaches to treatment of upper limb pain in SCI
- the physical, psychological and social challenges of upper limb pain in SCI from the clinician's perspective

4.2 Methods

4.2.1 Ethics

A detailed participant information sheet, consent form, questionnaire and topic guide were submitted for ethical approval, of which can be found in Appendix 8. Ethical approval was obtained from the Institute of Nursing and Health Research Governance Filter Committee, Ulster University; Office of Research Ethics NI and the Belfast HSC Trust; REC reference 17/NI/0062.

4.2.2 Study design

The study was mixed methods combining quantitative and qualitative data in the form of questionnaires and one-to-one interviews with healthcare professionals involved in the care of spinal cord injured patients. Open-ended questionnaires were distributed to the entire medical staff of the Regional Spinal Cord Injury (RSCI) centre, including medical consultants, nurses, social workers, physiotherapists and occupational therapists.

Participants were asked to complete the consent form and accompanying questionnaire and were asked to signal if they wished to be included in a one-to-one interview with the researcher (AMC). Semi-structured face-to-face interviews were utilised to further explore the medical perspective of the identification and treatment of upper limb injuries in the SCI population. Confidentiality was explained via a comprehensive participant information sheet and the allocation of participant identification numbers so as no participants could be identified during the dissemination of results.

4.2.3 Participants

Purposive sampling was used in order to identify potential participants who worked in the Regional Centre for Spinal Cord Injury Northern Ireland, who have direct daily interaction with patients with SCI. Participants were identified via the leading consultant (local collaborator) of the spinal injuries unit. Participants were asked the following question to ensure they met the inclusion criteria for the study: are you involved in the care of SCI patients who suffer with upper limb discomfort/pain/injury? Those who answered no to the above question were excluded. Potential participants were required to have a minimum of 3 months experience working in the area of SCI. Written informed consent was obtained from all participants prior to inclusion in the study, including consent to be audiotaped. The sample included occupational therapists, physiotherapists and medical doctors.

Questionnaires were distributed by the local collaborator to the entire staff of the Regional SCI Unit at their weekly multidisciplinary team (MDT) meeting (n=30). The local collaborator explained the background of the study and advised participants should they have any queries, that the researcher's contact details were listed on the questionnaire. One member of the MDT contacted the researcher for further information (occupational therapist) and a presentation was then given to the occupational therapy team. The invite was extended to the wider MDT however only the occupational therapy members attended.

4.2.4 Data collection procedure

Stage 1: Questionnaire

Participants were asked to complete a two-page questionnaire which had been condensed to reduce participant burden. Questions were formulated from the results of the systematic

review in Chapter 2 and wider literature, input from SCI patients following interviews in Chapter 3, and brainstorming and broad discussions with the researcher's supervisory team.

Thirty questionnaires were distributed by the local collaborator at their weekly multidisciplinary team (MDT) review meeting and participants were asked to complete the questionnaire and consent form at a time suitable to them. A box was stored securely in the office of the local collaborator for staff to return their questionnaires. Participants were asked questions regarding the type of treatments they provide for upper limb pain, what they perceived as the primary cause of upper limb pain, when did they perceive upper limb pain as becoming prevalent in SCI patients, did they feel upper limb injuries are preventable and their knowledge of wheelchair skills training provided.

Stage 2: One-to-one interviews

All interviews were conducted face to face on site at the RSCI. Interviews were scheduled at a mutually convenient time and were undertaken by the researcher (AMC). The aim of the interviews was to further delve into responses provided via the questionnaire and gain a greater understanding of the medical and rehabilitation approaches to treatment of upper limb pain. A topic guide was further developed following the questionnaire results and was informed by existing literature regarding patient-centred care and current rehabilitation approaches to treatment of pain in the upper limb. Participants were asked questions regarding the type of upper limb injuries they treat, the treatments prescribed, the facilitators/limitations of providing upper limb treatment, patient priorities when leaving the Spinal Cord Injury Unit (SCIU) and patient adherence to advice and education. Interviews were provisionally scheduled to last 25 minutes to reduce burden on participants.

4.2.5 Topic guide

Open ended questions were used to guide the format of the interviews. Participants were advised this was a guide only and were provided the opportunity to discuss relevant aspects they deemed relevant throughout the interview process. The questions asked within the interview are outlined below in Table 4.1.

Table 4.1: Outline of topic guide for semi-structured interviews

1	When a patient first presents/referred to you, what do you feel is their primary concern in relation to their personal lives e.g. managing family, work, children/spouse, managing activities of daily living (ADLs), general functioning.
2	What do you perceive as the primary cause of upper limb injury?
3	Do you feel the level of wheelchair training provided is adequate? How often is it provided and by whom? What does the wheelchair training cover?
4	Do you feel upper limb injury is a common occurrence among SCI patients? What kind of injuries?
5	Do you feel it could be prevented at an earlier stage? Split into two – prevent; and sooner/earlier?
6	Do patients adhere to preventative advice given to them to reduce risk of injury?

4.2.6 Data Analysis

Questionnaire data was input into Microsoft Word and collated. Open ended questions were analysed using thematic analysis (TA). One-to-one interviews were recorded on a *Roland Edirol R-09 Digital Voice Recorder 24-bit WAVE/MP3* and downloaded on to an encrypted computer. Recordings were transcribed verbatim into Microsoft Word and repeated listening ensured accuracy of data and an opportunity for the researcher to become immersed in the data. Thematic analysis was conducted via initial coding following Braun and Clarke's Theoretical Analysis framework (2006) (Figure 4.1).

Figure 4.1: Thematic analysis according to Braun and Clarke (2006) framework

PHASES OF THEMATIC ANALYSIS (ADAPTED FROM BRAUN & CLARKE, 2006)

	PHASES	DESCRIPTION OF ANALYSIS PROCESS
1	Familiarising myself with data	i) Narrative preparation, i.e. transcribing data ii) (Re-)reading the data and noting down initial ideas
2	Generating initial codes	i) Coding interesting features of the data in a systematic fashion across entire data set ii) Collating data relevant to each code
3	Searching for themes	i) Collating codes into potential themes ii) Gathering all data relevant to each potential theme
4	Reviewing themes	i) Checking if themes work in relation to the coded extracts ii) Checking if themes work in relation to the entire data set iii) Reviewing data to search for additional themes iv) Generating a thematic “map” of the analysis
5	Defining and naming themes	i) On-going analysis to refine the specifics of each theme and the overall story the analysis tells ii) Generating clear definitions and names for each theme
6	Producing the report	i) Selection of vivid, compelling extract examples ii) Final analysis of selected extracts iii) Relating the analysis back to the research question, objectives and previous literature reviewed

The codes and themes expressed by participants were then mapped to the International Classification of Functioning, Disability and Health framework (ICF) *Core Set for Rehabilitation* (2005). The core set has 30 ICF categories from the components of body functions, activities and participation. The core set serves as a framework for understanding functioning and disability in clinical populations and for reporting data within and across various healthcare settings. This core set is in the early stages of establishment and to date, provides generic guidelines for the rehabilitation setting. Prodinge et al. (2016) recommends including existing categories from the whole ICF set to compliment these categories “to ensure that at least a core set of information is comparable and can serve as the anchor for linking disparate data sets” (pg 8), as is done in this case. A total of sixteen additional categories were included in the analysis and are outlined below in Table 4.2.

Table 4.2: Additional ICF categories employed

Component	ICF code	Description
Body functions	b735	Muscle tone functions
	b760	Control of voluntary movements
	b810	Protective functions of the skin
Body structures	s720	Structure of shoulder region
	s810	Structure of areas of skin
Activities and participation	d155	Acquiring skills
	d440	Fine hand use
	d445	Hand and arm use
	d475	Driving
	d660	Assisting others
	d750	Informal social relationships
	d760	Family relationships
	d910	Community life
Environmental factors	e115	Products and technology for personal use in daily living
	e580	Health services, systems and policies
	e585	Education and training services, systems and policies

Linking rules by Cieza et al. 2005 (updated from 2002) were implemented to ensure each *“meaningful concept is linked to the most precise ICF category”*. The ICF is a particularly useful tool in comparing outcome measures or interventions across different settings when the measurements used are focused on contrasting principles or methods (Stucki et al. 2005). The ICF can be viewed as a connecting framework, as is the case in this instance. This allows identification of the primary issues in relation to upper limb pain in the SCI population; allowing it to be understood in a common language and applied to different healthcare settings or chronic conditions.

4.2.7 Rigour and validity

Rigour in qualitative methodology is a key component in ensuring validity and credibility of research findings (Stratford & Bradshaw, 2016). Meticulous record-keeping, demonstrating a clear decision trail, rich, thick verbatim transcriptions of interviews and member-checking of data was undertaken to ensure the study was conducted in a fair and ethical manner (Tufford & Newman 2012). Contradictory cases were considered throughout the coding process and were incorporated into the results and discussion.

4.3 Results

4.3.1 Questionnaire

Of the thirty questionnaires distributed, seven health care professionals completed the questionnaire (response rate = 23.3%). This cohort included three Occupational Therapists (OTs), two physiotherapists and two medical consultants, all of whom specialise in SCI. The questionnaire responses are collated and outlined in Appendix 9. An outline of the themes obtained from the questionnaire have been outlined below in Figure 4.2. In terms of the perceived most common cause of upper limb injuries, the majority of participants reported overuse of the upper limb as the primary causation of upper limb pain; two participants referred to the medical diagnosis of injuries such as “*bursitis, carpal tunnel syndrome etc.*” as the causation of injury. A variety of treatments were recommended which have been grouped under the following; 1) assistive technology, 2) adaptation of task, 3) manual therapy, 4) rest, 5) painkillers, 6) education.

The majority of the participants felt the risk of developing upper limb pain could be prevented or reduced in most cases however they were unsure of them being fully preventable. One participant felt they were “*inevitable*”. Participants felt the development of upper limb pain was not age-related but related to the length of time as a wheelchair user, which is in line with findings from Chapter 2. A general consensus was observed that upper limb pain is individual dependent, including activity levels, body habits and other medical issues which may be additional risk factors. Upper limb injuries were perceived to have a knock on effect on other aspects of SCI patients’ lives; social isolation, reduced activity levels and decreased mood were reported by several participants as a result of loss of independence:

“maintaining independence can be a struggle – upper limb injury compounds this struggle”
(MDT02).

Healthcare professionals were confident that a comprehensive range of wheelchair skills are covered during initial rehabilitation and intensive one-to-one training ensured patients met their optimum ability levels during their rehabilitation. One participant felt this could be further extended when patients leave the rehabilitation setting as she states:

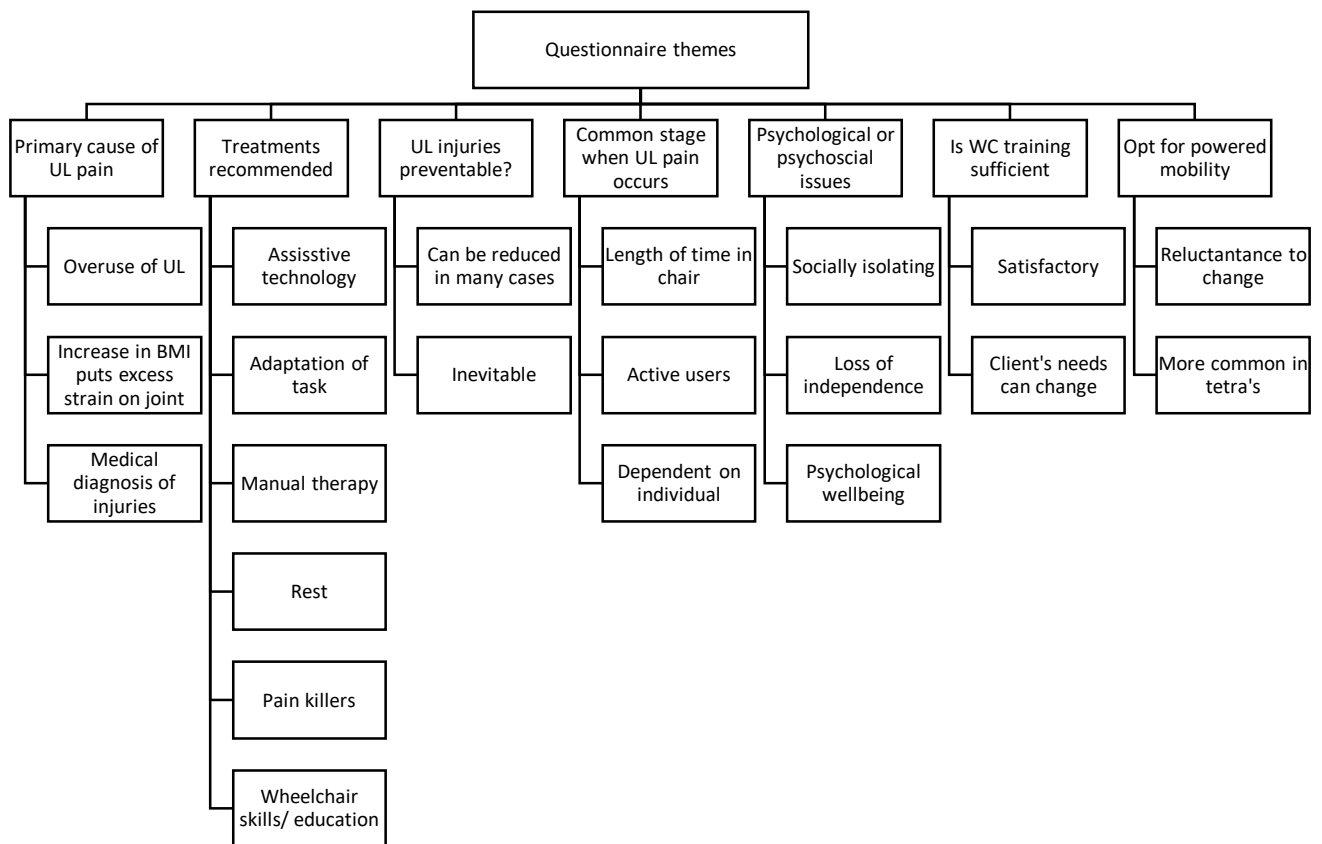
“in many cases it is sufficient but often a client’s confidence and therefore skill will grow in time as they recommence their lives with SCI post rehab” (MDT02)

Few participants had experience or knowledge of SCI patients opting for powered mobility as a result of upper limb pain and in the case where they did, participants reported patients underwent this *“reluctantly”* or *“only occasionally”*. One participant reported an intermediate step taken by some patients would be a power assist add on, and this would be more prevalent in tetraplegics who have upper limb weakness due to their level of injury:

“on some occasions patients with perhaps tetraplegia have considered power assist/smart drive devices privately particularly to cover long distances. Outdoor mobility powered wheelchairs have also been sought when ++ difficulties with continuation of a manual chair”
(MDT03)

A summary of the themes expressed in the questionnaire are illustrated in Figure 4.2, demonstrating the wide variety of approaches and perceptions of treatment for upper limb pain. In order to further delve in to this phenomenon, one-to-one interviews were conducted to gain a greater understanding of the impact upper limb pain has on SCI patients.

Figure 4.2: Staff questionnaire themes



4.3.2 One-to-one interviews

Three members of staff consented to interview, all of whom were OTs. Mapping of therapists responses to the ICF framework are outlined in Appendix 10. From initial deductive coding, a total of 46 codes were assigned to transcripts resulting in the culmination of four overarching themes: 1) patient priorities, 2) lack of outpatient service, 3) future concerns for UL injuries, 4) proposed method of improvement.

4.3.3 Overview of themes

Theme 1: Patient priorities

It was clear from interviewing the OT staff, they provide a comprehensive and intense initial rehabilitation period for those newly injured with an SCI. The staff are knowledgeable and acutely aware of the potential long-term risk of upper limb injuries and therefore try to

consolidate good transfer technique from the earliest point. Seating is the main priority for both therapist and patient and this is completed in the first 36 hours of admittance to the rehabilitation unit. Therapists are aware that this is a life changing injury for someone, but this is a setting where patients need to be pushed out of their comfort zone in order to adjust to their new circumstances.

“if able, we work on transfer technique and that happens in the first day or two because if they’ve come in being hoisted but we think they have the potential to transfer, we’d probably just introduce the board straight away and not hoist, or if they’re a low-level para we never give them a board. If you start them off with a board it’s very hard for them to get rid of it, so from day 1 they don’t get a board”

A spinal cord injury is a life changing event where patients understandably go through a range of emotions. Participants all reported the number one desire of patients is to return to their previous baseline abilities; to walk. This period of rehabilitation is an adjustment period in one sense, a step down prior to going home and encountering the world again, albeit in a limited capacity compared to their previous ability levels. It is difficult for therapists to definitively state whether a return of normal movement is possible, and sometimes that is more difficult to accept for patients than undergoing the rehabilitation therapy itself.

“And sometimes for the guys who are complete its very difficult to accept that, for the guys who have incomplete injuries it makes things maybe even more difficult in some ways because right now we’re dealing with how they are today, we don’t know how they’ll be in the afterwards so sometimes you have to say to people this is the way we’re working with you, we’re going to discharge you with this level of mobility, we cannot say that it will improve further, we cannot say that it won’t improve further so”

Goal setting is a key element of the OT process and addresses the needs of the patients. Participants all reported having good working relationships with their patients, a requirement for this line of work in order to ensure a common goal can be achieved. Both short and long term goals are set on a fortnightly basis and progress is monitored

throughout the duration of their stay. Patients undergo therapy on a daily basis, both physiotherapy and occupational therapy; both professional groups work closely throughout the patient's stay. Participants reported patients tend not to think any further than this point, focusing on their immediate goals.

“So we’d someone who was admitted there last week and their goal was to watch the Karl Frampton fight there on Saturday so a lot of the time they’re still thinking of the wee immediate goals of, will I sit up again, will I get out of my house, will I see my dog, they’re not really thinking long term”

Participants reported that their intervention can directly influence a person's ability or decision to engage with therapy. Wheelchair use in essence, aims to provide mobility for a person when their mobility may be impaired. It is no different in this case and becoming a new wheelchair user can take quite a bit of adjustment. OTs prescribe wheelchairs and pressure relief cushions for functional purposes, but often even if the chair is functional, if it is not comfortable, this can influence a person's motivation to attend therapy and also their ability to take part in therapy, as can be seen below:

“their brain wouldn’t be in that place yet but they know that they do need to be comfortable, if they’re not comfortable they’re not going to stay out of bed, if they don’t stay out of bed, they’re not going to build up their tolerance and they’re not going to benefit from therapy”

One of the most pressing issues for patients during initial rehabilitation is continence. Continence was perceived by all participants as a major barrier to patients achieving their goals. This issue is not restricted to the initial phase of rehabilitation as long-term kidney, bladder and bowel management are all major issues for people living with a spinal cord injury. Continence difficulties take away a degree of independence from patients and can have long lasting effects in terms of patient's ability to leave the house for periods of time, thus resulting in implications on social integration and community living. Participant MDT02 outlines below the psychosocial implications of continence if it is not managed adequately.

“And then in our ward one of the big pressing issues which is not strictly therapy, is more the nurses that would deal with continence, bowel and bladder function overlays everything else. If a reliable regime can be established where somebody can be continent throughout the day it then allows them to realise their previous life roles, it allows them to parent better, it allows them to return to work it allows them to think about driving”

Continence was also reported to affect patient’s mood and motivation to participate in rehabilitation. Rehabilitation is structured in a client centred manner in order for patients to reach their optimum functional abilities, however if a patient cannot attend rehabilitation, it adds a level of difficulty in achieving these goals and may act as a barrier to them achieving independence.

“And even on a basic early level, if continence is a problem they can’t even participate in therapy, they might come up and have an accident and have to return and the same patient might go to physio 4 or 5 days in a row but not actually get a physio session”

Participants highlighted a distinct difference between patients with varying levels of injury and their priorities during rehabilitation. Tetraplegics have a higher level of injury and therefore will have some level of upper limb impairment as a result of their injury, not necessarily from overuse injuries, as is the focus of this study. Alongside this, patients with complete versus incomplete injuries, albeit at the same level, can have very different priorities and goals. Participants highlighted that the therapy they deliver is always patient-specific, central to their individual needs and those with upper limb pain or injury already, often find it more difficult to achieve ADLs. One participant described an interesting observation regarding incomplete and complete injuries; it is possible for a patient to be independent as a wheelchair user, yet an incomplete SCI at the same level of injury with lower limb function may require more assistance than someone without lower limb function.

“so if they’ve had any degree of paralysis, they want to get back on their feet and in fact we would find that people who are paraplegic would nearly have a better outcome, you know if they’ve got full upper limb strength but can’t walk, they can still be fully independent from a

chair but some of the patients who walk but don't have good hand function are much more dependent you know on helping assistance as well so"

Theme 2: Lack of outpatient service

Participants highlighted the complex nature of SCI and the treatments required as one of the difficulties in providing specialised care. The current OT department is an inpatient unit only and does not allow for re-admittance of patients or review of outpatients. Participants reported feeling a desire to follow up with patients at a later date as they reported a lot of the learning comes from mobility in the home environment. The service does not cater for an outpatient department which was identified as a real barrier in delivering effective care. One of the difficulties reported was the lack of specialised care in the community, specific to SCI. One participant remarked there are excellent community teams but perhaps lack the specialised knowledge of therapists working in the spinal injuries unit.

"Now there are community services out there, there are community physios and community OTs and there's domiciliary OTs and there are rehab teams out there, but coming from a spinal injury background we might be better placed to look at the technique and more specialised transfers. Particularly the functional transfers when it comes to transferring in and out of the car or a shower chair or you know a lot of the patients it would have been 3 years ago and would have been using a different technique to what we're teaching now and they might benefit from learning new transfer techniques"

The lack of an outpatient department was seen as a huge barrier in terms of delivering patient centred care. An overwhelming sense of responsibility was echoed by all the participants in ensuring their patients have reached their optimum ability levels prior to discharge. On leaving the RSC centre, patients will no longer have access to the specialised services available to them as an inpatient, therefore the sole responsibility to ensure patients are independent lies with the therapists.

"yes so we do feel a bit of a responsibility to maximise somebody's potential before they leave here because you're painfully aware the next time they're out on a busy street, it's on their own"

In terms of providing intense upper limb rehabilitation, this is not provided by any community OT services and there are no specialised services that can provide rehabilitation to patients in their own home.

“It’s a huge issue because it’s very, very difficult to get outpatient hand therapy or upper limb therapy in the community, so there’s lots of functional rehab therapists that can look at how you’re managing to wash and dress yourself, but there’s nobody there that can sort of instruct you of an upper limb hand therapy programme”

The surgical outpatient clinics are organised in relation to specific injuries/surgeries, unfortunately for the spinal outpatient clinics, there is no funding for provision of OTs at these clinics. SCI specific clinics were initially conducted twice a year, with increasing demand this then increased to four times a year and they now run twice a month due to the increasing number of SCI patients requiring upper limb surgery. These clinics are the only upper limb surgical clinics not to have the presence of an Occupational Therapist to advise on upper limb rehabilitation programmes, transfer techniques, wheelchair propulsion or home adaptations. It is not without the want or the desire of OTs to be able to attend and provide their clinical expertise; unfortunately they are limited by the scope the service within which they are employed.

“we’re lucky that the upper limb surgeon wants us there as well and his own OTs have identified that they don’t have capacity you know to see those clients...The only clinics that there is none at are the spinal ones, and it’s probably the area that he feels less confident with so and we’re not able to help out there”

The lack of an outpatient service was seen as a major barrier in providing client centred care; although the therapists are based at the initial rehabilitation phase, the phase between leaving the RSCI and the home adjustment period can often prove difficult for patients. Patients have just left an intensive rehabilitation phase to then becoming accustomed to negotiating environmental barriers and transitioning to life at home. It is not uncommon for patients to feel at this point that they may need additional advice or services however it is difficult to receive that as an outpatient.

“we’re not funded for any outpatients here at all so we’re not involved at any of the medical reviews... So, in the past we have seen some (outpatients) but it depends on our own staffing and we can’t prioritise our own patients over the outpatients, so for whatever reason if we had a limited number of inpatients...sometimes we might try squeeze one in at the end of the day and that’s ringing the patient and making an appointment to come up. Or on some occasions the patient might ring themselves so we can’t just accept a referral like that we have to have it in writing”

MDT01 highlighted just how important their role is and the life changing difference a single piece of specialist equipment can make to a patient. That piece of equipment is the difference between a patient being independent and a patient requiring assistance from a family member or carer. The expertise the therapists have developed over years of working in the area is difficult to replicate in any other service provided, yet, technically, this is not permitted within the service.

“I have a few patients out there that can shave themselves with like a shaving strap that I’ve made for them. You can’t buy them, community OTs don’t make them, but if they didn’t get it they’d be dependent on someone to come in and shave them, so I’ll get the odd wee call of my feeding strap or my shaving strap is broken could you make me a splint and I’ll pop up and make them a splint and I’ll go away and nobody would ever know that they were here... actual face to face contact we’re technically not supposed to do it”

A sobering example from MDT03 highlighted how disorganised pre and post-surgical planning had been for one patient after being admitted for upper limb surgery. There had been no afterthought as to how this man would manage post-surgery and his transition from hospital to home while recovering from surgery was disjointed to say the least. Home adaptations or equipment provision had not occurred to any of the team involved in his care; something an occupational therapist would be perfectly positioned to advise on, at that point of planning.

“I’m just thinking of a particular gentleman who used a manual chair for many years who was admitted for surgery to his shoulder for whatever reason... anyways he was having huge

problems and was admitted for upper limb surgery on his shoulder... I think he had maybe been upstairs in the RSCI and then, hold on this man can't be discharged, he can't push his chair, he can't transfer, he has no equipment at home, so personally I feel if we had of been involved at that pre-assessment perhaps there could have been a bit of better planning"

Theme 3: Future concerns for upper limb injuries

In looking towards the future, prevention may be better than cure, however it is difficult to identify the specific movements or techniques that may be causing these injuries. Research literature is yet to determine at what point upper limb pain or injury becomes prevalent over the course of the SCI patient's life, however it could be determined that the overuse of the upper limb is a major factor. On questioning the participants about this phenomenon, they shared the same sentiments, particularly in the case of more active wheelchair users.

"yeah I mean the shoulders and wrists are not designed to do what your hip joints do in terms of lifting your whole body and helping mobilise you all day in the chair... Particularly if they're lifting the chair in and out of the car every day, particularly if they're very independent and driving and things like that, they'll always be lifting and loading as well so"

Debating whether these injuries are preventable or not, participants had mixed views. One participant felt they could be prevented however two participants felt that although injuries could potentially be delayed, they are more likely inevitable. The issue lies in being able to identify them at the earliest stage, there is no follow on service to assess this and it is difficult to know if patients are educated enough regarding these injuries to be able to self-identify them to their healthcare professional.

"could it be prevented at an earlier stage – yes perhaps. I don't know but if there were routine reviews like say like an outreach therapist or somebody had a review of their transfer techniques and their home environment and the chair that they're sitting in if it were reviewed on a regular basis you might have a role in preventing some of that wear and tear, it's just the resources and the service aren't there"

Often it can be too late when identifying these injuries and surgery is the only option to repair the damage. If patients are not routinely followed up then it is impossible to plan for the future; patient's abilities and muscle strength will inevitably change with age and with that comes more than just opting for powered mobility.

“they change all the time and not saying their level of injury if they're a complete injury they're going to remain the same but their function can change and their needs can change sometimes for the better and sometimes for the worst”

A transition to powered mobility is not a decision to be taken lightly, it affects numerous elements of a patient's personal circumstances and could be considered as losing a degree of independence, flexibility at the very least. As outlined below from MDT03, the patient in question had undergone surgery, however again there was no thought of aftercare. His baseline abilities had not been assessed prior to surgery and only at that point was it discovered that he may potentially need to switch to powered mobility on a long term basis due to age related changes.

“one I can remember that certainly was an upper limb definite that needed surgery but you opened the referral and thought it was maybe going to be an hour, but there was that many things that needed to be looked at ...he was getting on in age and you know, there was lots of discussion then you know, does he need a powered chair for part of the time, for all of the time, and then it was getting in to his vehicle and it was just, there was so much to it. And that was all down to having shoulder surgery”

The functional implications of upper limb pain are magnified for a wheelchair user as the upper limb is required for all activities of daily living. After surgical treatment however, although pain may have ceased, the upper limb is required to rest, it may be in a cast immobilising it to heal correctly or it may be non-weight bearing. Managing upper limb pain goes beyond the physical characteristics of pain itself, there are numerous elements that need to be considered and have huge implications particularly for active, independent wheelchair users as outlined below.

“If they’re not allowed to load their hand for 6 weeks, how are they going to transfer? How are they going to push their chair, do they need to go in to a powered chair for a temporary period of time. You know, do they need a carer to come for 6 weeks so this chronic pain has an opportunity to settle down and doesn’t get worse so, I think that some of the upper limb therapists wouldn’t have the level of expertise to look at it as a holistic package as opposed to thumb pain”

Many able bodied people can manage post-operative symptoms independently, however for manual wheelchair users, this period often confounds the existing difficulties they are already having. Specifically, for a tetraplegic who may already have limited use of the upper limb, to even temporarily lose more function can have life changing implications. Tasks such as eating, washing or dressing, can immediately become extremely difficult to complete independently after potentially already learning new techniques post SCI. Participant MDT02 shared this opinion:

“for somebody who might only have limited upper limb movement, to lose a little bit is magnified for them, they lose a whole lot more as a result, so they if they’ve only lost a little bit of range or a little bit of power it almost has a magnifying effect on their life”

Theme 4: Proposed method of improvement

The participants are of the opinion that there is plenty that could be done to help prevent upper limb injuries in SCI patients, but changes to the service would need to be conducted in order for this to happen. A top down approach would be required to implement the additional services they recommend but the backing of the service developers would be required. The lack of outpatient service was the strongest theme throughout the interviews and was echoed again in the sentiments of participants in relation to what can be done to improve the current situation.

“we would love to see patients face-to-face as outpatients again and I think it makes it more, it’s an easier transition for them because if they’re coming in for upper limb surgery or they’re having carpal tunnel pain it doesn’t just affect their hand, and I don’t think you can treat that in isolation”

Having additional services such as an outpatient clinic or outreach service could help in identifying when upper limb injuries occur and ensure early intervention is administered.

“I feel the real rehab starts whenever they go home and its getting used to a new environment and they’re having to do an awful lot more so they’re having to be more active at home. And I think it would be good to have a review of that of each patient to see how things are going, whether that would be leaving here and going to see them in their home environment at the house to look at their seating and pressure relief again. There, I think there’s a huge role there for OTs and especially for OTs that are working in spinal injuries where a lot of that might be passed on to community staff who don’t know the staff as what we do”

Early intervention is key however at the very least being able to assess patients pre surgical intervention would allow therapists to assess baseline ability levels and plan accordingly post-surgery. A once-off appointment with a patient is not enough to monitor patient’s progress; it is difficult to comprehend how they could adequately fulfil their duty to deliver client centred care with the constraints of the service.

“get an idea of their strength first of all as well and sometimes you’re just attending transfers and it would be a good idea to see what the joint was like beforehand and how well it was supported, how strong it was instead of just seeing them when they’re at their worst post op. And then to be able to bring them back and offer them that ongoing rehab would be great”

An outreach service was suggested as a possible service that could be provided to support patients both pre and post-surgery. Patients require a point of contact that can advise on any queries or issues they may be experiencing. Often patients may not realise a certain issue has occurred until they are home and experience it first hand; an outreach service would be perfectly positioned to go and visit the patient in their own home, assess the situation and advise or recommend accordingly.

“I personally think there would be a big role for an outreach service where for example, a physio and an OT could go out and assess somebody in their own home and look at their transfer technique or their equipment. Now there are community services out there, there are community physios and community OTs and there’s domiciliary OTs and there are rehab teams out there, but coming from a spinal injury background, we might be better placed to look at the technique and more specialised transfers”

Participant MDT02 also agreed with participant MDT03’s sentiments and recommended a routine review of functional mobility. Similarly, this would assist in early detection of injuries however, again this service is funding dependent.

“if there were routine reviews like say like an outreach therapist or somebody had a review of their transfer techniques and their home environment and the chair that they’re sitting in, if it were reviewed on a regular basis you might have a role in preventing some of that wear and tear, it’s just the resources and the services aren’t there”

Aside from recommendations for an outpatient service, wheelchair skills training was also recognised as a key factor in promoting correct propulsion and transfer techniques. Wheelchair skills training is provided to patients as a once off in the initial rehabilitation period. It is further reinforced by therapists and nursing staff alike on the wards but it is understandable for patients to forget technical skill involved in this over the course of their lifetime. It was therefore recommended a therapist could potentially deliver updated wheelchair skills training for patients on a yearly basis or similar.

“and the area of the wheelchair skills as well, we make time to do that because we see the benefit of it but I think if we had somebody in outpatients I think we could do more group work or a little bit more wheelchair skills or”

Life skills as a whole was highlighted by therapists as a very real issue for patients on leaving the RSCI. Participant MDT01 outlined below a skill that could often be easily overlooked; the ability to move and carry something at the same time. This skill applies to many aspects of life; lifting a baby, making a meal, carrying a drink, the possibilities are endless yet such a

simple skill can have a major impact on ADLs if it cannot be executed effectively. Similarly returning to work is a substantial transition period, yet with shorter hospital stays, many patients are not at the level just yet prior to discharge from the RSCI.

“we get requests for other things like parenting skills like how do I lift a baby, how do I change a nappy, how do I move and know that I’m not going to drop them...at the employment clinics we used to do a little bit more with disabled employment advisors about returning to work through patients are so fast at the minute that they’re all gone home really quickly they’re not really ready for work when they’re leaving us”

4.3.4 Summary of findings

In summary, the findings of this study align with the perspectives obtained from SCI patients in Chapter 3. Participants felt SCI patients during initial rehabilitation had more predominant goals during their rehabilitation, primarily mobility. An SCI is a life changing injury and as such patient’s primary goal is to return to their previous baseline ability. For most, this generally manifests as the ability to walk again. Rehabilitation can be quite intense as participants are coming to terms with their injury. At the same time, patients are also receiving an abundance of new information and therefore may experience an overload of information all at once. Long term goals may be as short as six months, with very few patients thinking of how they will manage in six years’ time.

Wheelchair skills training comprises a large element of rehabilitation however it is unclear whether patients adhere to advice given in relation to joint protection and energy conservation; in short, patients will move from A to B in the easiest way possible. Additionally, as there are no specialised outpatient SCI services, healthcare professionals are acutely aware that this period of rehabilitation may be the only time they receive such specialised care and therefore attempt to include as many rehabilitation goals as possible. Shorter length of hospital stays also plays a role as many patients are discharged prior to being medically fit to undergo vocational rehabilitation programmes or return to driving.

4.4 Discussion

The results of this study highlighted the current gap in services in relation to the treatment of upper limb injuries. Seven healthcare professionals completed the questionnaire and three OTs were interviewed. During interviews, all participants echoed the same sentiments of wanting to do more with their patients. This is a relatively niche area of research in that no OTs in the United Kingdom (UK) have participated in a study focusing on their perceptions of upper limb pain in SCI to the researcher's knowledge, and thus there is little evidence for comparison. Participants' felt they were in the prime position to identify and prevent the onset of upper limb pain, however within the current remit of the service, felt this was not feasible. Factors that influenced their perspectives included; shorter length of hospital stays, lack of access to upper limb surgical clinics, lack of OT outpatient services and a lack of specialised community services equipped with specialist knowledge. It should be acknowledged that an outpatient physiotherapy service does exist within the RSCI, however staff members declined interview and we therefore cannot report regarding their input.

Participants highlighted the importance of goal setting throughout the rehabilitation period as key to delivering client centred care and ensuring both patient and therapist shared the same ambitions. Goal setting at the initial post injury phase was that of small steps in regaining independence, with participant's reporting that the potential manifestation of upper limb injuries was not a priority to patients at that early stage. Goalsetting in itself, has the potential to provide psychological wellbeing to both the patient and healthcare professional in the rehabilitative process and thus is a key element of rehabilitation in measuring progress (Robinson et al. 2008). It is of no surprise that participants reported patient's initial short-term goal was to return to previous baseline mobility levels. This desire is shared by patients all over the world and has resulted in a recent push towards exploring new pharmacological and rehabilitation interventions aimed at enhancing mobility of SCI patients, specifically the function of walking (Dobkin et al. 2006). To date, there is no cure for paralysis and understandably therapists are not in a position to advise on whether a patient may regain function or not. They can however, ensure their patients reach their maximum level of independence, whether that be via the use of crutches or assistive technology such as wheelchair prescription.

A change in practice in the last decade has significantly moved away from the “pressure relieving lift” many SCI patients were previously recommended to complete at initial rehabilitation. This practice has since shifted towards “leaning” to reduce the strain on the upper limb (Coggrave & Rose 2003). Alternative measure of pressure relief is now more efficient and sustainable – the forward lean, side to side and backward tilt are recommended for pressure relief and require little effort by the patient. It could be argued that patients who are long-term wheelchair users who have not been reviewed by their medical team may be unaware of this change in practice. It is believed that this change would significantly reduce the prevalence of upper limb injuries, however there is no research to date to support this.

Participants reported a patient’s goals may change throughout their stay as an inpatient. Although participants were primarily involved at the rehabilitation phase of injury, they were acutely aware of the physical, psychological and social challenges faced by patients in the long-term. Each individual adapts to life with their injury differently and will experience many milestones throughout the course of their life post injury. All participants noted that “life skills” was neglected and there is a similar dearth in the literature. Life skills range from returning to work, adopting techniques to complete personal care, or as mentioned by one participant – *“how do I lift a baby...and know that I’m not going to drop them”*. These skills most people might take for granted, but they are key to independence for SCI patients, and highlight the need to incorporate all aspects of a patient’s life to deliver client-centred care.

Chapter 3 highlighted an area of wellbeing not documented in Chapter 2 regarding the impact of pain on sleep. Participants in Chapter 3 outlined how pain adversely effected their ability to fall asleep and also woke them at times. Psychosocial distress is highly associated with chronic pain in the upper limb among individuals with SCI; the relationship between perceived pain, depression, anxiety and social isolation are well documented in the literature (Rintala et al. 1998, Ballinger et al. 2000). Patients undergoing inpatient rehabilitation have the benefit of a multidisciplinary team equipped with knowledge as to how sleep could be enhanced or potentially pharmacological medication that could be prescribed. Unfortunately in the case of long term wheelchair users, it is not always feasible or practical to use pharmacological agents that may not be indicated for long-term sleep

treatment (Rintala et al. 1998), therefore it is crucial pain or injury is identified early to avoid long-term consequences.

The primary barrier identified in treating upper limb injuries was the lack of specialised spinal Occupational Therapy outpatient service. Currently, the RSCI houses a physiotherapy outpatient service which patients can self-refer to, however as this is a regional centre, not all patients are in the vicinity to attend for weekly physiotherapy treatment here. The alternative is for patients to seek treatment from their local healthcare provider, however as discussed in Chapter 3, patients reported dissatisfaction with their primary care provider due to their perceived lack of knowledge regarding spinal cord injury. Similarly, a recent study by Lofters et al. (2018), concluded that primary care physicians in the United States found that of the GPs surveyed, only 27.3% felt comfortable in assessing and treating SCI secondary conditions. It is therefore not surprising that patients in the UK have reported similar experiences where they felt their GP was unable to provide them with specialised care, as outlined in Chapter 3.

Participants' sentiments relating to the lack of outpatient service is not specific to Occupational Therapy services, nor to Northern Ireland specifically (Maddison et al. 2004). The constraints of the service are a notable factor but one has to wonder what the cost of hospitalisation for patients admitted for surgical repair of injuries, when the need for surgery could have been reduced, had the pain been identified at an earlier stage. That is not to say upper limb injuries are entirely preventable, but participants felt they were certainly more manageable by both patient and therapist when only a minimal level of pain exists, which is similarly observed in the literature (Hazard et al. 1996, Farrar et al. 2001, Breivik et al. 2008).

This issue has been recently identified in New South Wales (NSW), Australia, where the majority of SCI patients were based rurally and felt the community services available to them in their locality lacked the specialist knowledge of healthcare professionals in the RSCI. The RSCI identified this need and implemented a model of practice to meet the needs of rural patients with an SCI. This model encompassed the views of both therapists and patients in identifying what needs were not being met. Similar to the current study, patients

identified a lack of specialised care available in the community. They agreed that the care they received from the RSCI was satisfactory but had difficulty in accessing services specific to their needs in their locality. As a result, an outreach service was set up to improve equity of access for all patients and to educate therapists working in the community to identify and treat early symptoms of secondary complications as a result of SCI (Middleton et al. 2008).

A similar model could potentially be effective within Northern Ireland in educating community therapists in the identification and treatment of upper limb injuries. As identified in Chapter 3, several patients had not been reviewed by their consultant in several years; it is difficult to state the reasoning behind this whether the waiting list was long, a technical error occurred in calling patients for review, or if the RSCI policy did not include yearly review of SCI patients. Nonetheless, an outreach service could potentially lessen the burden on clinicians, medical practitioners and patients themselves, by educating community therapists with the same skills and specialist knowledge, to deliver interventions in the patient's own home. If the outreach therapist felt an issue was beyond their remit, they could then refer the patient back to the medical consultant who could then advise the patient to formally attend the RSCI or recommend a community-based intervention where applicable.

In discussing prevention strategies for upper limb pain, all participants felt that although upper limb injuries may not be entirely preventable, the onset of injuries could certainly be delayed if poor wheelchair practice was identified at an early enough point. Education was deemed to be the key aspect in this case and it is difficult to report if education patients receive at initial rehabilitation is satisfactory for life-long manual wheelchair users. It was agreed that patients' needs and abilities will change over time, particularly as they age and undergo degenerative changes. A change in ability may result in increased difficulties in completing activities of daily living, personal care, social or vocational activities, all limiting a person's independence and can potentially be socially isolating. Literature shows that educated patients are more informed about their condition and can therefore make informed decisions regarding their pain (Vermeiere et al. 2001). Educated patients are also more likely to identify the early symptoms of onset of injury and seek treatment than uneducated patients (Hibbard & Greene 2013).

Perhaps a yearly review of wheeled mobility may prove beneficial in reviewing both skill level of the wheelchair user and the wheelchair they use. This would ensure that their wheelchairs are consistently configured to their needs as their ability levels change. Additionally, reviews may provide further opportunities such as a refresher course in correct wheeling technique to reduce the adopting of abnormal wheelchair movements. This may result in earlier identification of upper limb injuries which in turn could reduce the risk of developing chronic pain.

To date, although there is little evidence relating specifically to SCI, the wider literature suggests that pain or chronic pain, when untreated can impact the peripheral and central nervous systems resulting in increased pain perception for patients (Coderre et al. 1993, Arnstein 1999, Tinazzi et al. 2000). It is therefore in the patient's and therapist's best interests to identify pain at the earliest point, to prevent it from impacting on functional and psychosocial elements of daily living. In the instance where a patient may develop chronic pain, as reported by the therapists, it is very difficult for patients to "rest" specifically, as would be recommended for able-bodied persons with an injury or pain. Rehabilitation and strengthening exercises are predominantly prescribed for the treatment of upper limb injuries (Chapter 3), however there is little evidence to support the surgical treatment of upper limb pain or injury.

The guidelines for the preservation of upper limb function in SCI (Paralyzed Veterans of America Consortium for Spinal Cord Medicine 2005) state conservative management of the injury should be sought initially, and if the pain or injury persists for longer than three months, surgical intervention should be considered. In looking at the wider literature in relation to able-bodied participants, the evidence is inconclusive as to which treatment method provides the best long-term outcomes to patients.

In relation to rotator cuff tears, Goldstein et al. (1997) reported limited to no decrease in pain post-surgery in the able-bodied population, with Robinson et al. (1993) contrastingly reporting more positive effects. Galatz et al. (2004), reported that within 24 months of performing rotator cuff surgery, 12 of the 13 participants had suffered recurrent tears. A recent systematic review by Chalmers et al. (2018) compared the intermediate and long-

term outcomes of patients who underwent conservative treatment versus patients who underwent surgical repair for rotator cuff injury. Surgical repair was associated with smaller tear size at follow up, and reduced need for further surgical intervention, however, patients who underwent conservative treatment compared to surgical intervention, were at no greater a risk of developing recurrent defects of the rotator cuff. It is therefore very difficult to definitively state whether surgical intervention can offer a better long-term alternative compared to conservative treatment. On this evidence, one could not recommend surgical intervention alone and it could be argued that ultimately better wheelchair practice may be more beneficial to patients in achieving their desired functional goals, also requiring less recovery time post-surgery and overall, being less invasive.

The findings from patients with a SCI in Chapter 3 and this study have identified the gap in resources available to SCI patients. Both views are aligned in that both parties felt more could be done, however this does not come without a cost. Identifying this need and addressing the issues would be costly to both the tax payer and the service, however investing in good follow-up care could potentially reduce costs to the NHS in the long term. Upper limb pain, although a debilitating injury, is not the only secondary complication in the SCI population. The cost of hospital admissions for secondary complications in SCI within the UK is unknown, however in the United States, the average annual cost per SCI patient to the health service ranges from \$27,568 in paraplegics to \$132,807 in high level tetraplegics (French et al. 2007). These figures are taken from the Veterans Health Administration statistics and are costed from one-year post injury therefore does not include the initial medical costs at injury.

From Chapter 3, patients in the community who reported a lack of specialised knowledge declined to seek treatment as they felt their needs would not be met; it is possible that they may also not seek treatment for more complex issues as outlined above, therefore resulting in further hospitalisation at a greater cost to the NHS. With increasing life expectancy in this population, it would not be unreasonable to argue that the UK and countries across the world will see more frequent hospital admissions in relation to SCI secondary complications, particularly upper limb pain as these injuries are associated with increasing length of time as

a wheelchair user. These would all result in an increased cost to the NHS, however, the investment in further services may potentially prevent the long-term cost of disability.

4.5 Study limitations

The sample size included in this study, albeit small, was a reflection on the relatively small pool of OTs specialised in RSCI. The study primarily implemented qualitative methodology and may not be generalisable to the wider population, however that was not the aim of this study. Qualitative research by nature is subjective and is designed to gain a greater understanding of a phenomenon; “to live through the experience of the participant” (Greenhalgh and Hurwitz 1999), as was achieved in this study. Interviewer presence may have influenced participant responses; however, participants were encouraged to answer questions openly and honestly, and informed of confidentiality procedures prior to consenting to participate.

4.6 Conclusion

This study is the first to the researcher’s knowledge exploring the perceptions of healthcare professionals involved in the care of the SCI patient, in relation to upper limb pain and injury. It has provided an insight into both the early phase of initial rehabilitation, and the adjustment process patients undergo throughout their stay. The findings of this study suggest that patients are not emotionally in a position to think long-term about the potential consequences of manual wheelchair use and upper limb injuries, and thus are not focused on preventative measures therapists initially educate them about during rehabilitation.

Participants highlighted the need to follow up with patients post rehabilitation to ensure they receive the specialised care they require. The lack of specialised spinal OT outpatient service was a common thread throughout the interviews in discussing the barriers to treatment of these injuries, however such a service would come at a cost to an already under pressure NHS. In addition, the findings of this study would need to be considered and further explored by service developers, managers and commissioners, to ensure adequate and cost-effective provision of care is implemented. The study has identified both positive and negative themes in relation to the care delivered to SCI patients; future research both

quantitative and qualitative could assist in complimenting the current service provision to SCI patients.

CHAPTER 5:

A SYSTEMATIC REVIEW OF
OBSERVATIONAL MANUAL
WHEELCHAIR SKILLS TESTS
AVAILABLE IN THE LITERATURE

Abstract

Introduction: The concept of wheelchair skills training was highlighted in both Chapters 2 and 4 as being key to both SCI patient's recovery and their ability to be independent. Following this a systematic review following PRISMA guidelines of wheelchair skills test was undertaken to identify the most reliable and valid tool to measure wheelchair skill ability in manual wheelchair users (Chapter 5).

Objective: To assimilate, review, evaluate and critically appraise literature pertaining to manual wheelchair skills tests

Study design: A comprehensive review following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al. 2009).

Methods: A systematic literature search was undertaken between February – March 2017 on manual wheelchair skills tests available in the literature. The search aimed to include actual performance-based manual wheelchair skills tests conducted with both children and adults. The databases used for selection of peer reviewed articles were PubMed (1971 – March 2017), Medline (1966 – March 2017) and OVID (1966 – March 2017). Only studies reported in English were selected. The terms “self-propel*” or “manual*” and “wheelchair” were searched concurrently with terms “skill*”, “test*”, “assess*”, “measure*”, “train*” and “mobility”. Data extraction tables were compiled and included participant demographic information, recruitment methods utilised, study design, quality, intervention groups and all assessment measures taken. Components of each of the skills assessments were also included; the skills included in the tests, details of the population for whom the test was designed, population to whom the test was administered, outcome measures and psychometric properties. The Critical Appraisal Skills Programme (CASP) tool specifically for cohort studies was used to assess the quality of the cohort studies included in this review and the Joanna Briggs Institute (JBI) checklist was used to critically appraise the cross-sectional study. Andresen's grading criteria was used to assess validity and reliability of skills tests included.

Results: Twelve studies fulfilled the inclusion/exclusion criteria. Ten different wheelchair skills test were identified. A comprehensive overview of wheelchair skills was included across all studies however, each test used its own scoring measures. The most comprehensive skills tests included a battery of skills focused on propulsion, ramps, sprints and transfers while also incorporating practical tasks such as picking an item off the ground, crossing a road and propelling a wheelchair while carrying an item in one hand. The review also highlighted that new manual wheelchair users were more likely to adhere to advice regarding correct wheelchair techniques compared to those who were injured longer and had adopted their own wheelchair techniques. The majority of tests had been tested with a variety of conditions and diagnoses and were therefore suitable for use with a wide population of manual wheelchair users.

Conclusion: This review highlights varying conditions and diagnoses greatly impact on the skill acquisition in the manual wheelchair population and thought must be given to the configuration of the participant's wheelchair. The Wheelchair Skills Test (Kirby et al. 2004) is the most valid and reliable tool to measure wheelchair skill acquisition however with the ever-changing development of new tools, there is still no agreed test to measure wheelchair skill performance.

5.0 Introduction

Wheelchairs are mobility support devices that can be prescribed by occupational therapists (OTs), for use in the instance where functional mobility or ambulation is impaired (Shields 2004). The use of manual wheelchairs is most prevalent in those with a congenital disease, traumatic injury to the spinal cord or those ageing, who require the use of assistive technology for mobility purposes (LaPlante 2003). Wheelchairs are a relatively fast and effective solution to mobility needs, however often specific skills training is not administered due to lack of time, resources or uncertainty of how to implement these skills in therapeutic practice (Best et al. 2015).

Environmental obstacles are the primary barrier to manual wheelchairs users for mobilising independently (Rosenburg et al. 2012). Current legislation is aimed at reducing discrimination against those with a physical disability; one example of this is The Disability Discrimination Act (DDA), 1995. This law made it illegal for an employer to discriminate against job seekers with a disability and to make reasonable adjustment to the built environment to reduce mobility barriers. The Act not only resulted in wheelchair accessible workplaces, but included shops, bars, restaurants and all public places resulting in greater access to social and leisure activities to wheelchair users.

Although significant changes have taken place in Northern Ireland, particularly through the DDA (1995), comparisons with other countries also suggest that much still needs to be achieved. In the USA 'The Americans with Disabilities Act' (1990), is much more comprehensive than the DDA (1995). Even so, the problems of ease of access have not been resolved. For example, a survey of shopping environments in the US in 2000 noted that: *'shoppers who are wheelchair mobile cannot count on compliance and cannot predict which physical architectural barriers they will find in shopping centres'* (McClain 2000, p. 178). In the instance that an area is not wheelchair accessible, wheelchair users may have to rely on a carer or family member to assist negotiating an environment. For independent wheelchair users, requiring assistance from someone is not always feasible and acts as a barrier to being truthfully, functionally independent. Even with legislative change, the ability to propel a wheelchair alone is no longer enough; wheelchair users need to be equipped with the

correct technique for freedom to move about as they wish. These skills can be the difference between independent and dependent lifestyles.

Current practice in wheelchair skills testing is in a relatively new era of developing a standardised method of assessing skills. It is important that skills tests encompass all areas of the person, environment and occupation to truly improve independence and occupational performance (Routhier et al. 2003). Observational skills testing provides therapists with the opportunity to monitor patient's skill levels which may fluctuate throughout their lifetime due to a number of factors (de Groot et al. 2010). It also provides the opportunity to use a standardised method of measuring skill level rather than subjective testing based on the patient's own opinion. In the case of degenerative diseases, skills testing may provide a standardised method of measuring the potential rate of decline of the patient's condition or diagnosis and provide quantitative measures which may prove useful in deciding if powered mobility may be required in the future due to disease progression (Damiano et al. 2002).

Skill acquisition will undoubtedly vary from person to person, however there is a consensus among wheelchair users of some basic skills required for everyday living such as propelling and transferring in and out of the wheelchair. Some of the more advanced skills such as getting up from the floor into the wheelchair may not be applicable for all manual wheelchair users, depending on their current lifestyles, type of injury or condition, and their personal preference. Some skills may not be required for certain people if they happen to live in wheelchair accessible environments. Additionally, some active wheelchair users may participate in sporting activities and learn new skills through their active engagement in sport. In an imperfect world, some skills need to be learned to promote functional independence.

5.1 Wheelchair skills training

Wheelchair skills training consists of teaching wheelchair users the relevant skills in order to use their wheelchair to mobilise independently. Wheelchair skills training may be delivered in an inpatient or a community setting and is one of the key elements of the rehabilitation treatment plan following an injury when the patient requires a wheelchair. Wheelchair skills

training may be delivered as a once-off session or multiple training sessions over a period of time, however it is not clear which method is more effective (Tu et al. 2017). Propelling a wheelchair and transferring are the basic skills required to be functionally independent for wheelchair users. Additional skills such as negotiating obstacles and back-wheel balance may be perceived as more advanced skills due to the nature of the skill – requiring increased strength, proprioception and balance. Should the individual wish to pursue community and social activities then they will require to negotiate public places, skills such as crossing a road or propelling the chair with a load attached on the back for example while shopping, will need to be learned. Manual wheelchair skill performance is also positively associated with community participation which supports users to actively engage in all aspects of life (Kilkens et al. 2005); as a wheelchair user gains more confidence in using their wheelchair in testing environments, it is important to equip them with the necessary skills to ensure they can fulfil this.

(ii) Testing of wheelchair skills

Assessment of wheelchair skills can be useful for both the client and therapist to gain a greater understanding of the limitations faced by wheelchair users, and advancement of skills for particular purposes dependent on the patient's own personal goals. In delivering any service or treatment, it is important to continually measure and assess whether the treatment is effective. It is therefore important to assess whether delivering wheelchair training is beneficial to the patient and include it as a rehabilitation goal within the treatment plan (Sawatzky et al. 2015). Occupational therapists primarily, as well as members of the multi-disciplinary team, use wheelchair skills tests to establish baseline functional mobility levels to inform treatment plans and goal setting. The World Health Organization has recognised wheelchair-skills assessment and training as important elements of the wheelchair-provision process (Khasnabis & Mines 2012). Wheelchair skills tests generally consist of assessing patients on the basic skills of using a wheelchair such as would be required on a daily basis. The number of wheelchair skills training programmes in Northern Ireland are not currently documented. It is currently not documented in the literature the amount of wheelchair skills training delivered in Northern Ireland, the individual skills taught, or how they are delivered.

(iii) Wheelchair skills tests

Previously, Kilkens et al. 2002, and Fliess-Douer et al. 2010, conducted systematic reviews on internationally available manual wheelchair skills tests. Kilkens et al. (2002) were the first to systematically appraise wheelchair skills tests and consisted of an in-depth description of each test and comparison of skills included. Fliess-Douer et al. (2010) updated this review specifically focusing on skills tests available for use with patients specifically with a spinal cord injury (SCI). Both reviews concluded that there were large inconsistencies among the wheelchair skills tests available therefore making it difficult to determine the best available wheelchair skills test. This current review will aim to describe and evaluate skills tests relating to all manual wheelchair users and establish if recent research literature has established any further wheelchair skills tests, if these tests are valid and reliable and if they are applicable for all manual wheelchair users.

5.2 Methods

5.2.1 Search and study selection

A systematic literature search was undertaken between February – March 2017 on manual wheelchair skills tests available in the literature. The search aimed to include actual performance-based manual wheelchair skills tests conducted with both children and adults. The databases used for selection of peer reviewed articles were PubMed (1971 – March 2017), Medline (1966 – March 2017) and OVID (1966 – March 2017). Only studies reported in English were selected. The terms “self-propel*” or “manual*” and “wheelchair” were searched concurrently with terms “skill*”, “test*”, “assess*”, “measure*”, “train*” and “mobility”. Furthermore, a hand search of the reference lists of all identified relevant papers was carried out.

5.2.2 Selection criteria

The following criteria were applied to retrieved journal articles:

Inclusion criteria:

- the test was an observational skills test conducted in a real-life environment
- the population was manual wheelchair users only and was intended to assess wheelchair skills performance
- statistical data was available regarding reliability and validity

- tests must satisfy the first two questions on the Critical Appraisal Skills Programme (CASP) tool for cohort studies

Exclusion criteria:

- the test was specifically designed for powered wheelchair users
- tests were performed in virtual environments
- the primary assessment was qualitative in design where subjective responses may provide biased results
- tests and outcome measures included physical performance measures
- the test was used to assess the effectiveness of an intervention e.g. wheelchair skills training

5.2.3 Data collection process

Data extraction tables were compiled and included participant demographic information, recruitment methods utilised, study design, quality, intervention groups and all assessment measures taken. Components of each of the skills assessments were also included; the skills included in the tests, details of the population for whom the test was designed, population to whom the test was administered, outcome measures and psychometric properties (Appendix 11).

5.2.4 Psychometric properties

A range of reliability and validity evidence was accepted for inclusion in this review. Studies including analyses of the reproducibility of scale measurements - test-retest reliability (administering an outcome measure twice and comparing pre and post scores), or inter-rater reliability (multiple raters administering the test) were included. Test re-test reliability is used to assess the internal validity of a test and ensures that the measurements obtained in one sitting are both representative and stable over time (Hendrickson et al. 1993). Measurement of structure or properties within the tests, the extent to which test items measure the same construct (internal consistency reliability) was also included.

5.2.5 Reliability and Validity

Reliability and validity was assessed using Andresen's grading criteria for outcome measures used for research in people with disabilities (Andresen 2000). The tool is designed to outline favourable characteristics of outcome measures used with people with physical disabilities and covers areas such as instrument bias, respondent burden, reliability, validity, responsiveness, accessibility and cultural or language adaptations. For the purpose of this review, the validity and reliability sections were used to compare the psychometric properties of skills tests included. The tool allocates a grade of A, B or C in relation to the evidence provided by studies. Grades of "A", "B" and "C" were allocated to tests regarding the reliability coefficients reported; A ≥ 0.75 , B > 0.40 but < 0.75 and C ≤ 0.40 . Where correlation data was available, Andresen's grading criteria was applied following the guidelines above for validity. A grade of "A" was applied for constructs of 0.6 or higher, "B" where between 0.3 and 0.6 was reported and "C" where less than 0.3 was reported.

5.2.6 Quality appraisal of tests

The Critical Appraisal Skills Programme (CASP 2017) tool specifically for cohort studies was used to assess the quality of the cohort studies included in this review. CASP has been used to evaluate the quality and utility of published research literature worldwide and provides analytical evaluations of the quality of the study, in particular the methods applied to minimise bias in a research project (Singh 2013). Questions are then scored on a scale of 0-10. The CASP manual states that the initial two questions asked are excluded from the scoring scheme as these are screening criteria of which all studies should meet in order to be included in the review. If the study does not satisfy these criteria, then they are deemed unsuitable to be included. The remainder of the questions were scored using a Yes/No scale and if the information was not available or could not be located "can't tell" was abbreviated to CT. If a study was awarded a Yes to a question – 1 mark was awarded, if it was awarded No or if the information could not be located, zero marks were allocated. Articles are then given a score out of ten marks.

5.3 Results

There are some notable skills tests that have been excluded from this review that were previously included in systematic reviews conducted by Kilkens et al. (2002) and Fliess-Douer et al. (2010). The inclusion criteria above were applied stringently as the purpose of this review was to inform a follow-on study as part of this PhD research study. Therefore, although wider skills tests were available, this review only included tests that included samples of manual wheelchair users only and where the observational skills test was the primary outcome measure. Studies which may be deemed as having taken place in a laboratory setting measuring heart rate, peak flow or other body function were excluded, alongside studies where powered wheelchair users were included in the sample, as they were not deemed to be directly related to the aims of this study.

The systematic search returned 905 papers in total (Figure 5.1: PRISMA Flow Diagram). Each title was screened by a single reviewer for relevance and added to the shortlist if appropriate, or if further clarification was required, the abstract or entire paper was reviewed. On removal of duplicates (393), 9 papers in total were approved. An additional 3 papers were found via hand search and review of relevant reference lists in the subject area totalling 12 papers. Eleven studies used cohort study designs including repeated measures design and test-retest design, while Fliess-Douer et al. (2012), used a cross-sectional study design.

5.3.1 Study Design

All studies took place at either a rehabilitation hospital, university rehabilitation setting or recruited participants via Veteran Affairs services. Only two studies conducted test-retest assessments on the same day allowing a short rest between tests (Askari et al. 2013 and Harvey et al. 1999). McClure et al. (2011) required participants to complete up to four transfers per test as energy levels allowed and retesting was conducted between 4-72 hours after. Time between tests varied widely from one day to 6 months in the case of Middleton et al. (2003). In this study, participants were recruited from acute inpatient initial SCI rehabilitation and were tested within 72 hours of first mobilising in a wheelchair. Locomotor and mobility outcomes were measured at 1 month, 2 month, 3 month and 6 months from initial testing. Similarly, Kirby et al. (2004) recruited both inpatient and outpatients who

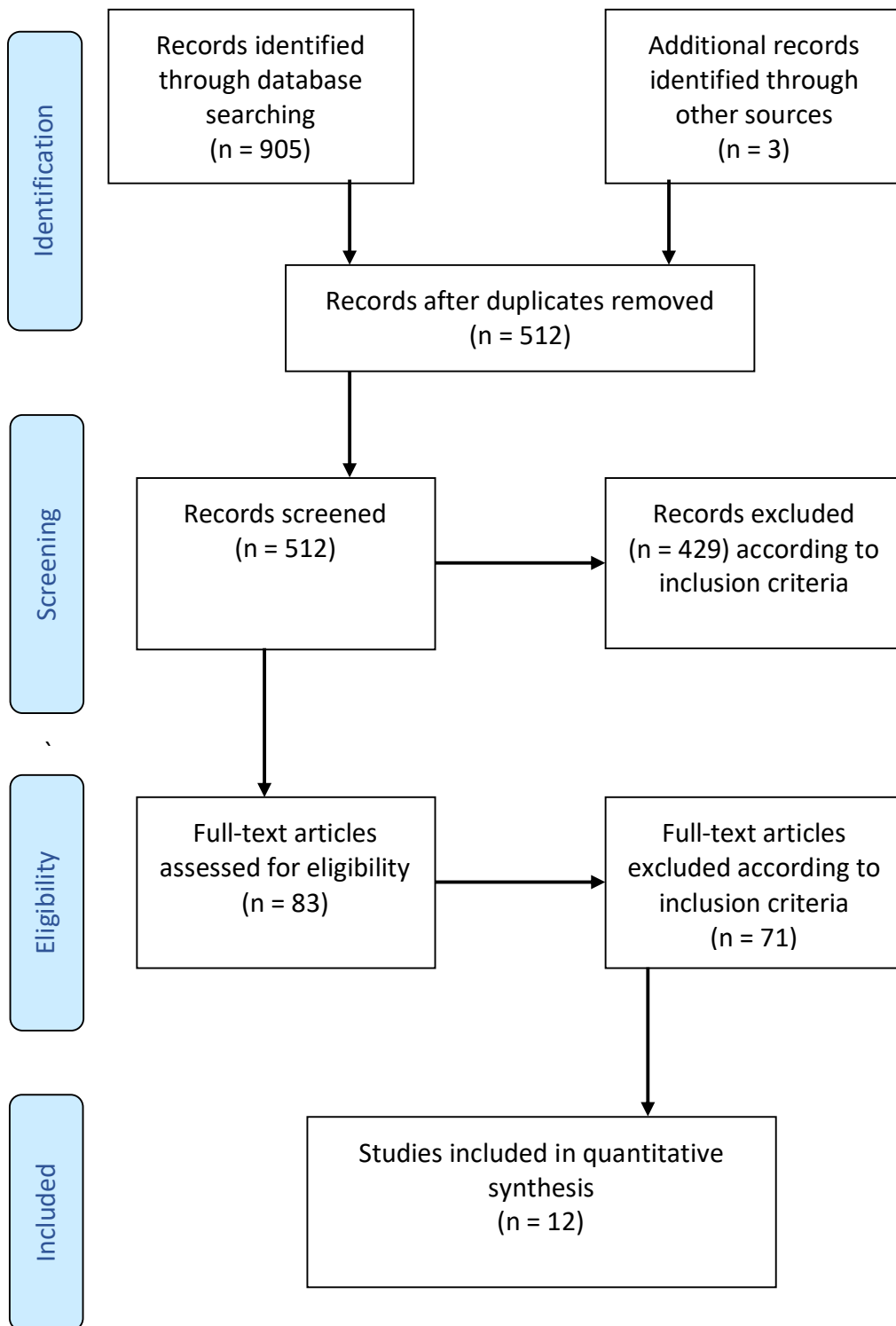
attended rehabilitation for treatment of their SCI at a rehabilitation centre. Repeated measures was used to assess participants one day apart. In Kirby et al. (2002), participants were assessed 10 days apart. Three studies allocated one week between testing (Fliess-Douer et al. 2012 & 2013 and Gagnon et al. 2011). Lindquist et al. (2010) allocated between one to two weeks between testing with Cowan et al. (2011) stating testing was conducted on non-consecutive days with a maximum length of 15 days between tests. The longest time between tests was Vereecken et al. (2012) who stated a maximum length of 3 weeks between tests.

5.3.2 Study Characteristics

Of the twelve studies reviewed, twelve different wheelchair skills tests were identified. The study characteristics are included in Appendix 11 and include (in no particular order); The Manual Wheelchair Slalom Test (MWST), The Wheelchair Assessment Instrument for People with Multiple Sclerosis (WAIMS), The Wheelchair Circuit, Test of Wheeled Mobility (TOWM), The Short Wheelie Test, The Wheelchair Skills Test (WST) Version 1.0, 2.4 and 4.1, The Transfer Assessment Instrument (TAI), a 6 Task Assessment tool, The 5 Additional and Locomotor (5-AML) test and The Wheelchair Propulsion Test (WPT). All but one study (Harvey et al. 1998) stated their purpose was to assess the validity, reliability or measurement properties of a skills test specifically designed for manual wheelchair users.

The primary objective in the study by Harvey et al. (1998) was to quantify the mobility of patients with paraplegia. Sampling for all tests used a non-probability based sampling technique in the form of convenience sampling. All tests took place in either a gymnasium, rehabilitation centre, laboratory or research area where the authors readily had access to the necessary equipment and space required for completing the skills. Spinal Cord Injury (SCI) was the most commonly observed physical disability from demographic data, followed by amputees and stroke (4), multiple sclerosis and musculoskeletal disorders (2), traumatic brain injury (TBI) and Guillian-barre syndrome (1). Kirby et al. (2004) also included able bodied volunteers.

Figure 5.1: PRISMA Flow Diagram



5.3.3 Content of tests

A wide variety of skills were included across tests and are detailed in Appendix 11. The number and type of tasks participants were requested to complete varied across all studies. Askari et al. (2013), Gagnon et al. (2011) and McClure et al. (2011) only had one task to complete. Middleton et al. (2002), Harvey et al. (1998) and Vereecken et al. (2012) consisted of 5, 6 and 8 tasks respectively. Cowan et al. (2011) Manual Wheelchair Circuit consisted of 14 tasks. Fliess-Douer et al. (2012 & 2013) combined the TOWM and the Wheelie Test resulting in 38 tasks. Both Kirby et al. (2002 & 2004) and Lindquist et al. (2010) used the WST, albeit adapted for their specific studies, and included 42 and 30 tasks respectively. Incorporating a large range of skills is beneficial in that all aspects of functional skills are covered, however the feasibility of administering this in a clinical setting may not be deemed appropriate and is further discussed below.

Propulsion was the most commonly included skill in twelve tests. Following this slopes and transfers (n=11), kerbs and obstacles (n=10), wheelie (n=7), crossing a threshold (n=5), sprints (n=3), wheeling over uneven surfaces (n= 4), opening and closing doors (n=3) and moving from supine to sitting (n=2) were implemented. The only additional skills were those implemented across the different versions of the WST. The WST version 1.0 and 2.4 included reaching for high objects, wheelchair breakdown tasks such as applying the brakes and removing the footrests, picking an item off the floor and reaching into a bag on the rear of the wheelchair (Kirby et al. 2002 & 2004).

Skills have been grouped broadly into four key areas; propulsion, transfers, castor flicking and slopes. Within each of these areas, a breakdown of the classification of the type of skill has been further elaborated upon. Achieving some of the basic wheelchair skills can lead to the successful completion of more advanced skills. For example, a participant attempting to flick their castors onto a high kerb should first attempt flicking their castors over a low door threshold. In this way, a graded approach can be used in order to facilitate learning of more advanced skills resulting in greater wheelchair mobility independence. There is a risk of participants attempting a skill too early where they have not acquired the basic techniques resulting in unsafe practice and poor technique. All studies incorporated safety techniques such as the use of spotters. A spotter is someone who stands behind the participant when a

skill is being undertaken to provide a level of safety, where if the participant was to tilt too far back in their chair, the spotter is in position to return them to an upright position. Only one test provided detail on the training administered to spotters (the WST). Specific spotter training was administered to those assisting with the testing of participants and provided training on correct posture and manual handling techniques to avoid injury. Kirby et al. (2002 & 2004) also utilised spotter straps where a strap is placed on the back of the wheelchair of participants. Similar to above, if the wheelchair was to tilt back, the spotter is in a position to up-right them, however the use of spotter straps is to ensure the spotter does not injure themselves in up-righting the participant.

Propulsion

Propulsion was assessed by means of propelling over a fixed distance or as distance covered in a specific time frame. The skill of propelling the wheelchair over a fixed distance was assessed in nine studies. Of these, the TOWM was the only study to include allowances for use of lower limbs to propel the wheelchair, taking into account preferences and current practices of participants (Fliess-Douer et al. 2012 & 2013). Additionally, they included a propulsion task where wheelchair users propelled with one hand only. Both Cowan et al. (2011) and Vereecken et al. (2012) tested propulsion over a fixed time period; 3 minutes and 6 minutes respectively. This method required participants to wheel continuously where a greater distance covered resulted in a better overall score.

Sprints were formally assessed in three studies (Cowan et al. 2011, Lindquist et al. 2010, Vereecken et al. 2012) with both Cowan et al. (2011) and Vereecken et al. (2012) implementing a distance of 15 metres. Lindquist et al. (2010) used a slightly shorter distance of 10 metres. Sprint time was expressed as the time taken in metres per second with a lower time resulting in a better overall performance score.

An additional element of propulsion was that of negotiating obstacles (n=10). Negotiating obstacles was deemed separate to that of propulsion alone, where two or more directional turns/manoeuvres were required in undertaking the skill. The slalom was the most common method administered where participants were required to wheel around obstacles within a given time frame. Lindquist et al. (2010) was the only study to utilise moving obstacles

during the test. Additional manoeuvring skills were conducted in the WST by Kirby et al. (2002 & 2004) which included 3-point turns, parallel parking and turning in place.

Additionally, travelling over uneven surfaces may be deemed a skill of propulsion. This skill was included in 4 tests, and consisted of travelling over grass, sand, gravel or other artificial textured surface which adds an extra level of difficulty in propelling a manual wheelchair. As well as this, the most recent version of the WST 4.2 investigated by Lindquist et al. (2010), also included manoeuvring over a 15cm (diameter) pothole.

Transfers

Transfers were the second most common skill included in eleven tests and are a critical skill for everyday living for manual wheelchair users. Transfers were primarily assessed from the wheelchair to a level surface such as a plinth or another chair however vertical transfers were assessed in three studies (Harvey et al. 1998, Lindquist et al. 2010, Middleton et al. 2002). Vertical transfers were composed of participants lifting oneself from the floor into their wheelchair and required significant strength and power of the upper limbs. It is arguable that not all participants would be suitable to undertake this skill as it could be classified as an advanced skill. Authors used a graded approach in ensuring participants only attempted vertical transfers on successful completion of a standard or horizontal transfer and spotters were used for safety.

Kerbs

Propelling up and down kerbs is a key skill primarily used in outdoor wheeling. In order to complete this skill, a lower height to flick the castors upon is an easier skill to achieve for manual wheelchair users initially. Door thresholds were assessed in five studies and consisted of heights of 1.2cm, 2cm (n=3), and 4cm (n=2). Larger kerbs were assessed in 10 studies and ranged from 2.5cm to 5cm. Only two studies assessed the ascent and descent of the same height kerbs (Kirby et al. 2004 and Lindquist et al. 2010), with the remainder assessing the ascent only.

Similar to kerbs, the “wheelie” may be perceived as a more advanced skill. It is based on the same principle as that of kerbs where participants are required to flick and hold their castors

above ground. In this instance the castors are required to be held significantly further off the ground where a comfortable weight distribution and balance is obtained in order for participants to successfully hold the pose. Wheelies were assessed in 7 tests, most commonly to hold a stationary wheelie pose for a period of time only (n=5). Fliess-Douer et al. (2012 & 2013) were the only studies to include a comprehensive range of wheelie related tasks via the Short Wheelie Test. Tasks included a stationary hold, one handed wheelie, moving forward and backward 10 metres while holding wheelie, circle forward, wheelie over uneven surfaces, accelerating and stop in wheelie and wheelie backward over a 5cm kerb.

Slopes

Slopes were utilised in eleven tests with little consistency between measures. In all of the tests, slopes are defined in terms of inclination, ratio and length; ranging from 3%-15%, 1:16 – 1:8, 3.05 metres to 21 metres. Only two studies assessed the ascent and descent in the form of a circuit (Middleton et al. 2002 and Harvey et al. 1998). Middleton et al. (2002) required participants to push up the ramp, around a cone and back down the ramp. One circuit was defined as 30 metres (15 metres x 2) and time taken to complete the task was irrelevant. In the study by Harvey et al. (1998), participants were required to propel up the ramp, turn around a cone at the top and return to the bottom where the sequence was repeated. A time frame of 120 seconds was allocated and participants obtained a higher performance score based on the number of circuits completed within the timeframe. In the three studies investigating the WST, both the ascent and descent of slopes was assessed. Kirby et al. (2002 & 2004) both used inclines of 5°, however for practical reasons Lindquist et al. (2010) used a slope of 7.5° as this was the size of ramp available to the researcher without additional costs of sourcing a lower ramp. Vereecken et al. (2012) also included the ascent and descent of slopes (5% and 10%), with the remainder of studies assessing the ascent only.

Measurement scales

Many different scales of measurement are used within the selected skills tests. The choice for a specific outcome measure depends on the objectives of the study and what the researcher intended to achieve from the study. Tests can be used to determine the feasibility of manual wheelchair propulsion, to measure the level of independence in wheelchair Activities of Daily Living (ADLs), or to evaluate the effects of interventions. Time was the primary measure in assessing propulsion. Askari et al. (2013) recorded the time taken for participants to propel 10 metres and the number of propulsions required. Participant's scores were expressed in metres/second, cycles/second and metres/cycle. Gagnon et al. (2011) recorded the time taken for participants to manoeuvre around a slalom course.

Both Cowan et al. (2011) and Vereecken et al. (2012) calculated the distance covered in a set time via use of a circuit; 3 minutes and 6 minutes respectively. Although this was a test of wheelchair propulsion, it could be argued this was a test of endurance, where the emphasis is on obtaining a greater distance over a fixed time. The remainder of skills tests used ordinal scales to quantitatively measure skills. The objective of these studies was to observe, describe and analyse the level of independent mobility for each participant and hence each study used an ordinal scale as a measure. There was no comparable scale used by any two tests to measure these skills across the studies. An outline of scoring methods is included below in Table 5.1.

Table 5.1: Scoring methods of skills tests

Author & name of test	Scoring methods
Askari et al. 2013 Wheelchair Propulsion Test	Speed (m/s), Push frequency (cycles/s), Effectiveness (m/cycle)
Cowan et al. 2011 Adapted Manual Wheelchair Circuit	Propulsion: Distance covered in 3 minutes Remainder: Max performance time allowance given 0 = unable to perform task in time frame 1 = able to perform task in time frame Performance score = time needed to complete
Fliess-Douer et al. 2012 Test of Wheeled Mobility and Short Wheelie Test	1 = task completed successfully 0.5 = successful at second attempt 0 = failure or didn't attempt
Fliess-Douer et al. 2013 Test of Wheeled Mobility and Short Wheelie Test	1 = task completed successfully 0.5 = successful at second attempt 0 = failure or didn't attempt
Gagnon et al. 2011 Timed Manual Wheelchair Slalom Test	Time taken to complete slalom
Harvey et al. 1998 Own Assessment Tool	Score of 1-6 dependent on distance covered in specified time frame
Kirby et al. 2002 The Wheelchair Skills Test Version 1.0	Score of 0-2 0 = failure to complete task safely 1 = partial completion 2 = successful and safe completion
Kirby et al. 2004 The Wheelchair Skills Test Version 2.4	0 = fail 1 = pass NA = not applicable NG = not a goal
Lindquist et al. 2010 The Wheelchair Skills test version 4.1	Grade of pass/fail and safe/ unsafe given
McClure et al. 2011 Transfer Assessment Instrument	Comprehensive scoring using Likert scale covering arm position, set up phase, conservation, and quality
Middleton et al. 2002 5-AML	Score of 1-7 applied where 1 = total assistance and 7 = complete independence
Vereecken et al. 2012 WAIMS	Propulsion: Distance covered in 6 minutes of completing loop Remainder: Max performance time allowance given 2 = successful 1 = minor error 0 = more than 2 errors

Legend: M = metre; S = second; NA = Not Applicable; NG = Not a goal; Max = maximum

Additional outcome measures were included by Fliess-Douer et al. (2012 & 2013) and Kirby et al. (2002). Unusually, Fliess-Douer et al. (2012 & 2013) included an anxiety scale as a secondary outcome measure to gain a greater understanding of the patient experience. Wider research relating to behaviour has shown that ability and confidence can both be determinants in a person achieving a task (Bandura 1997). Similarly, within wheelchair related research, greater confidence in one's own ability is positively related with frequency of participation, particularly in older adults (Sakakibara et al. 2012). It could be argued that confidence levels could be the difference in participants achieving a skill or not attempting a skill, which Fliess-Douer et al. (year) attempted to investigate. The study found that lower anxiety scores were associated with higher self-efficacy in wheeled mobility perceptions therefore, it is reasonable to argue that confidence plays a role in skill acquisition in manual wheelchair users and low confidence may also be perceived as a barrier to participation.

Feasibility

The time taken to administer each of the tests ranged from several minutes up to 90 minutes. Gagnon et al. (2011) and McClure et al. (2011) reported the lowest time taken to administer the test, less than 60 seconds and 2-3 minutes respectively. Askari et al. (2013) reported the whole assessment session took less than 60 minutes, however does not provide information on the time taken to complete the skills test specifically. Harvey et al. (1998) and Middleton et al. (2002) stated the time taken to administer their respective tests was less than 15 minutes. Fliess-Douer et al. (2012 & 2013), Kirby et al. (2002 & 2004) and Lindquist et al. (2010) all reported times of less than 40 minutes to administer their specific skills tests. Cowan et al. (2011) test took the longest to administer at 90 minutes, however the time recorded refers to the time spent at the testing day by participants, not the skills test specifically.

Many of the skills tests reported on were administered in clinical settings where researchers administered the assessment. For the purpose of replicating this in clinical practice, allied health professionals (AHPs) would be administering the assessment within the National Health Service (NHS) or private practice. Time constraints within any clinical setting are the norm in the current climate, whether it is public or private care, therefore allocating hours to one assessment may not be deemed feasible. The tests need to be succinct, in that all

skills are covered, yet not too lengthy in case the participant becomes fatigued and cannot finish the test in one sitting. Skills must be achievable by the participants; they should be at least able to, at minimum, attempt the skills. As stated above there is also a risk of participants attempting a skill too early which may result in unsafe practice or injury. Due care must be taken in ensuring staff receive correct training and are competent in the manual for the assessment and the tasks involved. Risk assessments must be undertaken to ensure the test area is safe and suitable and to allow for forward planning of to reduce the risk of any adverse incidents.

Cost and equipment are not clearly reported in all of the studies. The studies took place in clinical, research or laboratory environments, with all required equipment readily available. Kirby et al. (2002) noted that the equipment required in their study was what one would expect to find in any medium-sized rehabilitation centre, however many hospital and/or community settings may not have access to this equipment. Equipment included cones for negotiating obstacles and for marking out a set distance to be travelled. Ramps, curbs and doorway saddles were used within the study setting which were already present, however these may not be common pieces of equipment in a standard occupational therapy or physiotherapy department and would come at an additional cost. Where required, uneven surfaces were manufactured at a minimal cost – sand, gravel or grass, or alternatively an outdoor area where these were already present was utilised.

Participants primarily used their own manual wheelchair in all studies except three. Askari et al. (2013) used a standard wheelchair to assess concurrent reliability. In the Adapted Manual Wheelchair Circuit investigated by Cowan et al. (2011), all participants used their own wheelchair except for five participants. These participants used a laboratory wheelchair configured to their needs as an alternative as they were either in the process of obtaining a new chair, were without use of their previous chair or it was too burdensome for participants to transfer their chair to the testing centre. Participants completed both tests in the same wheelchair for standardisation. Kirby et al. (2002) also reported, that three participants completed the second test in a different wheelchair than the first test as they received a new wheelchair between tests.

Target population

Eight tests were used with a wide array of study populations, with just four tests designed for a specific population of manual wheelchair users (Appendix 11). The primary skill included in all tests was propulsion which is a necessary skill for daily mobilising. Askari et al. (2013) was the only study to record the direction of propulsion of participants. The standard method for manual wheelchair propulsion is using the upper limb to propel the wheelchair forward, however for some participants this was not their preferred method of propulsion. Due to the nature of their condition some participants foot propelled their wheelchair backwards, rather than the norm of propelling forwards. None of the remaining studies took into account this method and it is therefore possible that participants who foot propel were scored lower in terms of performance on this test in comparison to Askari et al. (2013) wheelchair propulsion test. Backward propulsion, however would not be applicable to all participants. In the case of amputees or SCI patients, it would not be possible to use the lower limb therefore a difficulty arises in standardising a test for all manual wheelchair users. Other types of tests may also be unsuitable for assessing wheelchair skills in individuals with other impairments. Therefore, further research to validate and to test the reliability of the type of tests used in a variety of levels of disability is advised.

Quality assessment

The CASP tool was utilised to appraise included studies and further detail is outlined in Appendix 12. Tests scored minimally to moderately well on the CASP tool scoring between 3-7 on the scale. The majority of studies recruited their sample by means of convenience sampling; little information was documented regarding power calculations or statistically significant sample sizes in order to observe an effect size. Only four studies reported acceptable recruitment methods; Kirby et al. (2002 & 2004), Middleton et al. (2002) and Vereecken et al. (2012). The highest scoring studies were from Kirby et al. (2002 & 2004) and Vereecken et al. (2012) all of whom scored 7 points on the CASP scale. Following this Askari et al. (2013) scored 6 points. The remaining studies scored lower than 6 due to inconsistencies in addressing bias and lack of information relating to the length of the follow up undertaken.

5.3.4 Psychometric properties

In-depth data regarding psychometric properties can be found in Appendix 13. Most studies used a repeated measures design, except for the Fliess-Douer et al. (2013) study which, was a cross-sectional study design. Their study included retesting at various stages to assess reliability and validity of the assessments. The rest time between each study varied ranging from retesting within a few minutes of completing the initial assessment, to retesting up to 6 months which is too long to determine a true treatment effect. Test re-test reliability analyses can be conducted over a relatively short period of time to ensure the results obtained are not time-related rather than due to poor test stability. Using multiple raters in scoring and administering tests improves rigour and tests for inter-rater reliability, however not all studies stated how many raters were used in assessing reliability within their cohort.

Reliability and validity

Content validity was reported in six tests primarily via the use of expert groups composed of clinicians and experts in the area. Only two studies included the use of service users in the design of the test (Fliess-Douer et al. 2012 and Kirby et al. 2004). Kirby et al. (2002) reported that 91% of therapists endorsed the skills (30/33). Askari et al. (2013) assessed content validity qualitatively by means of a focus group and assessment of the literature. Kirby et al. (2002) established face/content validity in the initial design of the WST version 1.0 which was incorporated into the following versions of the WST; version 2.4 and 4.0. Three studies did not document how face/content validity was established (Cowan et al. 2011, Gagnon et al. 2011, Vereecken et al. 2012).

Validity

Instrument validity is displayed below in Table 5.2. Construct validity was undertaken by Askari et al. (2013) to examine if the derived measures were influenced by wheelchair user demographics and variables such as age, gender, type of wheelchair used and the surface on which propulsion was assessed. Higher speeds in younger participants with rigid frame wheelchairs while propelling on tiles versus carpet were observed, implying that a lighter wheelchair and smoother surface resulted in a greater overall performance score. Similarly, Fliess-Douer et al. (2012) investigated the correlation between perceived self-efficacy of wheelchair mobility scores and test scores. No correlation was found between the above

however, lower anxiety scores were highly correlated with higher test scores, implying that increased confidence levels may result in greater wheeled mobility ability.

Different versions of the WST were investigated in three studies with two reporting on validity. Kirby et al. (2002) investigated if WST scores were able to detect change in a participant's status. Global rating scores were graded by Occupational therapists who were present for the administration of the WST. Results showed a statistically significant difference in global rating scores in those categorised by therapists as improved compared to those in the unchanged category, however this was not clinically significant. This was attributed to the inter-subject variability in the performance of the test some examples include: different wheelchairs used at the second assessment for three participants; 8 participants had either a period of illness; additional health priorities (in addition to wheelchair skills) such as extensive bowel and bladder issues or on holidays.

The authors attempted to refine these issues in their assessment of the WST version 2.4 with the removal of several skills and altered scoring mechanism (Kirby et al. 2004). The term "not a goal" was introduced to the scoring sheet to make the test more clinically relevant, where if a skill was not deemed appropriate to a participant's rehabilitation goals it was not tested. A negative Pearson correlation was reported between test scores and age, where, similar to Askari et al. (2013), greater test scores were reported in younger manual wheelchair users. Lower scores were observed in those who had used their manual wheelchair for fewer than 21 days compared to more experienced manual wheelchair users. Additionally, higher scores were observed in those using lighter wheelchairs however, this was not statistically significant compared to those using ultra-light wheelchairs. It could therefore be argued that similar to Askari et al. (2013), availability of lighter wheelchairs may play a role in skill acquisition in manual wheelchair users.

Table 5.2: Instrument validity

Name of test	Face/ content	Construct/ concurrent
Wheelchair Propulsion Test	Approval by healthcare professionals and experts in area	R = 0.92-0.99
Adapted Manual Wheelchair Circuit	NR	NR
Test of Wheeled Mobility and Short Wheelie Test	Approval from expert group and service users	Anxiety r = 0.88 Wheelie test r=0.47
Timed Manual Wheelchair Slalom Test	NR	NR
Own Assessment Tool	Approval by healthcare professionals	NR
The Wheelchair Skills Test Version 1.0	Approval by healthcare professionals	Therapist global rating r=0.45
The Wheelchair Skills Test Version 2.4	Approval by healthcare professionals and service users	Age r= 0.434
The Wheelchair Skills test Version 4.1	NR	NR
Transfer Assessment Instrument	NR	NR
5-AML	Approval by healthcare professionals	Group specific
WAIMS	NR	NR

Legend: NR = Not reported; r = correlation coefficient

Discriminative validity was investigated by Cowan et al. (2011) and Middleton et al. (2002). Sum ability scores and sum performance times were greater for participants with paraplegia compared to tetraplegia, indicating the primary outcomes have discriminative validity. In Cowan et al. (2011), ceiling effects remained in the group with paraplegia where they achieved all skills which could imply that the test was too easy for this sample population. The authors recommend adding advanced skills such as vertical transfers to challenge this population to remove ceiling effects. However, to include the advanced skills will disadvantage the participants with tetraplegia, as no ceiling effect was observed in that group. This was due to their level of injury, individuals with tetraplegia may not achieve more advanced skills due to their physical capacity alone, not their performance, as observed in this study. It could therefore be argued that the test was suitable for use with participants with tetraplegia only, or the inclusion of more advanced skills would be more suitable for individuals with paraplegia only. Further research would be required in assessing capacity versus performance alone in this population.

Middleton et al. (2002) also reported discriminative validity for the 5-AML. Unlike Cowan et al. (2011), a vertical transfer was included and showed greater responsiveness in the subgroup with paraplegia compared to tetraplegia, and less ceiling effect in the former group. Three wheelchair propulsion tasks better discriminated between neurological impairment level and were more sensitive to change in locomotion in comparison to the Functional Impact Measure (FIM), specifically over a period of six months. A ceiling effect was reported in the group with paraplegia in relation to bed mobility, however demonstrated high responsiveness over time in the group with tetraplegia. Interestingly, ceiling effects were also observed in the push on the flat task with the group with paraplegia, even though participants were required to push at a maximum speed. There was no ceiling effect for the group with tetraplegia and the task was sensitive to change over time for them also.

Reliability

Instrument reliability is displayed below in Table 5.3. Intra-rater reliability was reported in six studies. Askari et al. (2013) reported no clinically significant difference between trials. The highest Intraclass Correlation Coefficient (ICC) values were observed in speed, followed by push frequency and effectiveness. Again, no clinical significance was found by Fliess-Douer et al. (2012), however ICC values were the highest reported compared to previous studies investigating the TOWM. Significant differences were found between the skill tasks of uneven surface and accelerate and stop in a wheelie and the remainder of tasks, which could indicate that these skills are more advanced and were not categorised accordingly. The author attributed this to skill maturity not clearly defined and tester bias, where the tester may potentially be aware of the participant's previous score thus clouding their judgement in grading objectively.

Overall, ICC values were excellent except for one task of propelling forward. A minor difference between participants scores resulted in low variance. In order for reliability to be demonstrated, a larger variance between participant scores would need to be observed. This may be attributed to the simplicity of the task in question, where it could be assumed that most manual wheelchair users already have the ability to propel forward in their wheelchair, therefore little variance within this skill is expected.

All three studies investigating the WST reported excellent intrarater reliability. Kirby et al. (2002) reported overall reliability was average in relation to the measurement properties of Version 1.0 of WST. Several skills were not applicable to all participants therefore different sample sizes were reported per skill assessed. For example, one task asked participants to remove their footplate, however in the case a participant's wheelchair consisted of a fixed footplate this was not applicable. This resulted in large variance between participant's overall performance scores. Thought should be given to skills potentially not applicable, alternatively a different scoring mechanism could be applied or the skill may be altered or removed to ensure generalisability. Kirby et al. (2004) included this in the revised version of the WST, version 2.4, where they incorporated a binary pass-fail scoring system, including "not applicable" or "not a goal" where the skill was not relevant to participant's rehabilitation goals.

Table 5.3: Instrument reliability

Name of test	Intrarater	Interrater	Test/retest
Wheelchair Propulsion Test	ICC= 0.72-0.96	0.80-0.96	NR
Adapted Manual Wheelchair Circuit	NR	NR	ICC=0.20-0.98
Test of Wheeled Mobility and Short Wheelie Test	ICC=0.91	ICC=0.99	NR
Timed Manual Wheelchair Slalom Test	NR	NR	ICC=0.972
Own Assessment Tool	NR	K range= 0.82 ± 0.96	NR
The Wheelchair Skills Test Version 1.0	R=0.96	R=0.95	ICC=0.65
The Wheelchair Skills Test Version 2.4	ICC=0.96	ICC=0.97	ICC=0.904
The Wheelchair Skills Test Version 4.1	ICC=0.95	NR	ICC=0.901
Transfer Assessment Instrument	ICC= 0.643	NR	NR
5-AML	NR	K range = 0.82-0.96	NR
WAIMS	0.82-0.96	0.75-0.95	NR

Legend

NR = Not reported; ICC = Intraclass coefficient; K = Kappa coefficient; R = correlation coefficient

Intrarater reliability was higher than interrater reliability in the WAIMS assessment investigated by Vereecken et al. (2011). Interrater reliability refers to the level of agreement between raters. Within this study, a large number of raters were included as the test manual specified that the participant's current occupational therapist administer the assessment at the second assessment. It could be argued the high number of testers and the level of training they received could alter the scoring and agreement between raters. Additionally, the ICC values were found to be unreliable between researcher and occupational therapist. Again, the researcher may be more familiar with the tool from experience gained during the design and more exposure to the assessment prior to formal administration of the tool to participants. Further standardisation of training administered to assessors could assist in rectifying this issue, or as the authors recommend, clarity of user manuals and scoring tools would improve the accessibility of the tool.

Agreement between raters was high in Middleton et al. (2002) study, where they reported the same scores for participants 82% of the time, and only ever differed by one score 17% of the time. Interrater reliability was also reported in seven studies and all studies scored average to strong reliability. Excellent interrater reliability was demonstrated in Fliess-Douer et al. (2013). No significant differences were observed between the two raters and the total quality score between TOWM and Wheelie Test was ICC = 0.99. The task of level propulsion forward was the only task to score poorly which again could be attributed to the simplicity of the task, where it could be assumed that most manual wheelchair users can propel their wheelchair forward.

Test retest reliability

Varying levels of test-retest reliability was observed across all studies, with both Askari et al. (2013) and Fliess-Douer et al. (2012 & 2013) reporting no significant change between testing. Cowan et al. (2011), Gagnon et al. (2011), Kirby et al. (2002 & 2004) and Middleton et al. (2002) reported moderate to excellent scores. Cowan et al. (2011) reported excellent scores in ten of the fourteen tasks with crossing a 0.012m doorstep and 0.10m kerb both scoring low reliability. This is mirrored in an earlier study investigating the FIM where these original skills also had low reliability scores. Distinctly, the ability to perform a stationary wheelie but not performance time, was found to be reliable in this study. Generally, more

advanced skills would be perceived as less reliable due to higher skill level required, however the authors attributed this to the previous wheelchair experience of participants. Those who potentially already complete a wheelie as part of their normal routine are more likely to score higher performance times but those who do not, did not actually attempt the skill during the test. Therefore, those who successfully completed this skill were already competent at performing a wheelie. This links to Fliess-Douer et al. (2012) where they reported confidence levels of individuals influenced their decision to attempt a skill or not.

Further exposure and experience completing this skill may, in turn, result in greater reliability of the task within a skills test. Ten discrepancies were found in the data analysis in the Kirby et al. (2004) study which impacted the reliability of the results. Human error such as, incorrect transfer of data from scoring sheets to electronic sources, videotaping errors and misinterpretation of pass/fail scoring item, resulted in allocating incorrect scores to participant's performance scores.

5.3.5 Andresen's grading criteria

Andresen's grading criteria was used to assess the validity and reliability of tests included as seen in Table 5.4. These psychometric properties are important for determining the evidence base behind each assessment. Reliable and valid tools are critical in assessing whether a tool is concise and designed in a way that is fit for purpose. Reliability was extensively reported across all studies however, only six studies reported data related to validity. The TOWM and Short Wheelie Test, The WST and the WAIMS were the only tests to provide data relating to both reliability and validity. The best performing assessment was the WST which has undergone several revisions to ensure it possesses adequate reliability and validity for use in clinical practice. Both the WAIMS and WPT scored well based on Andresen's criteria however both require further refinement in relation to reliability and validity. Both tests are also limited in that the WPT tests the skill of propulsion alone, while the WAIMS is designed to be used with a sample of Multiple Sclerosis participants only, limiting the generalisability of these studies. More research is needed to assess the psychometric qualities of the other tests described in the current review before these tests can be recommended for use.

Table 5.4: Grading scores for wheelchair skills tests following Andresen’s criteria

Name of test	Reliability	Validity
Wheelchair Propulsion Test	B	B
Adapted Manual Wheelchair Circuit	C	NR
Test of Wheeled Mobility and Short Wheelie Test	A	A
Timed Manual Wheelchair Slalom Test	A	NR
Own Assessment Tool	A	A
The Wheelchair Skills Test Version 1.0	B	B
The Wheelchair Skills Test Version 2.4	A	B
The Wheelchair Skills test version 4.1	A	NR
Transfer Assessment Instrument	B	NR
5-AML	C	NR
WAIMS	B	B

Legend	
Reliability	Validity
NR = not reported	NR = not reported
A = ≥ 0.75	A = ≥ 0.60
B = > 0.40 but < 0.75	B = > 0.0 but < 0.60
C = ≤ 0.40	C = ≤ 0.30

5.4 Discussion

The wheelchair skills assessed in each test varied widely, where each author reported different distances, measurements of kerbs, ramps, slopes, inclines, door thresholds and scoring sheets. A difficulty lies in comparing which individual skill was most beneficial due to the heterogeneity of studies making comparison almost impossible. Several tests were also in the early stages of development and with further research they may be further utilised in the assessment of wheelchair skills tests.

Wheelchair use has become more and more prominent over the last decade. The primary goal of rehabilitation for a manual wheelchair user is mobility as this is seen as the gateway to independent living (Dicianno et al. 2009). Within this review, a range of variables were observed relating to participant demographics; diagnoses, age, level of injury, type of wheelchair used, the surface wheelchair users propel on and the participants’ current wheelchair skills levels. Most of these factors were accounted for across studies, however

only one study provided demographic information relating to the type of wheelchair used (Askari et al. 2013).

Ultralight wheelchairs by nature are easier to propel than standard wheelchairs due to their ergonomic design and can be configured to a greater degree to make a chair more versatile (Boninger et al. 2000). The use of such, may also result in greater wheeled mobility or further ease completing some skills, in particular the wheelie. Many wheelchair users who, due to their condition, may not be suitable for a high-performance wheelchair still perform best in a wheelchair that is optimally adjusted to their personal characteristics (Rice 2015). Cowan et al. (2011) reported participants using different wheelchairs on different test occasions, which may have affected sensitivity to change and test-retest reliability. Additionally, this may bias comparisons between participants having wheelchairs of different quality. The configuration of a wheelchair may also greatly impact the mechanical efficacy of completing skills thus affecting the validity of results. Often the configuration of a wheelchair can significantly impact the usability and thus the ability to achieve wheelchair related tasks.

Wheelchair configuration can also impact highly on weight distribution across the chair which in turn may impact on the force required to propel the wheelchair (Brubaker 1986). Cowan et al. (2011) used a standardised wheelchair for 5 participants and configured to their needs, however many wheelchair users have a familiarity for their own wheelchair and may need a chance to adapt to the new wheelchair provided. Similarly, three participants used different wheelchairs in the first and second assessment in Kirby et al. (2002) WST. Therefore, it could be argued the results from these studies may not be an accurate reflection of skill acquisition, or as the authors refer to, scores may be under-reported in these cases.

It should also be noted that due to a participant's condition or level of disability it may not be physically possible for them to complete a skill (Kirby 2016). For example, a participant with high spasticity may require a chair in tilt and additional supports added on to the chair. A participant may be seated in a tilted position where there is a greater weight distribution over the front castors. In this case, a participant may be unable to complete tasks such as

flicking castors over door thresholds or kerbs and may always rely on a carer for these tasks. If this was to be assessed formally, no improvement would be observed as the participant does not have the capacity, however it would still result in a lower overall performance score.

Wheelchair use is not without its consequences, as discussed in Chapter 2 where wheelchair use can result in physical strain and injury. Physical pain is not the only consequence of manual wheelchair use; a depth of literature exists around the emotional turbulence of wheelchair use (Bates et al. 1993, Kailes 1985, Wheeler et al. 1996, Chan et al. 2007). In 1994, Cahill & Eggleston published an insightful paper on managing emotional stress for manual wheelchair users. The study discussed “humouring embarrassment”, describing situations where wheelchair users can be exposed to embarrassing or invasive encounters on a daily basis. Slight environmental discrepancies which able-bodied individuals may take for granted, could cause substantial difficulty to a manual wheelchair user. Something as simple as a slight dip at the bottom of a kerb could result in a wheelchair user tipping forward out of their wheelchair and will require assistance from a carer or passer-by. It is therefore unsurprising that a large number of wheelchair users have lower levels of self-confidence and quality of life and are reluctant to engage in social activities (Phang et al. 2012, Rushton et al. 2013, Miller et al. 2012). Equipping manual wheelchair users with the knowledge and skill on wheelchair mobility can result in greater social integration and quality of life, highlighting the importance of wheelchair skills training (Hosseini et al. 2012). It is therefore, essential that wheelchair skills training is rigorously assessed to ensure the skills delivered are relevant to each user mobility needs.

Confidence potentially plays a role in skill acquisition of manual wheelchair users. Fliess-Douer et al. (2012 & 2013) were the only studies to incorporate an anxiety scale to measure self-efficacy in wheeled mobility. Taking Cahill & Eggleston (1994) findings into account, a fear of falls may be a predictor of social exclusion, particularly in older wheelchair users. Similarly, in research involving able-bodied participants, older adults with a fear of falls are more likely to be over-cautious in their home environment thus limiting their social interaction (Delbaere et al. 2004). The same could be said for manual wheelchair users, where if an individual feels they may not possess the skill required to achieve a task, there is

a greater likelihood that they will not attempt the task for fear of falling or injury. Indeed, this was discussed by Cowan et al. (2011) specifically in relation to the wheelie task. Of those who successfully completed the wheelie task, all participants already completed a wheelie as part of their daily mobility. Those who had little or no experience of completing a wheelie did not actually attempt the skill. It is reasonable to argue that those who did not attempt the wheelie task, potentially would not attempt the skill in a real-life scenario either. The risk of rear-tipping while attempting a wheelie could potentially outweigh the benefit of manoeuvring past the obstacle. Additionally, this may act as a barrier to those individuals who would not wish to attempt the skill on their own, therefore reducing their likelihood of participating in social activities or mobilising in public places independently (Brasile 1990). The provision of wheelchair skills opportunities is therefore critical in facilitating manual wheelchair users to become confident and allow them to attempt skills or subsequent skills training, in a safe environment.

It is important to note, that in order to deliver client-centred therapy, emphasis should be placed on technique and safety first rather than improving performance levels (Fearing et al. 1997). Kirby et al. (2002 & 2004) and Askari et al (2013) both addressed this issue with the addition of safety mechanisms. It was also emphasised to participants that the test was not time driven, but on their ability to complete the task safely. McClure et al. (2011) encompassed the global assessment of the participant by determining the optimal technique, rather than the quickest time required to complete the skill. Adding time pressures to participants may add greater incentive to complete the skill by any means possible, however this could be detrimental to their overall rehabilitation goals.

It is also possible that there is an interdependency between performance and exertion, where participants are aware of the need to perform better to obtain a greater overall score. In this case, the participant may employ an incorrect technique, which may not be that of normal daily mobility and therefore is not an accurate reflection of their real-life wheeling ability. Adoption of abnormal movement patterns is not uncommon in manual wheelchair users as outlined in chapter 2. The repetition of these abnormal movement patterns may contribute to the development of upper limb injuries, therefore key emphasis should be placed on quality of movement not just time driven (Kilkens et al. 2005).

Replicating time driven tasks in real life scenarios may not be feasible or practical. It is anticipated that in day-to-day life, participants will mobilise at their ease and therefore it is not possible to generalise these results with their method of mobilizing in their regular home environments. In addition, these false results could also have implications for their clinical management where a false perception of their actual wheelchair ability had been recorded. Then on discharge, the participant may not be as competent in using their wheelchair as recorded which may have substantial implications for independent mobility and living (Mack et al. 1997). This highlights the need for the administration of wheelchair skills training where the participants can practice relevant skills, correct technique and energy conservation methods to ensure an overall improvement in performance. Alternatively, a level of quality could potentially be introduced on scoring sheets where participants are scored if they use a safe and correct technique rather than a time driven assessment.

The balance between including all relevant skills and being conscious of participant's tolerance of high-energy assessments is critical in ensuring the reliability and validity of tests (Inkpen et al. 2012). The WST investigated by Kirby et al. (2002 & 2004) and Lindquist et al. (2010) included a battery of skills for participants to complete, with the most recent version including 50 skills. The content of skills covered is excellent with a comprehensive range covering all tasks necessary for wheelchair mobility. Although the test demonstrated excellent reliability and validity, fatigue may be an issue in relation to participants with a low tolerance for strenuous exertion. Fatigue may also be a factor which influences participant's motivation and skill level to complete tasks and has the potential to skew test results (Van Der Woude et al. 1999). Particularly in the case where participants undergo testing and retesting at a single time-point, the performance at post-test may potentially be lowered as fatigue can be a limiting factor on performance as testing progresses (Rodgers et al. 1994). In contrast to the WST, some tests included only one task or was focused on one area of wheelchair mobility alone. Fatigue would not be an issue in this case, as these tests may be deemed less burdensome on participants. In the case where multiple tasks are included and a therapist wished to assess all aspects of wheelchair mobility in one sitting, participants could potentially experience fatigue which may skew results.

A difficulty lies in ensuring all aspects of wheelchair skills are covered within the test but also being conscious of a participant's tolerance to complete the test. Assessing the skill acquisition of manual wheelchair users can be beneficial, however, in some circumstances it may also put more strain on the participant. Participants were initially screened in all the studies for comorbidities and those deemed unfit to participate based on the nature of their conditions were excluded. For example, in the case of degenerative conditions, strenuous exercise or stress may exacerbate the participant's symptoms of their condition. In these cases, the fatigue and issues experienced outweighed the benefit of completing the assessment. In the case that a participant knows he/she is being tested, further exertion may be applied to better their performance. In this case assessors may observe an improvement in their skill score, however the participant may experience an increase in pain or fatigue, thus implying these are interdependent.

The ordinal scales of dependence are subject to interpretation by the raters. For example, in Middleton et al. (2002) a large number of occupational therapists were required to administer the second test as the manual specified the need for the participant's own OT to assess and score at the second test. The variance between scores from the first and second test may be attributed to the training or usability of scoring sheets where researchers may have had further exposure to the test. A bias also lies with the use of the participant's OT as he or she may have prior knowledge or their ability which could influence the scores allocated. Therefore, objectivity may be difficult to achieve in this instance.

In relation to feasibility of delivering skills assessments, an alternative form of skills test has been developed namely the "Wheelchair Skills test – Questionnaire" (WST-Q). The WST-Q is based on the same principles as the WST except it is a subjective questionnaire completed by participants in relation to their own wheelchair mobility. The test is particularly useful in the case where access to equipment or time may be limited (Rushton et al. 2016). The test takes less than ten minutes to administer and can also be used as a screening questionnaire in assessing someone's previous baseline mobility. Both the WST and WST-Q demonstrated high correlations implying the WST-Q is an accurate predictor of wheelchair ability. The test however is not without its drawbacks as performance scores recorded in the WST-Q were higher in comparison to the observational skills test scored by a trained tester. The tool

requires further testing focusing on reliability and validity, however it shows promise as an alternative to lengthy observational skills tests.

5.5 Limitations

There are some notable skills tests that have been excluded from this review that were previously included in systematic reviews conducted by Kilkens et al. (2002) and Fliess-Douer et al. (2010) which may be viewed as a limitation. Although wider skills tests are available, this review only included tests that included samples of manual wheelchair users only and where the observational skills test was the primary outcome measure. Studies assessing the effectiveness of a skills training programme or where the skills test was not the primary outcome measure were not included. Additionally, studies which may be deemed as having taken place in a laboratory setting measuring heart rate, peak flow or other body function were excluded, alongside studies where powered wheelchair users were included in the sample, as they were not deemed to be directly related to the aims of this study.

5.6 Conclusion

This systematic review demonstrates there are some excellent outcome measures available for testing wheelchair skill performance, each with their own strengths. Several tests are in the early stage of development however, with further research on their validity and reliability these will add to the clinical utility of assessing wheelchair skill acquisition.

The use of many different tests makes it difficult, if not impossible, to compare study results. Standardisation of the content of skills included in tests and the measurement instruments utilised are needed to enable comparisons between studies. Varying conditions and diagnosis greatly impact on the skill acquisition in the manual wheelchair population and thought must be given to the configuration of the participant's wheelchair. Future research could best concentrate on further validation of existing tests instead of developing more and more tests as seems to be the case in recent years. Combining the most relevant skills used on a daily basis with the applicability to transfer these skills into ADL activities may lead to the development of a high-level test.

Taking into consideration the varying degree of difficulty for lower and higher functioning manual wheelchair users may be an idea where the one skills tests can be graded dependent on ability. In this way, participants may proceed to the next level of the tests as their skill set improves. Wheelchair skills training will go hand-in-hand with this development and the improvement in technique and training will further improve the independence of manual wheelchair users. In conclusion, this review shows that there are some excellent assessment tools available to measure wheelchair skill acquisition, however, as of yet, no agreed consensus as to a single standard test for all manual wheelchair users.

CHAPTER 6:

THE EFFECTIVENESS OF AN EIGHT MONTH WHEELCHAIR SKILLS TRAINING PROGRAMME FOR YOUNG MANUAL WHEELCHAIR USERS: A PILOT STUDY

Abstract

Introduction: Wheelchair skills training was identified as a key aspect of upper limb injury prevention in manual wheelchair users. It could be argued that upper limb pain sustained from manual wheelchair use is not specific to patients with a spinal cord injury but broadly all manual wheelchair users. Preventative measures to date have provided short term relief only and specialised services are lacking in the community. Rather than treat these injuries when they manifest, the researcher proposed to explore the efficacy of delivering a wheelchair skills training programme to young manual wheelchair users. Young manual wheelchair users are undergoing a transition period where they may have previously relied on their parents for their mobility needs. A wheelchair skills training programme was designed by the Regional Wheelchair Skills training therapist and was implemented as a checklist graded for use with children, to assess skill level pre and post an eight month skills training programme.

Aim: To explore the efficacy of delivering wheelchair skills training and evaluate its effectiveness on skill acquisition and ADL performance in young manual wheelchair users.

Setting: Community Leisure Centre

Design: Prospective cohort study

Sample: 11 participants were recruited with 8 participants completing the full programme. The mean age was 10.5 years. Participants physical disability diagnosis included Cerebral Palsy (5), Spina Bifida (4), Muscular Dystrophy (1), Spondyloepiphyseal Dysplasias Congenita (1). All participants were manual wheelchair users.

Outcome measures: Demographic questionnaire; The Activity Scale for Kids (ASK) (Young et al. 2000); an Impact questionnaire; Northern Ireland Regional Manual Wheelchair Skills Assessment Checklist.

Testing: The wheelchair skills programme took place in the Joey Dunlop Centre, Ballymoney over an eight-month period consisting of two testing days (pre/post wheelchair skills

training) and six monthly training sessions. The regional wheelchair training occupational therapist (OT) carried out the wheelchair skills training while the PhD researcher carried out pre and post-testing. The skills test used was developed by the regional wheelchair skills training therapist and was adapted. The test was split into three levels – basic, intermediate and advanced skills. Some advanced skills were removed to grade for use with children.

Results: Eight participants completed the full intervention (one not tested, one opted out mid pre-test, one was sick for the post-test). All eight participants showed an increase in the basic (6%), intermediate (29%), and advanced (38%) skills levels, with a significant increase in the intermediate and advanced levels; ($p = 0.083$), ($p = 0.017$), ($p = 0.042$) respectively. The ASK questionnaire showed little to no increase in performance post skills training (mean = 1%; SD = 12.8). Participants and parents reported enjoying the sessions, and created a social outlet for their children to meet other wheelchair users and parents to converse. In addition, participants reported feeling more confident and independent following the training sessions.

Conclusion: Overall, there was an improvement in basic, intermediate and advanced levels of the NI Manual Wheelchair Skills Assessment Tool in this cohort. In addition, participants reported improvement in their confidence and independence. The researcher recommends wheelchair skills training be administered at key milestones in young manual wheelchair users' development to further enhance their skill acquisition and ADL performance as they age and grow.

6.0 Introduction

The nature of this study is framed around promotion of functional independence and skill acquisition in young wheelchair users. Wheelchair skills training refers to the formal teaching of the techniques required to mobilise in a wheelchair for maximum independence and energy conservation. The majority of wheelchair users conduct all activities of daily living (ADLs) while in their wheelchair therefore it is important to equip them with the skills to enable them to use their wheelchair to the best of their ability.

The use of a wheelchair is also beneficial in conserving energy where a participant has the ability to walk however, due to their condition, may cause more undue stress than use of a wheelchair (Cooper et al. 2008). As outlined in Chapter 2 however, poor wheeling can have long term effects on upper limb injuries within the manual wheelchair using population. Conclusions drawn from this systematic review indicated that wheelchair skills training can potentially improve this outcome and it is well documented in the literature (Oyster et al. 2012, Rodgers et al. 2001, Westgaard & Winkel 1997, Boninger et al. 2005). As outlined in Chapter 2, research has indicated that wheelchair skills training can potentially reduce joint degeneration and adoption of abnormal wheeling techniques, thus reducing the overall strain on the upper limb during wheelchair related activities. Providing a more efficient method of independent mobility enables children to conserve energy for more meaningful activities which would normally be used during locomotion (Cox 2003).

In Northern Ireland, significant developments have taken place in terms of how the wheelchair service is strategically and operationally delivered via the “Proposals for Reform of the Northern Ireland Wheelchair Service 2008”. In 2008, the department of Health and Social Services and Public Safety (DHSSPS) Northern Ireland, launched this report in order to identify inequities in wheelchair provision throughout Northern Ireland. Recommendations published in the report were based on partnership working with both service users and healthcare staff. Wheelchair service users identified manual wheelchair skills training for children as a priority area to be addressed. The review highlighted that throughout the region, there was an inequitable provision of skills training opportunities for children. Some health and social care trusts offered skills training via local clubs, while other trusts relied solely on charities including “Go-kids-Go” and “Whizz Kidz”, both of which are UK mainland

based charities. Skill mix and sporadic engagement with the charities resulted in uncoordinated, unregulated wheelchair skills training for children across Northern Ireland.

As a result of this report, several specialised wheelchair posts were created to address these inequalities. One such post was the Northern Ireland Regional Wheelchair Training Occupational Therapist (OT), (clinical link - ER), who designed a wheelchair skills training programme which was adapted and implemented in this study. The protocol was administered as a wheelchair skills test initially and then revised as a wheelchair skills training programme. This research project aims to explore the efficacy of delivering a wheelchair skills training programme and evaluate its effectiveness on skill acquisition, ADL performance and independence in young manual wheelchair users across Northern Ireland.

This mixed methods study implemented a quantitative wheelchair skills test and training programme to enable young manual wheelchair users to optimise their wheelchair performance. The complimenting questionnaires were administered to gain a greater understanding of the participant's performance in the context of their home, and feedback sought for a qualitative aspect of what participants enjoyed most about the training. The study was informed by the World Health Organisations guidelines on provision of wheelchairs (Borg & Khasnabis 2012). The guidelines outline the process of wheelchair prescription and the follow up intervention required to provide a high, standardised, level of care to all manual wheelchair users.

This study relates to the way in which society supports individuals living with a physical disability. Some of the factors influencing this work include: changes in health behaviours; people living longer with chronic disease; a move towards more home based care and the growing strength of the social model of disability within a legislative context (DWP, 1995) that supports an inclusive society. This study was modelled on a research study by Sawatzky et al. (2012) who conducted a pilot study on wheelchair skills training in children. The authors conducted a similar skills training programme implementing the Wheelchair Skills Test (WST) by Kirby et al. 2004, including a two-day skills training programme where participants were tested pre- and post-training. Building on the results from this work, this

study implemented a longer period of skills training over six months to improve skill acquisition and ADL performance.

6.1 Rationale

Manual wheelchair users generally live highly independent lives, completing activities of daily living (ADL), travelling to and from work and competing in sports, with ease (Tolerico et al. 2007). In order for manual wheelchair users to mobilise independently, a general level of wheelchair skill is required to ensure they are equipped to negotiate all environments, as well as pursuing leisure activities; with a higher skill level positively associated with better community participation and quality of life (Hosseini et al. 2012). Propulsion and transferring are the basic skills required for mobilising in a manual wheelchair, with the upper limb required to generate substantial force to propel the wheelchair (Mercer et al. 2006). As discussed in Chapters 3,4 and 5, an increasing trend in the manual wheelchair user population is the overuse of the upper limb and resulting pain incurred (Cooper et al. 2008).

Previous research has focused on reducing upper extremity demand during wheelchair propulsion by modifying wheelchair propulsion technique (Boninger et al. 2005; Mulroy et al. 2005; de Groot et al. 2003). Research literature highlights that these injuries occur throughout the life span of wheelchair users, particularly in those whose wheelchair use has spanned decades (Asheghan et al. 2015), with young wheelchair users at a higher risk of developing upper limb injuries in later life due to an increased number of years ahead of them in their wheelchair.

To date, the majority of research evidence focuses on overuse injuries in manual wheelchair users with an SCI, however that is not to say these injuries are specific to this cohort only. Other congenital or degenerative conditions resulting in manual wheelchair use are less studied, however it is reasonable to argue that these manual wheelchair users may also suffer from overuse injuries. In NI, as part of the inpatient rehabilitation process, the RSCI centre offers SCI patients' wheelchair skills training to ensure they reach the optimal level of independent wheelchair mobility. It is unclear whether other manual wheelchair users will receive this same level of specialised intervention if they have not sustained a traumatic injury i.e. a congenital condition.

Of the 20,850 adult manual wheelchair users in NI for whom wheelchairs have been provided by the NHS, 861 patients are recorded as having an SCI. Alongside this, there is a population of young wheelchair users in NI, whose wheelchair use stems primarily from congenital diseases diagnosed at birth. Naturally, parents worry about their children particularly when they have additional needs, however research shows that children requiring a wheelchair should be encouraged to do so from an early age to promote independence and develop cognitive, social and emotional skills (Law et al. 2007). As they grow and mature, many young wheelchair users become highly independent and attend mainstream school. A consequence of this is that they do not receive specialised care they may have received, had they attended a special needs school (Cox 2003).

The ability to master wheelchair mobility changes with factors such as age, degeneration of condition/injury or wheelchair configuration, affecting the ability to complete even basic skills. Similarly, as children get older they grow and their life goals change, as do their wheelchair needs. Ideally the researcher would have liked to investigate the effects of wheelchair skills training on overuse injuries via a longitudinal study, however due to the time constraints of the PhD programme of research, this was not deemed feasible. In taking a “prevention is better than cure” approach, the researcher opted to seek a younger cohort of young manual wheelchair users who were at the prime age to learn new techniques and who may not have developed poor wheeling techniques at such a young age.

The aetiology of traumatic SCI by nature results in a higher level of adults sustaining SCI compared to young people; road traffic collisions and sporting accidents are the primary causes. Young manual wheelchair users are therefore more likely to have a congenital condition resulting in their wheelchair use compared to a traumatic injury, hence a broad range of conditions and diagnoses were considered for inclusion in this study. In planning for future research, the researcher undertook this study to assess the feasibility of delivering a wheelchair skills training programme prior to undertaking a larger longitudinal study with the view that it may inform future pieces of work. With such a young cohort, it was not within the scope of the study to assess upper limb pain or injury at this point; as

reported in Chapters 2 and 4 where findings indicate the development of pain is related to length of time as a manual wheelchair user.

6.1 Aim

The aim of this study was to explore the feasibility of delivering a wheelchair skills training programme and evaluate its effectiveness on skill acquisition and ADL performance in young manual wheelchair users.

6.2 Methods

6.2.1 Ethical approval

Ethical approval was obtained from Ulster University Research Governance Filter Committee, NRES Committee Yorkshire & The Humber - South Yorkshire, REC reference:15/YH/0383; IRAS project ID: 169094 and governance from the Northern Health and Social Care Trust (NHSCT), in March 2016. Informed consent was sought from parents/carers of participants to participate in the study and consent was also sought for videography and photography during the programme (Appendix 14).

6.2.2 Participants

The study was aimed at self-propelling manual wheelchair users, aged 5-15 years. Participants were recruited from the Causeway Occupational Therapy (OT) Department, Northern Ireland. Statistics related to young manual wheelchair users was limited. The local collaborator had records of 42 young people aged under the age of 18 in Northern Ireland who used a high performance or lightweight wheelchair. Unfortunately, there was no record of figures relating to all young manual wheelchair users in Northern Ireland, therefore conducting a power calculation to determine effect size in this sample was not possible. Participants were included if they were aged 5 to 15 years and were a self-propelling manual wheelchair user. For the purpose of this study, participants who had a life-limiting condition, were powered wheelchair users, had a cognitive issue which would prevent them from following verbal instructions, or any predisposing condition that may worsen as a result of partaking in wheelchair skills testing or training were excluded.

Thirty information packs were posted to participants on the caseload of the local collaborator who met the inclusion and exclusion criteria. Participants were contacted by the local collaborator involved in their care and posted an information pack including participant information sheets for both children and parents, consent forms and contact details of the researcher should they have any queries (Appendix 15). Participants signalled their intent to be included in the study by returning the consent form, after which the researcher contacted them to confirm the start date and time of the study.

The researcher worked closely with a wheelchair club in the area, namely “Causeway Wheelers”. As this was a social group, there were other young manual wheelchair users who did not meet the inclusion and exclusion criteria but would still have benefited from manual wheelchair skills training. It was agreed they were permitted to attend the skills training sessions to ensure that all young manual wheelchair users benefited from the skills training however, these wheelchair users were not included in the data collection for this research study.

6.2.3 Outcome Measurements

Demographic questionnaire

The demographic questionnaire was administered to participants on first arriving at the testing day. This included details on gender, age, primary diagnosis, medication, type of school attended, class group in school, participation in physical education in school, type of chair used, make and model of wheelchair used, years using wheelchair and any previous wheelchair skills training.

Northern Ireland Manual Wheelchair Skills Assessment Tool

The Regional Wheelchair Training OT had developed a graded wheelchair skills test namely, the “Northern Ireland (NI) Manual Wheelchair Skills Assessment”. Initially, the researcher anticipated using the “Wheelchair Skills Test (WST)” by Kirby et al. 2004 following a systematic review of wheelchair skills tests (Chapter 5). The WST is a proven valid and reliable test of wheelchair skills in manual wheelchair users, however as this study took place in a community leisure centre, the researcher did not readily have access to the standardised equipment required.

The NI Manual Wheelchair Skills Assessment is a three-tier assessment tool categorised into basic, intermediate and advanced skill levels. The assessment has previously been used with adults, therefore the researcher adapted the tool to ensure the criteria was applicable to children and young adults. The assessment tool was graded so that each task increased with difficulty, therefore a large proportion of the skills removed were skills which were deemed too advanced for the study participants. Several basic skills were also removed as they were not applicable to this specific cohort; all participants had fixed footplates and armrests therefore making these skills not applicable. The list of tasks removed can be seen below in Table 6.1: Skills removed from assessment tool.

On arrival at the initial testing day, participants were greeted by PhD Researcher (AMC) and brought to the testing area. The researcher (AMC) administered the skills test as outlined in Appendix 16. Participants were asked to complete each assessment at their ease with no time limit per task. Participants attempted each skill once, however if a participant requested a second attempt, that was permitted. A separate area was cordoned off for some fun activities and ice breakers for participants to engage in, should they find themselves waiting to be called. The assessment was explained to participants as a small test to see how they manage in their wheelchair and they were encouraged to join in the fun games after they had completed their test. The primary emphasis was on fun and engagement and the researcher explained that there was no competitive aspect. An OT was in attendance to act as a spotter for each participant as a safety precaution during the assessment, and all participants' parent/guardian were present for the assessment. On completing the skills test, participants and their parents were asked to take a seat and complete the ASK and demographic questionnaire. In the case that the researcher was running behind schedule, some participants were asked to complete the questionnaires prior to completing the skills assessment test.

Table 6.1: Skills removed from NI Manual Wheelchair Skills Checklist

Remove the armrests	Swing away and replace footplates
Fold and safely lift the wheelchair	Locate the tie down points on wheelchair
Maintain and control a back wheel balance in a stationary position for 10 seconds	Move between deep and shallow balance independently
Upright the wheelchair when falling backwards	Back wheel balance and move forwards/backwards from a stationary position (5 metres)
Back wheel balance and turn 360 degrees in full circle	Negotiate a simple obstacle course using forward and backward techniques during back wheel balance
Go up a 4" kerb on back wheels	Go down a 4" kerb on back wheels
Negotiate wheelchair in crowded situations	Cross a road safely
Go down a slope on back wheels straight	Go down a slope on back wheels weaving
Go down a slope on back wheels, stop halfway and maintain balance	Go down a 4" kerb landing on all four wheels
Fold wheelchair	Get in/out car with ultra-light wheelchair
Back wheel balance and move forward over uneven ground on sand	Back wheel balance and move forward over uneven ground on gravel
Back wheel balance and move forward over uneven ground on sand	Remove wheels of wheelchair

The Activity Scale for Kids Performance Measure

The Activity Scale for Kids (ASK) Questionnaire Performance version (Young et al. 2007) is a valid and reliable outcome measure applicable with children aged 5-15 years. The tool is a self-reported measurement tool that facilitates young people to accurately report their physical functioning levels. In this study, children and their parents were asked to complete the questionnaire, either together or independently and return to the researcher. The questionnaire itself takes no longer than 30 minutes to complete and consists of a five-point ordinal scale for responses. The ASK has its own scoring mechanisms, such that each score is easily calculated. The individual questions asked related to activities of daily living such as mobility, washing, dressing, leisure activities, and the responses include how the young person feels they manage these tasks, even if they require an aid such as a walking frame or wheelchair. Both the questions and responses are written in language that is comprehensible to children.

Impact questionnaire

To gain a greater understanding of the participant's experience with the programme, an impact questionnaire was administered. The impact questionnaire was a general evaluation of what participants enjoyed most about the study and what they felt would have improved their experience. The questions included were:

1. Did you enjoy the wheelchair skills sessions?
2. What was your favourite part?
3. Was there any part you did not enjoy?
4. How do you think we could improve this?
5. Would you come back to wheelchair skills training again?
6. Do you feel more confident in using your chair?
7. Is there anything you couldn't do before the training that you feel you can do now since the training?

Wheelchair skills training programme

The research study was conducted over eight months in total, an initial testing day, six training sessions over a six-month period, and a final testing day. The Regional Wheelchair Training OT delivered the training programme as 2-hour sessions on the first Saturday of every month for six consecutive months. The skills taught during the training programme were those that were assessed during the testing stage, as these were deemed the most necessary and functionally relevant by the therapist on creating the assessment tool. Six occupational therapists from the local area who were either wheelchair therapists or specialised in paediatrics, assisted in delivering the training. Each OT was given a specific role each morning of the training days which ensured the smooth running of each session. Additionally, a buddy system was used where two manual wheelchair users aged 18 assisted by providing peer support and demonstrations to participants during the skills training sessions.

The training sessions were graded for all levels and abilities and focused on functional activities such as negotiating obstacles, flicking the castors, and moving up and down curbs. Refreshments were provided by Causeway Wheelers at the midpoint through the session which provided participants with a small rest period. In the case of fatigue, participants had

the option to sit out if he or she wished, and the OT staff on hand monitored this. Additional wheelchairs were provided and brought to the sessions where both parents and siblings could join in the games with the emphasis on fun and social engagement.

6.2.4 Safety

As highlighted from Chapter 5, safety was a key aspect of all wheelchair mobility tests. As this was a physical activity, the researcher acknowledged that there may be a risk of injury. Participants' safety was given the highest priority while undertaking the test to avoid unnecessary injuries and a comprehensive risk assessment was conducted to address this. The risk assessment was undertaken in collaboration with Ulster University's Health and Safety Officer to ensure all adverse scenarios were taken into consideration. Skills which were deemed the most high-risk were those that involved back wheel balancing where participants were required to remove their anti-tipping mechanisms to complete tasks. A comprehensive risk assessment and preventative measures were therefore implemented to ensure the safety of all participants undertaking the test (Table 6.2).

Table 6.2: Risk Assessment of skills test

Skill	Hazard
Locate balance point	Risk of rear tip in chair
Independent back wheel balance	Greater risk of rear tip as the participant is expected to hold position for 10 seconds
Self-protection	Participant is required to upright the wheelchair when falling backwards thus increased risk of rear tipping/forward/sideways fall
Travelling forward on a back-wheel balance	Risk of rear tipping
Turning on a back-wheel balance from a stationary position	Risk of falling sideways/forwards out of chair
Back wheel balance and negotiate an obstacle course	Risk of combination falls, forward/rear/sideways falls; injuries due to contact with the environment or a wheelchair part
Go up a 4" kerb on back wheels	Risk of rear tipping
Go down a 4" kerb	Risk of forward falling out of chair
Back wheel balance and move forward over uneven ground	Risk of rear tipping or combination falls, also risk of jarring the chair, risk of lower limb hyper flexion if the feet were to catch on any environmental obstacles
Go down a slope on back wheels	Risk of both rear tipping and forward falling

Preventative Measures

Supervision: The research team closely supervised all participants during the testing.

Use of spotters: The incidence of rear tipping was highlighted as a recurring risk in many tasks above. The primary method to counteract this risk was the use of spotters. The purpose of spotters was to act as a safety net behind each individual so that if they did tip backwards, they were in a position to upright participants and avoid or limit any injury. Spotter straps were incorporated to reduce the risk of injury to the spotter themselves. Spotter straps were attached to the rear of all wheelchairs where if a risk of rear tipping was present, spotters could pull up on the strap from a safe position. This reduced the risk of injury incorporating safe manual handling practices for the spotter also. Online training as well as video guidance was undertaken by all spotters as detailed on the Kirby et al. (2004)

wheelchair skills test, to ensure they were up to date with current methods used. Spotters were also in a position to provide immediate advice if a participant got into difficulty in undertaking a task to advise safe return to their original position, but not to provide prompts or guidance to complete the skill. Spotters were in place for each participant in all aspects of the test.

Training of the Testing Team: All members of the testing team were trained in the use of the wheelchair skills test by the regional wheelchair training OT. Training days consisted of all members undergoing the test and training themselves to provide first-hand experience of what risks exist and when they are most likely to occur. All members had up to date manual handling training completed and had a comprehensive knowledge of wheelchair use and the programme. All members were also briefed on the documentation relating to the protection of children and disclosure of confidential information.

Safety Equipment: Participants were required to wear their safety belts at all times during the testing and training.

First Aid: A first aider was present in the case of any injuries or adverse incidents.

6.2.5 Data Storage and Analysis

All data was collected and input into Excel under participant identifier numbers. All participants' material was stored under their unique identifier code. Consent forms were stored in a locked filing cabinet onsite at Ulster University within a locked office space. For statistical analysis, the data was exported into Statistical Package for Social Sciences (SPSS) version 22.0 (SPSS Inc. Chicago IL). Due to the small sample size, a Wilcoxon t-test was used to establish baseline differences in the wheelchair skills test and ASK outcome measures. The quotes from the impact questionnaire are used to support the quantitative findings of the study.

6.3 Results

6.3.1 Demographic Results

Of the eleven participants recruited, eight completed the full programme; three female and five male. One participant opted out mid pre-test, one had to go home prior to his pre-test and another became ill prior to the final post-test and was unable to attend. The mean age was 10.45 years \pm 2.84. The majority attended mainstream school with the exception of two. Almost all participants had attended either a wheelchair sports club or previous wheelchair skills training. The demographic questionnaire results can be found in Table 6.3.

Table 6.3: Demographic Questionnaire Results

Parameter	
Number of participants	8
Age (mean) years	10.45 \pm 2.84
Gender M:F	5:3
Attended previous wheelchair training/sports club	87.5%
Type of wheelchair	
Quickie Neon	4
Ottobock Ravo Racer	1
Quickie Simba	2
Argon	1
Type of school attended	
Mainstream	75%
Special School	25%
Participate in Physical Education in school	100%

Legend

M: male

F: female

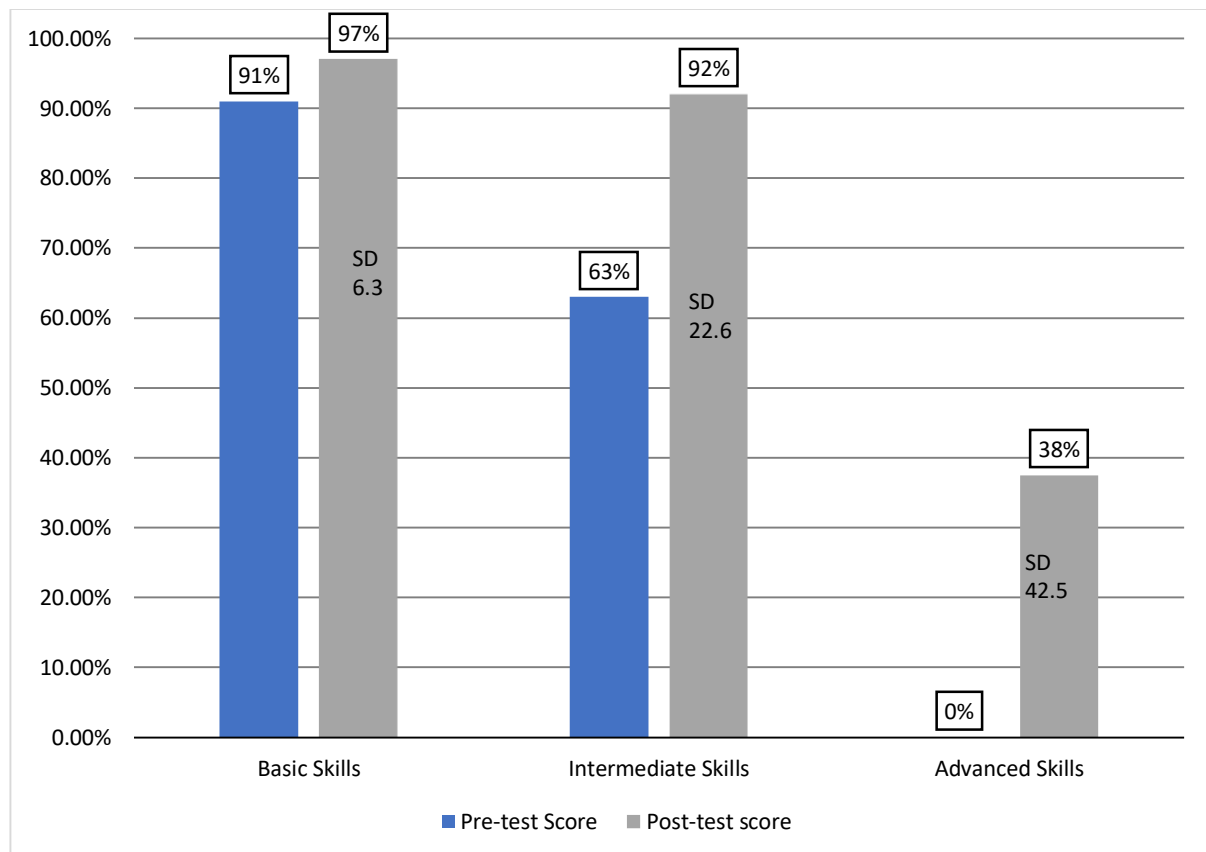
\pm : plus minus standard deviation

6.3.2 Northern Ireland Manual Wheelchair Skills Assessment

Figure 6.1 displays the results of the manual wheelchair skills test. The skills test levels were stratified into three levels – basic, intermediate and advanced. A higher score post-test indicates an increase in skill improvement. All participants showed a significant increase across intermediate and advanced levels; intermediate 29% increase ($p=0.017$); advanced

37% increase ($p=0.042$). An overall increase of 6% was observed in relation to the basic skill level however this was not statistically significant ($p=0.083$). The greatest increase was observed in the advanced skill level, consisting of three tasks only; locating the balance point, independent back wheel balance and self-protection.

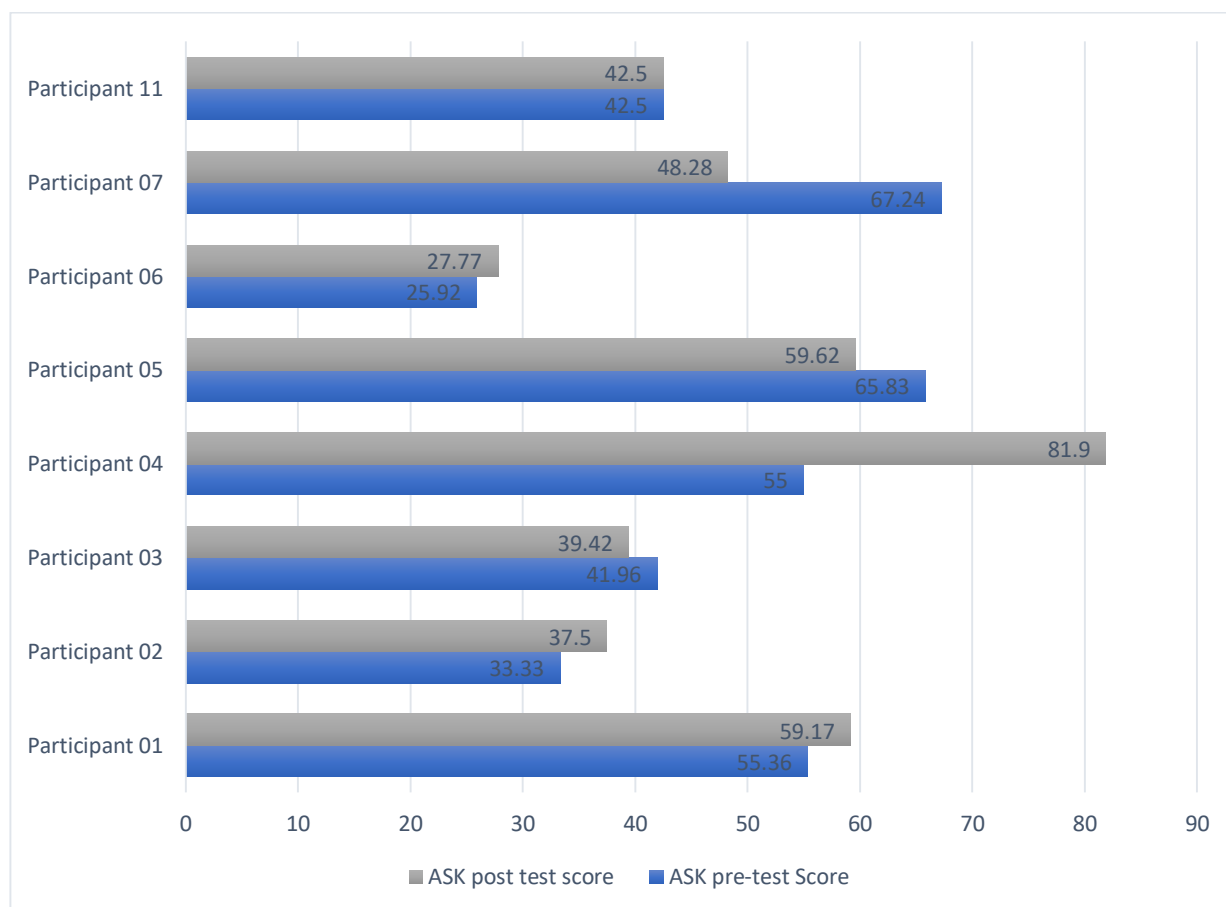
Figure 6.1 Northern Ireland Manual Wheelchair Skills Assessment Results



6.3.3 Activity Scale for Kids (ASK)

To measure performance in relation to activities of daily living, the Activity Scale for Kids (performance version) was used (Figure 6.2). Several participants scored lower at post-test than pre-test with an overall 1% increase observed, although not statistically significant ($p=0.799$). This indicated little to no increase in performance post skills training. The greatest increase observed for individual participants was 27%, with one participant showing a regression in performance of 19%.

Figure 6.2: Activity Scale for Kids (ASK) results



6.3.4 Impact Questionnaire

The impact questionnaire was used to elicit personal perspectives of the skills training programme and a general evaluation of what elements participants benefited from most. Due to time limitations and practicalities on the final day of testing, only two impact questionnaires were returned to the researcher. Overall the research study was very well received by both parents and participants. Some of the encouraging feedback received included “...sessions were very well structured/supported and the children were encouraged productively to participate” and “X really benefited from attending the sessions”. Although the ASK questionnaire reported little to no increase in performance, it was promising to receive feedback relating to participant’s confidence in using their chair such as; “X practiced the techniques at home to develop her ability to use her chair more confidently”, “better at wheelies – helping to get up over kerbs, going down slopes” and “I don’t mind the wheelchair being tilted back now”.

6.4 Discussion

The purpose of this study was to explore the efficacy of delivering a wheelchair skills training programme and evaluate its effectiveness on skill acquisition and ADL performance in young manual wheelchair users. Significant improvements were observed for participants at the intermediate and advanced levels but not at the basic level. The training programme was well received by both participants and parents with both reporting positive feedback. The wheelchair skills test and impact questionnaire both showed promising improvements in skill acquisition.

The results of this study show that monthly formal manual wheelchair skills training is effective at improving skill acquisition in young manual wheelchair users aged five to fifteen years. In comparing the results of this study to the wider literature, results obtained are in line with that of the adult population. Within the adult population, Kirby et al. (2016), assessed the skill level in both generic manual wheelchair users and specifically adults with a spinal cord injury (SCI) reporting levels of improvement between 7% and 30%. Best et al. (2005), reported improvement in skill level in the adult population of 20-25%. Sawatzky et al. (2012) is the only identified study to date to assess wheelchair skills training in a cohort of young manual wheelchair users as far as the author is aware. They reported skill level improvements of 14% in children aged 5-15 years over two intensive days of wheelchair skills training. Sawatzky et al. (2012) included a relatively small sample size of 6 participants specifically participants with a spinal cord injury or spina bifida; similarly in this study, a sample of convenience was utilised due to the smaller than anticipated cohort of young manual wheelchair users in Northern Ireland.

An overall increase of 22% was observed within this study which builds on the hypothesis that skills training over a six-month period may also improve skill acquisition further. Due to the nature of the current study design, testing was only conducted immediately pre and post skills training. It would be interesting to assess whether participants retained their skill level over a longer period of time, for example at one-year post skills training.

The ASKs results showed little to no increase in performance, however it is difficult to interpret if these results are an accurate reflection of true performance levels in relation to ADL.

There are several possible explanations of the nil effect of the ASK. At the pre-test, the ASK was completed jointly by the participant and parent or guardian on completion of the wheelchair skills test. At the post test, again the participant and parent jointly completed the questionnaire, however there was no rigour applied to how or whom completed the assessment. In some cases, a mother and father may have different roles in the family dynamic. Additionally, a carer may only be involved in certain aspects of the participant's daily routine and may therefore have underestimated or overestimated the participant's abilities in relation to the constructs of the questionnaire (Horn & Weiss 1991). Perhaps the parent/guardian completed it based on their own knowledge of the child's ability without input from the child themselves. It could be argued that different parents or carers may have different perspectives of the participant's ability and this may have skewed results from the questionnaire.

Contrastingly, the nil effect may also be explained if the child completed the questionnaire on his or her own. Day to day activities can become normalised and difficult to recall for most. It could be argued children are not reliable at recalling such tasks as they perhaps are not consciously aware of the sequential knowledge required to undertake the task (Stephens et al. 2007). Seasonal variances may also play a role; participants were initially tested at the end of March and follow up tested at the end of October. Children are perhaps more active during brighter spring days in comparison to darker Autumn days where there is less opportunity for recreational activities (Kolle et al. 2009). In future, the researcher recommends documenting who completes the questionnaire on the day and ensuring the same parent/carer completes the questionnaire with the participant for rigour.

It was observed during the wheelchair skills training that most children did not require encouragement to participate. In some of the fun games, a competitive aspect was introduced where children raced against each other. In general, children appeared more confident during the fun games than during the assessment, implying that confidence plays a role in wheelchair skill acquisition. During the fun games, participants conducted some of the skills without hesitation; in contrast during the assessment, many participants did not attempt the skill. Additionally, children actively sought thrills during the fun games when a competitive aspect was introduced. This may be attributed to the atmosphere at the fun

games and heightened emotions or competition. Young manual wheelchair users have less wheelchair experience in comparison to older adults therefore most likely have not experienced regular falls or injury. It could be argued that older manual wheelchair users are more cautious as a result of their previous experiences (Sakakibara et al. 2013). This would imply that younger wheelchair users may achieve more advanced skills quicker than older adults thus in a greater position to learn from wheelchair skills training. For this reason, earlier exposure to wheelchair skills training as implemented in this study, may improve skill retention and improve overall skill acquisition in young manual wheelchair users.

In recent years, there has been a push towards including children with additional needs in mainstream schools (Pitt & Curtin 2004). Although this reduces the perceived segregation of children based on ability levels, it also means there are fewer specialised services or activities for a child with a physical disability to take part in (Salend & Duhaney 1999). Additionally, very rarely does a child have the opportunity to engage with their parents and siblings as a fellow wheelchair user, therefore engaging with them in this context normalises their disability. The participation of parents also provided them with first-hand experience of wheelchair use which may impact on their role as a carer. It is uncommon for carers or parents to receive wheelchair skills training on how to assist their child therefore they rely solely on instruction from their child to assist (Henderson et al. 2008).

As outlined in Chapter 5, some participants due to their condition, may not have the physical capacity to achieve some skills and may always rely on a carer for assistance negotiating environments. Kirby et al. (2004) conducted a study on the knowledge of carers involved with manual wheelchair users where none of the caregivers had any previous experience of wheelchair skills training for assisting a wheelchair user. In this cohort, caregiver skills training improved by 22% and was clinically and statistically significant, highlighting the benefits of formal training to caregivers. Although viewed as a limitation of this study, manual wheelchair users instructed their caregivers at times how to assist them which in turn potentially biased results, as they aimed to measure the skill set of the caregiver alone. It could be argued that for those whose capacity is limited, a combination of wheelchair skills training for manual wheelchair users and skills training for the caregiver

may prove beneficial in enabling independence and improving overall skill acquisition. Additionally, satisfaction of parents and children in relation to wheelchair provision has been associated with a combination of an adequate assessment by the therapist and education of all those who will handle the equipment, not just the participant themselves (Aldersea 1999).

A child with a disability often has complex medical needs and may be perceived as vulnerable, where parents may feel the need to protect their child (Heah et al. 2007). While parents acknowledge the physical health and social benefits of participating in physical activity, they have also voiced concerns about the injury risk associated with participating in sporting activities (Sanders 2006). These concerns have the potential to manifest as barriers to social participation, particularly in the case of a child with a disability, where parents may already have concerns for their safety. In a study by Boufous and Finch (2004), over one quarter of parents or carers surveyed reported discouraging children from playing sport or physical activity because of concerns for injury. Parents may also consider mobility as the primary rehabilitative goal in their child's development; often this manifests as the desire for their child to walk (Wiat & Darrah 2002). Particularly in the case where a child may be transitioning to wheelchair use or may use a wheelchair part time, the use of a manual wheelchair may be perceived as a regression in their condition or disability. The perspectives of parents and carers are therefore critical in designing and implementing services relating to young people or children to ensure they reach their rehabilitation or treatment goals.

Within this study, the presence of parents was requested primarily for safeguarding reasons. Many participants had never undertaken a formal wheelchair skills assessment previously, therefore it was envisaged that the presence of a parent may provide comfort to a participant if they became unsettled. It is normal for a child to have a reliance on a parent or care giver however when this becomes an over-reliance, children may develop a learned helplessness where they solely rely on their parents for assistance. Throughout the wheelchair skills training programme, participants were encouraged to mobilise independently within their capacity however, they are in a transitioning period where parental guidance and assistance is expected. If a participant did have an over-reliance on

their parent or carer this had the potential to impact on their ability to perform the skills to the best of their ability in the assessment (Kanters et al. 2008).

At the beginning of testing, all participants were advised they did not have to participate if they did not want to and could opt out at any time. One participant became unsettled mid pre-test and the researcher concluded the assessment at this point. It was clear the participant was not comfortable in the testing environment and understandably sought reassurance from their parent. The participant was more than happy to join the ongoing fun games in the next room and no lasting effects were noted. To avoid causing undue stress to participants and avoidance of these scenarios, it may be beneficial to discuss with the parent and participant prior to commencement of the skills test, the skills that will be assessed and how they will be assessed.

Additionally, it should be asked whether the participant would prefer the presence of the parent or not. Parental presence may be comforting for participants however, it may also add additional pressure on the participant to perform better (Babkes & Weiss 1999). Each participant has individual needs and priorities and therefore a client-centred approach is critical in ensuring the participant is comfortable, safe and consenting to participation (Coyne 2010).

Due to illness, one participant was unable to attend several of the wheelchair skills training sessions however, they returned for the final day of skills training. It was observed that the period of time away from the skills training resulted in a regression of their skill level, strength and confidence, although the latter was not formally assessed. It is difficult to determine whether this was primarily due to the period of illness or if the time away from skills training resulted in a lower overall score. This may also be reflected in their lower ASK score. This participant also missed sessions relating to the more advanced skills and therefore had no exposure to the tasks or opportunity to practice them thus it could be argued had less confidence in attempting these skills at the final day of testing. This may imply that wheelchair skills training would be beneficial at key milestones of a child's development. For example, after periods of illness or when starting a new school where they may encounter a new environment or on obtaining a new wheelchair. It is difficult to

confirm this hypothesis, however the researcher would recommend continuous skills training throughout the child's development, to further build on skill acquisition.

The type of wheelchair used poses an additional challenge in generalising results within this study. Children by nature will grow and their strength will increase. As a child develops, so too will their needs, specifically their mobility needs such as wheelchair use. The process for obtaining a manual wheelchair through the National Health Service (NHS) can be a lengthy process and often children may have to use a wheelchair that is unsuitable for them until a replacement has been manufactured. Prolonged delays in wheelchair provision can mean lengthy periods of time where a child is expected to use an alternative wheelchair or mobilise in a wheelchair not configured to their needs.

One participant in the study was unaware that they required a new wheelchair. The OTs on hand identified this issue to the parents and felt that due to the participant's growth spurt over the summer months, a larger wheelchair would be beneficial in facilitating increased mobility compared to their current wheelchair. It could be argued that this participant did not complete the final skills test in a wheelchair configured to their needs, however even if this was identified at an earlier point, it is possible the wheelchair would not have been manufactured in time for the final skills test. Sanders (2000) stated the average time from referral to delivery of a new wheelchair in the NHS is approximately 6 months. This is a considerable amount of time in a child's life where they are still growing and by the time a new wheelchair is issued, the child's needs may have changed again. In these circumstances a child may lose a degree of independence if they cannot mobilise in their wheelchair, thus compounding the need for continuous skills training at various mile stones in a young person's development.

As mentioned above, a difficulty lies in conducting research with children due to growth and their change in ability over time. It is difficult to generalise the results of this study as several variables could have impacted the results. It is possible that an increase in skill level or ASK score could be attributed to the increase in growth and strength however this was not formally assessed. Alternatively, a decrease in skill level could be attributed to a regression in illness, period of sickness or the degenerative nature of some physical disabilities which

may also be reflected in their ASK score. Retention of skills between sessions may also have impacted on skill acquisition. More advanced skills which were covered in the latter stages of the wheelchair skills programme may have been fresher or more pertinent to participants as they were the most recently covered. Learning effects are also well documented in relation to repeated measures studies where participants are already aware of the questionnaire/assessment constructs and therefore have a potential to bias results at post-test (Wu et al. 2003, Hopkins 2000, Crowder 2017). Additionally, the atmosphere at the final day of testing where participants knew they were being assessed could have heightened emotions impacting on test scores. Participants were also encouraged to practice their skills they learned at home, thus further practice of skills may increase confidence resulting in a higher wheelchair skills test score over time.

6.5 Implications for future research

Children with physical disabilities may at times experience feelings of indifference from their fellow classmates or peers (Lindsay & McPherson 2012). The use of a manual wheelchair provides a child with means to mobilise however, it may also exclude them from participating in activities designed for able-bodied peers (Connors & Stalker 2007). The integration of fun games in this study was key to ensuring the inclusion of all participants as well as providing the opportunity for siblings and parents to join in. Fun games provided opportunity for participants to form new friendships and participate in childhood play as able-bodied children. Integrated physical activity has been shown to normalise play for children with disabilities, and reinforces their social identity as “normal” children (Taub & Greer 2000). The use of the buddy system gave participants a chance to play and liaise with their peers, and let them see first-hand how they have managed their disability. The peer buddies gave the participants a figure to look up to, speak about relevant issues as part of growing up such as socialising, transitioning through education, learning to drive and other modern day concerns young people may have growing up. In future research studies, a similar mentoring or buddy system may prove beneficial in improving participant’s confidence and knowledge of their wheelchair and how to apply this to daily living.

6.6 Study Limitations

Although the results of this study proved significant, it is important to acknowledge the limitations of the study. The sample size was smaller than anticipated and may not accurately represent the general population of young manual wheelchair users aged five to fifteen years. Although the NI Manual Wheelchair Skills Assessment encompassed a wide variety of skills, the outcome measure is yet to be tested for reliability and validity and is therefore a limitation. Scheduling the sessions on a weekend day may have been a limitation as often for parents who work full time, the weekend may be the only chance they can engage in their own personal activities. Potentially parents may have already had a full schedule, as many participants have other siblings who have other recreational activities at the weekend, and it may have proven difficult for families to commit to a full eight-month programme.

6.7 Conclusion

In conclusion, the training was positively received by both participants and parents/carers. Monthly wheelchair skills training sessions can potentially improve skill acquisition in young manual wheelchair users; training should be ability matched and on-going throughout the child's development years, particularly in the case of illness where skill regression may occur. The training programme should be revised in line with the researcher's findings should it be used with children to exclude skills not applicable as outlined above. Further research would be required to include a greater sample size in order to make findings applicable to the wider young manual wheelchair user population and a larger, more diverse sample is needed to ensure the generalisability of the results.

CHAPTER 7:

GENERAL DISCUSSION: MAIN
FINDINGS, CLINICAL IMPLICATIONS
AND AREAS FOR FUTURE RESEARCH

7.1 Overview of Research

Wheelchairs are the most effective solution for individuals with a spinal cord injury with impaired mobility, enabling these individuals to be functionally independent, without the assistance of a carer (Sim et al. 2017). Although wheelchairs provide a level of independence, use of them can have detrimental effects on the MSK system. Manual wheelchair users often experience persistent and chronic pain of the upper limb, primarily attributed to the overuse of the structures and muscles of the upper limb (Chapter 2), where excessive force is required during wheelchair propulsion and wheelchair transfers. The anatomy of the upper limb is not designed to conduct these types of weight bearing activities and the repetitive nature of these movements can result in upper limb pain (Finley et al. 2004, Gagnon et al. 2008). Upper limb pain in manual wheelchair users negatively affects participation in social and recreational activities, completion of ADLs, sleep and vocational activities (Rice & Rice 2017). Treatment of upper limb pain in manual wheelchair users can often prove difficult, as with many injuries, relative rest is required in order for the upper limb to recover. As the upper limb is required for mobility on a daily basis for manual wheelchair users, relative rest is not feasible.

The overall aim of this research was to gain an understanding of upper limb injuries in patients with an SCI. A programme of research was undertaken using an evidence-based approach to explore the international literature, the patient experience of managing upper limb pain and the therapist's experience of treating upper limb injuries. A systematic review was undertaken to identify the prevalence of upper limb injuries sustained by SCI manual wheelchair users (Chapter 2). Following this, patient and therapist views of upper limb pain, the medical and rehabilitative approach to treatment, how upper limb pain affected daily life and therapists' experience of treating these injuries, were explored using qualitative methodology and thematic analysis (Chapters 3 & 4). Findings from chapters 2 to 4 informed the development of the final study; wheelchair skills training for young manual wheelchair users. A systematic review was undertaken to identify the most valid and reliable tool for assessing manual wheelchair skill (Chapter 5). Following this, a six-month wheelchair skills training programme was administered to a sample of young manual wheelchair users in Northern Ireland (Chapter 6). Each study presented in this research has provided its own novel additions to knowledge in the area of manual wheelchair use. This chapter

summarises the findings from each study, the clinical implications and areas for future research.

7.2 Summary of major findings

7.2.1 Systematic review prevalence of upper limb pain in SCI

In Chapter 2, a systematic review following the Preferred Reporting Items of Systematic Reviews and Meta-Analysis (PRISMA) guidelines was conducted to examine the prevalence of upper limb injuries in the SCI population. Prevalence rates of upper limb pain varied widely, with the shoulder the most common site of pain investigated. Pain was significantly associated with length of time since injury but not age. Pain was exacerbated primarily by outdoor wheeling, pushing up ramps and inclines and wheelchair transfers. The presence of pain was primarily attributed to the overuse of the upper limb for mobility purposes. Two studies outlined additional factors such as poor wheeling technique and the adoption of abnormal movement patterns which may contribute to poor wheeling techniques.

Little information was available regarding treatments prescribed for upper limb pain or how effective the reported treatments had been. In the studies that had reported previous treatment interventions, medication was primarily used to manage pain. Recommendations for the prevention of upper limb pain included education of participants on joint protection and energy conservation techniques, and education on correct wheeling techniques to avoid abnormal movements which may contribute to the development of upper limb pain. In one study, participants stated they were fearful undergoing invasive treatments such as steroid injections and surgery, as the pre-requisite of rest in order for these treatments to take effect, was not deemed feasible (Pentland & Twomey 1994). The results of this review highlighted a significant gap in knowledge; upper limb pain is prevalent in SCI manual wheelchair users however, little information on the most effective treatments prescribed was available. This review highlighted the need for further research to establish the medical and rehabilitative approaches to treatment and the functional impact of pain for patients with an SCI.

7.2.2 Qualitative Exploration of upper limb pain: patients with an SCI

Based on the findings of Chapter 2, the studies presented in Chapters 3 and 4 were designed to address the issues highlighted. A mixed methods study was undertaken to establish the prevalence of upper limb injuries in the SCI population of Northern Ireland and the treatments availed of by this cohort for management of upper limb pain. This study consisted of a questionnaire, review of medical notes and one-to-one interviews to explore the functional impact of pain. Shoulder pain was the most prevalent site of pain reported as is reflected in the wider literature (Chapter 2), followed by neck, back, elbow, hand and finger pain. Prevalence of pain was poorly reported in the medical notes, with little to no information regarding any treatments availed of by participants documented. During one-to-one interviews, participants reported that pain affected them in all aspects of daily life and this was reflected in 24/32 domains of the ICF core set for SCI: chronic setting, during interviews.

In relation to treatment, participants primarily reported self-managing their pain. Participants reported a lack of specialised services in the community equipped with adequate knowledge regarding SCI, to provide them with advice on managing their pain. Participants reported positive benefits from attending allied health services such as physiotherapy and occupational therapy; unfortunately, they reported only short-term relief from treatments overall. The majority of participants had a particularly negative view of the Regional SCI (RSCI) centre. Many had not been called for review in over ten years, and one participant's medical notes were unable to be located. Overall this study highlighted how patients with an SCI felt their needs were not being met in relation to their upper limb pain and highlighted a lack of specialised services available to them in the community.

7.2.3 Qualitative exploration of upper limb pain: occupational therapy perspective

The sentiments of occupational therapists echoed that of the SCI participants in that they felt there are no specialised SCI services in the community. An outpatient physiotherapy service located at the RSCI centre is in place however, no SCI outpatient occupational therapy service exists. In relation to treatment of upper limb injuries, participants reported that at the acute phase of injury, upper limb pain such as that of an overuse injury, was not prevalent, as these injuries tend to manifest over time. Participants did not treat upper limb

injuries directly, except in the case of patients with tetraplegia, where their upper limb pain was attributed to their level of injury, not an overuse injury as is investigated in this study. The primary rehabilitative goal for therapists during initial rehabilitation was to provide the patient with sufficient mobility to undertake normal daily activities.

At this stage of the rehabilitation pathway, it is possible that joint protection advice may not always be adhered to as it is not the patient's primary concern. Therapists reported advising patients of joint protection techniques however it was unclear if all patients followed this advice; they felt patients will mobilise from A to B using a method they find easiest. Goal setting was a key element of rehabilitation however, therapists reported how often patients did not think any further than their discharge date, which may imply patients are not consciously aware of the risk factors of developing upper limb pain at this point. Therapists reported a strong sense of responsibility in treating their patients as they were distinctly aware that on leaving the RSCI, they may never receive the same level of specialised care in the community. This sense of responsibility has increased over the years due to shorter hospital stays, where often therapists do not have adequate time to prepare patients fully, to reintegrate into their previous life roles.

7.2.4 Systematic review wheelchair skills tests

Wheelchair skills training was identified as a key element of rehabilitation in the acute phase and was recommended as a preventative measure of upper limb pain in Chapter 2. Intensive wheelchair skills training took place from day one at ward level with formal training delivered by charities at the RSCI centre annually. Therapists identified this as a critical element to a patient's recovery, in that if they could not propel their chair, they could not attend therapy, therefore slowing down their rehabilitation. Therapists reported how they would like to deliver further wheelchair skills training for patients post discharge however, due to the nature of the inpatient unit, outpatient interventions of this nature were not feasible. Therapists also highlighted how very few community therapists could deliver formal wheelchair skills training, and if so, they were unaware of what skills this included or at what stage of a patient's rehabilitation it was delivered.

The concept of wheelchair skills training was highlighted in Chapters 2, 3 and 4, as being key to both patients with an SCI initial rehabilitation and their ability to be independent. Following this a systematic review, following PRISMA guidelines, of observational wheelchair skills tests was undertaken to identify what wheelchair skills tests exist and the most reliable and valid tool to measure wheelchair skill ability in manual wheelchair users (Chapter 5). The review highlighted ten different skill tests, each measuring various aspects of wheelchair use. The most comprehensive skills test included was the Wheelchair Skills Test (version 2.4) by Kirby et al. (2004), which included a battery of skills focused on propulsion, ramps and transfers, while also incorporating practical tasks such as picking an item off the ground, crossing a road and propelling a wheelchair while carrying an item. The test had also been utilised with a variety of conditions and diseases, thus was suitable for use across a broad range of manual wheelchair users. The researcher anticipated implementing this tool in Chapter 6, but due to the costs involved in sourcing the standardised equipment, unfortunately this was not feasible.

7.2.5 Wheelchair skills training programme for young people: a pilot study

As outlined in Chapter 2, poor wheeling can have long-term effects on upper limb injuries within the manual wheelchair using population. Conclusions drawn from this systematic review indicated that wheelchair skills training can potentially improve this outcome (Oyster et al. 2012, Rodgers et al. 2001, Westgaard & Winkel 1997, Boninger et al. 2005). Research indicated that wheelchair skills training can potentially reduce joint degeneration and avoid the adoption of abnormal wheeling techniques, thus reducing the overall strain on the upper limb during wheelchair related activities. Young manual wheelchair users are also undergoing a transition period where they may have previously relied on their parents for mobility purposes and may now wish to be more independent. Providing a more efficient method of independent mobility also enables young manual wheelchair users to conserve energy for more meaningful activities which would normally be used during locomotion (Cox 2003). In support of this type of training a study by Sawatzky et al. (2012), reported that a longer period of skills training, over six months, would be more beneficial to young manual wheelchair users.

A wheelchair skills training programme was designed by the Regional Wheelchair Skills training therapist and was implemented as a checklist in this study. All participants showed a significant increase across intermediate and advanced levels; intermediate 29% increase ($p=0.017$); advanced 37% increase ($p=0.042$). An overall increase of 6% was observed in relation to the basic skill level however, this was not statistically significant ($p=0.083$). The ASK questionnaire showed little to no increase in performance with more promising results from the impact questionnaire, where participants reported feeling more confident in attempting skills. The results of this study show that a six-month wheelchair skills training programme is effective at improving skill acquisition in young manual wheelchair users aged five to fifteen years. A decrease in skills level was observed in one participant after a period of illness; therefore, the researcher recommends skills training be administered at critical milestones of a child's development. Overall, the programme was feasible to deliver and enabled participants to mobilise independently while increasing their confidence as a wheelchair user. This programme is also currently being rolled out across Northern Ireland with several occupational therapists now trained in the delivery of wheelchair skills training.

7.3 Key research areas

7.3.1 Upper limb pain as a priority

The results from chapter 3 outlined how patients felt that upper limb pain was not a primary concern, due to the complex nature of SCI and more pressing medical issues. Similarly, therapists' sentiments highlighted how often patients are only thinking of their short-term goals during their inpatient stay and upper limb pain may not be a concern at this point. Priorities of patients with an SCI have previously been investigated; Simpson et al. (2012) conducted a systematic review on the life and health priorities of patients with an SCI post injury and found that baseline mobility, bowel and bladder management were cited as the most important issues requiring management post injury. Additionally, Duggan and Dijkers (2001) reported that after initial injury and the resettling phase post injury, the life and health priorities of patients with an SCI can change dramatically. Initially, patients who use a manual wheelchair for mobility may report a desire to return to their previous baseline mobility levels however, it could be argued that as they age and find pain more prevalent, their priority may change to managing pain, where the prevalence of pain may limit their initial priority of mobility.

Sentiments from therapists in Chapter 4 outlined how shorter length of hospital stays made it difficult for therapists to prepare patients fully for community integration on discharge. Therapists cited factors such as time, physical strength and emotional readiness of patients which may have deterred them from completing further rehabilitation in preparation for life post discharge. The length of stay post initial injury in SCI rehabilitation centres is primarily cost driven (Cao et al. 2011). Eastwood et al. (1999), reported that length of stay is dictated by a number of factors including type of injury, level of injury and medical complications however, generally discharge should occur when a patient's functioning begins to plateau. Contrastingly, the views of healthcare professionals in chapter 4 was that they felt patients are now leaving rehabilitation when they are medically fit. It could be argued that patients leave when they have met their initial rehabilitation goals however, further therapy such as vocational rehabilitation is becoming less and less prevalent.

7.3.2 Life post discharge

Therapists (in Chapter 4) reported one of the major desires of patients post injury, was to return to their previous life roles. In ensuring patients can successfully reintegrate into their previous life roles on discharge, it could be argued that vocational rehabilitation may be one aspect that is currently overlooked. Evidence relating to return to work post rehabilitation suggests only one third of patients with an SCI successfully gain employment post injury (Krause 2003, Krause et al. 2010). Additionally, early intervention in relation to vocational activities at the initial rehabilitation stage, has been associated with higher employment rates post discharge in patients with an SCI (Chan et al. 2006, Dutta et al. 2008).

The presence of upper limb pain, specifically shoulder pain, has been attributed to greater periods of unemployment in patients with an SCI (Gerhart et al. 1993). The National Spinal Cord Injury Statistical Centre (2015) reported that only 12% of patients with a SCI are in employment one year after injury. In a study by Ferdiana et al. (2014), predictors of employment for patients with an SCI were poor overall regardless of level of injury; low trajectory levels of employment were reported for more than half of participants. Returning to work post SCI is more common in patients who were injured at a younger age and those with higher functional independence (Lidal et al. 2007). Thus, the limiting nature of upper limb pain may act as a barrier to patients with an SCI in pursuing or continuing employment.

Employment is a key aspect of community participation therefore limiting employment further restricts participant's ability to be fully independent (Barclay et al. 2016).

7.3.3 Dissatisfaction with services

In Chapters 3 and 4, the researcher aimed to gain an insight into upper limb injury and pain and how these affected participants on a daily basis. It is difficult to ignore the fact that both patients with an SCI and staff of the RSCI centre felt there was a lack of services available to patients on leaving the RSCI centre, and a dearth of specialised knowledge in the community. With the current push towards home-based care, it is difficult to determine what pathway exists, if any, for treatment of upper limb pain. To add to this, several participants had also not been reviewed in several years at the RSCI centre, potentially highlighting a lack of follow up care received. There are no clinical guidelines relating to how often a patient with an SCI should be reviewed, what elements should be reviewed at this point or who should conduct this review.

Follow up healthcare plays a critical role in preventing the risk of associated secondary or chronic conditions in long-term care (Rimmer and Rowland 2008). Dissatisfaction with services is not a new phenomenon in relation to SCI, with wider evidence focusing on the impact of community care and social integration of patients with an SCI (Craig et al. 2015, Donnelly et al. 2007, Platt et al. 2016). Evidence suggests that although newly injured patients receive excellent care at the acute and post-rehabilitation phases, they feel increasingly unprepared for transitioning home, particularly in relation to their psychological and community functioning needs (Cott 2004, Wallace and Kendall 2014, van Loo et al. 2010).

7.3.4 Lack of specialised knowledge

As is reported in this thesis, the lack of specialised knowledge in the community may not be specific to Northern Ireland only. In a study by Cox et al. (2000), 81% of patients with an SCI reported the greatest barrier to receiving adequate care in the community was the perceived lack of specialised knowledge available to them. Similarly, Stillman et al. (2014), reported that 79% of patients with an SCI sought treatment for a secondary condition from their primary care provider however, of these, only 54% of participants reported being

satisfied with the care they received. Access to healthcare for patients with any long-term condition is key to promote quality of life and community participation (Epping-Jordan et al. 2004). The lack of community services not only acts as a barrier to receiving adequate care, but also acts as a barrier to independent living and community participation.

The lack of specialised knowledge in SCI specific community services has been associated with lower health outcomes, social isolation and the development of life threatening complications in patients with an SCI (Cott 2004, Dickson et al. 2011, MacAweeney et al. 1996). There are many community organisations in Northern Ireland such as charities and sports clubs supporting the wider needs of patients with an SCI, but there are very few designed to cater specifically for their medical needs. Unmet needs have the potential to not only increase the impact of disability on the individual, but place further strain on their families and carers (Dryden et al. 2004).

7.3.5 Follow-up care

In looking towards the wider literature in relation to community management of secondary complications in SCI, a systematic review by Bloeman-Vrencken et al. (2005) aimed to compare follow up community care programmes for patients with an SCI. The care programmes utilised across studies included telemedicine, outpatient consulting hours, home visits and miscellaneous programmes such as social outings and peer education. The studies primarily aimed to reduce hospital admissions in relation to pressure ulcers, however it could be argued that an aspect of managing upper limb injuries could be incorporated into these programmes. Although some programmes showed promising results, the low quality of studies included and small sample sizes made it difficult to draw generalisable conclusions from results, therefore more research is needed to evaluate the effectiveness of such.

To the author's knowledge, there are no SCI specific follow up services available to patients with an SCI in Northern Ireland. These services are critical in supporting not only their medical needs, but their long-term physical and emotional health needs that are essential to independent living. Creation of services such as an outreach therapist specialised in SCI may improve overall patient care, thus improving quality of life for patients with an SCI (Barker et

al. 2009), however further research is required to establish the feasibility and cost effectiveness of delivering this proposed service.

7.3.6 Cost of secondary conditions

It should be acknowledged that although upper limb pain impacts negatively on ADLs, there are additional more life threatening secondary conditions associated with SCI. Diseases of the genitourinary system such as urinary tract infections (UTI's), respiratory issues and pressure ulcer development, are all more commonly suffered by SCI population and can often result in hospitalisation (Jensen et al. 2011). The cost of hospital admissions for overall secondary complications in SCI within the UK is unknown, however in the United States, the average annual cost per SCI patient to the health service ranges from \$27,568 in patients with paraplegia to \$132,807 in patients with high level tetraplegia (French et al. 2007). These figures are taken from the Veterans Health Administration statistics and are costed from one-year post injury therefore does not include the initial medical costs at injury.

Upper limb pain is only one complication of SCI however, it could be argued that in addressing some of the concerns raised by both patients with an SCI and the staff involved in their care, the overall cost to the NHS for treatment of these conditions could be reduced. For example, a literature review by Stinson et al. (2013) reported the average cost of pressure ulcer management in the UK is one of the highest worldwide, costing the NHS £1.7 billion annually. If musculoskeletal upper limb injuries could be averted, this would be one less cost for the NHS. Additionally, if a follow up service existed within the RSCI centre, perhaps the manifestation of these secondary conditions could be identified at an earlier point. Further research is required to establish whether the development of a service to conduct yearly reviews of patients with an SCI would reduce NHS costs in the long-term. This service could potentially facilitate early detection of secondary complications rather than when they have progressed significantly resulting in costly hospitalisations.

7.3.7 Self-management of pain

The management of upper limb pain has proved difficult due to a number of factors, in particular, the prerequisite of rest as reported in chapters 2 and 3. Patients primarily reported self-managing their pain via the use of medication and seeking private

physiotherapy. The use of medication may be effective for minor injuries or pain however, many medications are not recommended for long term use. Therefore, medication may be viewed as a “quick fix” to a bigger issue. The short-term relief reported from medication in this study is in line with wider evidence where several studies found medication does not provide “meaningful” pain relief for the majority of SCI patients with pain (Cardenas et al. 2002, Warmis et al. 2002, Widerstrom-Noga and Turk 2003).

An alternative option to management of pain via medication is that of upper limb surgery. Surgical interventions have shown mixed results for treatment of upper limb pain. Goldstein et al. (1997) found that of patients with an SCI who underwent surgical repair of the rotator cuff, none of the participants noted any improvement in shoulder function or range of movement post surgery. Contrastingly, Robinson et al. (1993) found patients reported less pain and increased range of movement post surgery. More recently, Popowitz et al. (2003) found patients reported increased functional capacity and decreased pain post surgery however, outlined the demands of the postoperative rehabilitation programme, that if not adhered to correctly, may result in failed rotator cuff repair or reoccurrence. Fattal et al. (2014) conducted a retrospective study on rotator cuff repairs on patients with an SCI and found when the wider multidisciplinary team delivered joint protection education post surgery, the rate of recurrence was reduced. It could be argued that surgical intervention for upper limb pain is not suitable for all patients with an SCI. There are mixed feelings whether such surgical interventions are effective and whether the post-operative rehabilitation is suitable for patients with more active lifestyle needs, where considerable rest and rehabilitation post surgery may temporarily limit independence.

7.3.8 Wheelchair skills training in Northern Ireland

More recent evidence relating to management of upper limb pain has focused on preventative measures such as exercise (Cratsenburg et al. 2015, van Strateen et al. 2014), joint protection education and wheelchair skills training, as outlined in Chapters 2 and 5. Unfortunately, if patients are not being reviewed regularly, it is unclear whether this advice or education is being delivered. As outlined in Chapters 5 and 6, it has proven difficult to obtain a detailed overview of wheelchair skills training delivered in Northern Ireland. For the population with an SCI, wheelchair skills training is administered during initial rehabilitation

however, it is unclear if this is followed up at a later point. This may potentially be attributed to the knowledge of therapists in the community regarding wheelchair skills training. Several studies have outlined that wheelchair skills training delivered to therapists is suboptimal (Bullard and Miller 2001, Cohen et al. 2001). The consequences of therapists not being educated in wheelchair skills training themselves is that they are less confident and therefore less likely to administer it to patients (MacPhee et al. 2004). If therapists are not confident in their ability to teach wheelchair skills, they may also be less likely to encourage their patients to attempt more advanced skills, even if it is within the patient's functional capabilities (Kirby et al. 2004).

The lack of evidence relating to wheelchair skills training in Northern Ireland is not surprising. It is promising however to report that several occupational therapists have now received formal training in delivering wheelchair skills training to patients. This is a relatively new venture delivered by the Regional Wheelchair Training Occupational Therapist and shows promising results in enabling therapists to improve wheelchair skill acquisition in their patients while also furthering their own professional development. Additionally, a unique aspect identified from Chapter 6 was a regression in skill level after illness. With more therapists now being trained in the delivery of skills training, the potential to administer skills training at key milestones of young manual wheelchair users' development will be more attainable with increased education of therapists.

7.4 Areas for future research

Research on the effect of long term manual wheelchair usage is very limited in Northern Ireland and it could be argued manual wheelchair user's voices are underrepresented. The proposals for the reform of the Wheelchair Service (2008) was the first publication to address the lack of services and it is hoped this research may bridge the gap towards fully understanding the needs of wheelchair users in Northern Ireland. Further research should include higher level studies such as randomised controlled trials or longitudinal studies to determine if wheelchair skills training can effectively reduce, if not eliminate, the prevalence of upper limb injuries in manual wheelchair users. Specifically, for patients with an SCI who are life time manual wheelchair users; there is currently no cure for paralysis therefore their requirement for a mobility aid will not change. This magnifies the importance of such

research in this population as there are limited options available; seek powered mobility at a significant financial cost or manage pain with short term relief solutions such as medication.

With patients living longer with chronic conditions, shorter length of hospital stays and the ever-increasing costs to the NHS, a clear pathway would be beneficial to both patients with an SCI and staff involved in their care. For staff who may not feel competent in treating these injuries, a service to which therapists could refer to would facilitate in identifying these injuries earlier. Similarly, if a patient felt the early onset of an injury, (s)he could identify their injury before it became life limiting and seek treatment.

7.5 Methodological Considerations

A range of informative methods have been utilised within this programme of research to gain a greater understanding of upper limb injuries. The research presented in this thesis were limited by external factors impacting on the timely completion of the studies.

Identification of the potential cohort of patients with an SCI in Northern Ireland proved difficult where little was known regarding exact figures. The RSCI centre collects all patient and medical information in hard copy and no electronic records exist. It was not possible to stratify potential participants by disease or condition therefore the researcher was required to contact all patients who previously attended the RSCI centre.

Chapters 3 & 4 consisted of a mixed methods study including questionnaires and a qualitative aspect to elicit participant perspectives. Accessing patient notes proved particularly difficult within this study where participants were not keen to share this information with anyone outside their medical team. Additionally, little was documented in the medical notes regarding the presence of upper limb pain. This process was also quite time consuming; screening of each participant's medical notes took approximately two days. In future research, particularly in a larger scale study, devoting such time to this may not be practical, particularly when little information was documented in the notes. A greater sample could potentially have been recruited however, due to the associated limits on time and funding of completing a PhD, it was not possible to continue recruitment beyond November 2017.

7.6 Implications for clinical practice and service delivery

The research detailed in the above studies highlighted that more could be done to support manual wheelchair users with an SCI to manage and treat upper limb injuries. Preventative measures to date have provided short-term relief only and specialised SCI services are lacking in the community. Rather than treat these injuries when they manifest, the researcher proposed to explore the efficacy of delivering a wheelchair skills training programme to young manual wheelchair users which proved effective at improving skill acquisition in this population. The research discussed in this thesis has implications for not only patients with an SCI, but manual wheelchair users throughout Northern Ireland. Additionally, several implications for clinical practice have been highlighted which are discussed below.

There is a distinct gap in services available to not only patients with an SCI, but broadly manual wheelchair users in general. The establishment of norms or routine services as outlined above may prove beneficial in incorporating education, wheelchair skills training and energy conservation techniques into the rehabilitation process. This could be followed up by establishing a protocol where these services are accepted as key elements of a manual wheelchair user's treatment plan, to include what, when and how they are delivered to patients. Additionally, a general guideline of the expected goals or skill level that a patient could potentially achieve based on their strength, condition and age would be beneficial. Skills training should be ability-matched, and incorporated into a patient's treatment plan based on their projected recovery or baseline ability as a manual wheelchair user (Hosseini et al. 2012). This could include a list of defined skills such as kerb height, slope length and gradient to allow comparison between patients. Further research is needed to examine how practical it would be to incorporate this into clinical practice in Northern Ireland.

7.7 Limitations of studies

The researcher would have liked to include a larger sample size across all studies and the researcher acknowledges that the results may not be an accurate representation of the wider population investigated in these studies. The researcher recommends the results from these studies be interpreted with caution due to the lack of generalisability of results.

The therapists interviewed in Chapter 4 may be considered a limitation as they did not directly treat MSK overuse injuries. It could be argued that a more specialised sample could have been recruited from community therapists, however with no community therapists specialised in SCI, it is difficult to determine if they could provide as much detail than those in the RSCI centre. A physiotherapy outpatient service does exist at the RSCI and it would have been beneficial to have recorded their thoughts, however, all declined interview and the researcher therefore cannot report on their perspectives.

The use of self-reported questionnaires was a limitation of this research. Self-reported questionnaires were utilised in Chapters 3, 4 and 6. Self-reported questionnaires are useful when the data required is not normally collected via audits or medical practice or when database analysis is deemed too expensive or time consuming to conduct (Short et al. 2009). Despite the widespread use of these, there is little consensus regarding the accuracy of information reported and the validity of findings.

In Chapter 3, a potential bias lies in the over or under-reporting of upper limb pain by participants, such as recall timeframe where participants may suffer memory decay (Jenkins et al. 2002). Literature shows an increased number of hospital or healthcare visits results in an under-reporting of the number of visits therefore those who reported seeking treatment of their pain may not have accurately reported the frequency of treatment (Bhandari and Wagner 2006). Although this may question the validity of the findings, this was the most efficient method of collecting this information as it was not documented in the medical notes (Corser et al. 2008).

Chapter 6 provided novel findings that have implications applicable to the wider international context, however the small sample size utilised may not accurately represent the general population of young manual wheelchair users aged five to fifteen years. Although the Northern Ireland Manual Wheelchair Skills Assessment encompassed a wide variety of skills, the outcome measure is yet to be tested for reliability and validity and is therefore a limitation. The administration of the Activity Scale for Kids (ASK) questionnaire, requires further rigour in relation to how or whom the assessment is completed by. In future, the researcher would recommend documenting who completes the questionnaire

and ensuring the same parent/carer completes the questionnaire with the participant for rigour.

7.8 Strengths of studies

Aside from the limitations outlined above, there are several strengths of this research which may improve client centred care for manual wheelchair users. A strength of this research is the range of methodologies used to answer the research question. Both quantitative and qualitative methodologies were used in Chapters 3, 4 and 6. Qualitative research is widely documented as useful in exploring a research topic, particularly when the information required cannot be obtained via quantitative methods (McCusker and Gunaydin 2015). In Chapter 3, semi-structured interviews provided rich personal descriptions of participants' own sentiments relating to how upper limb pain affects them on a daily basis. In truly listening to the needs of patients, providing them with an opportunity to express their concerns or experiences assists in understanding what needs are being met, or what discrepancies in services exist (Gutterman et al. 2015).

Furthermore, qualitative methods enabled the researcher to gain an in-depth understanding of an issue not previously investigated before. The prevalence of upper limb injuries is well documented however, little was known regarding the functional impact these injuries had on daily life from the patient perspective. Asking participants to answer these questions on a predetermined questionnaire with strict categories would have proved difficult in comprehending the extent to which they felt pain impacted on their daily life, and the diverse array of treatments and coping strategies they employed. The quantitative methods of the questionnaire and review of medical notes complimented the qualitative methods used and reduced bias associated with using self-reported questionnaires (Goulet et al. 2013).

In Chapter 4, qualitative methods were also utilised. To the author's knowledge, this is the first study to date investigating the perspectives of health care professionals regarding upper limb pain in patients with SCI. As little is known about this topic, the information elicited in this study provides novel information regarding how staff perceive their role and how they feel they can better support their patients. Although only three therapists were

interviewed, this was the full complement of the OT department at the RSCI centre and therefore their concerns expressed are that of the entire RSCI OT department.

Chapter 6 was based on a study by Sawatzky et al. (2012) which is the only study to the author's knowledge to date which has previously conducted formal manual wheelchair skills training with children. The recommendations from this study stated how more research was required to assess whether a longer period of skills training would prove beneficial in improving skill acquisition. This study successfully addressed that question and an improvement in skill acquisition was observed. Manual wheelchair skills training for children is in an early stage of development and the findings presented in this study contributes to the significant gap in knowledge surrounding skill acquisition in young manual wheelchair users.

7.9 Conclusion

In conclusion, this research contributes knowledge to an evidence-based approach of identifying factors relating to upper limb pain in manual wheelchair use. It has been established that upper limb pain is prevalent, however with the small sample size utilised in all studies, results should be interpreted with caution. Information has been obtained regarding the treatment of upper limb injuries, the functional impact pain has on daily life for SCI manual wheelchair users, and the clinical perspectives of what can be done to ensure patients are better supported in the community. In addition, the efficacy of delivering wheelchair skills training in the community has been examined, and found participants not only showed an improvement in skill level, but they also felt more confident and independent as a wheelchair user going forward.

The programme of research undertaken within this thesis has highlighted both positive and negative themes in relation to the care delivered to patients with an SCI. In conclusion, further research is required in both the area of service development and the relationship between wheelchair skills training and upper limb pain sustained from manual wheelchair use. Below are the main areas for future research and clinical recommendations from this thesis.

7.9.1 The main clinical recommendations made in this thesis:

- Creation of specialised outpatient services equipped to manage secondary conditions associated with spinal cord injury to provide specialised care, home exercise programmes, advice on home adaptations or grading of tasks based on patients' abilities
- A clear treatment pathway for patients with an SCI who suffer upper limb pain; where to seek treatment, how to access such services and what treatments are available to them
- Annual reviews for patients with an SCI to discuss any issues or concerns they may be having and facilitate the early identification of upper limb injuries
- Increased patient education regarding upper limb injuries; how to recognise these injuries, reporting them to their healthcare professional and self-management of pain where possible
- Further research regarding the current service delivered by the RSCI both qualitative and quantitative, may assist in complementing the current service to ensure adequate and cost-effective provision of care is implemented
- Wheelchair skills training is effective at improving skill acquisition in young manual wheelchair users; training should be ability matched and on-going through a child's development particularly at key milestones throughout their developmental years

7.9.2 The main areas for future research resulting from this thesis:

- A uniform measurement for assessing upper limb pain in patients with an SCI would be useful to compare prevalence rates across levels of injury
- Further research is required regarding the type of treatments available for patients with an SCI with upper limb pain and what are the most effective at relieving pain
- Further research regarding the aetiology of upper limb injuries and risk factors of obtaining same to take a prevention rather than cure approach
- Higher quality studies such as randomised controlled trials comparing treatment methods for relief of upper limb pain in manual wheelchair users with an SCI

- Longitudinal studies comparing subgroups of persons with an SCI and their activities undertaken to identify predisposing factors which may increase the likelihood of obtaining upper limb injuries
- Higher level studies to investigate if wheelchair skills training can effectively reduce, if not eliminate the prevalence of upper limb injuries in manual wheelchair users
- Standardisation of the content of skills included in wheelchair skills tests to enable comparison between studies, building on established skills tests with strong reliability and validity
- Further research regarding the NI Manual Wheelchair Skills Assessment for reliability and validity will strengthen its status as an outcome measure to be used with young manual wheelchair users

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APPENDIX 16 Northern Ireland Regional Manual Wheelchair Skills Assessment Checklist

Appendix 1A: Study Characteristics

Author & year	Design	N=	Aims	Follow up	Method	Outcome measures	ADLs
Aljure, Eltorai, Bradley, Lin, Johnson 1985	Cross sectional	47 (91 hands)	To assess the prevalence of carpal tunnel syndrome in patients with paraplegia	N/A	Electro physiological studies of the median and ulnar nerves Physical exam	Standardised protocol for conducting tests according to Johnson 1980	No
Ballinger, rintala, Hart 2000	Cohort	89	To determine if shoulder pain and ROM problems can be predicted by demographic, injury related, body weight and radiographic data over 3 years	3 years	Radiographic assessment of shoulders in anteroposterior position Questionnaires Physical exam	FIM CHART	Yes
Boninger, Towers, Cooper, Dicianno, Munin 2001	Cross sectional	28	To use magnetic resonance imaging (MRI), plain radiographs, questionnaire and physical exam to gain insight into the prevalence of shoulder disorders	N/A	MRI X-ray Questionnaire Physical exam	MRI clinical protocol for identification of rotator cuff tears (RCT) X-rayed in AP, scapular AP and supraspinatus position	No
Dalyan, Cardenas, Gerard 1999	Cross sectional	130	To determine the frequency and severity of UE pain and its association with functional activities	N/A	Postal questionnaire	Non-validated questionnaire	Yes
El Essi, El-Shafie, Al Hawamdah, I Zaquot 2012	Cross sectional	80	Examine the prevalence of shoulder pain and its effects on ADLs	N/A	Interview Questionnaires	WUSPI Shoulder Rating Questionnaire (SRQ)	Yes
Eriks-Hoogland, de Groot, Snoek, Stucki, Post, van der Woude	Cohort	138	Examine whether MSK shoulder pain at first discharge are associated	5 years	Questionnaire Physical exam 3 wheelchair related tests	Passive ROM test FIM motor score Wheelchair skills test Transferring oneself	Yes

2016			with ADL restriction at 5 years			Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) 2 subscales from the sickness Impact Profile 68 (SIP68) (mobility range and social behaviour scales)	
Escobedo, Hunter, Hollister, Patten, Goldstein 1997	Cross sectional	37	To use MR imaging to evaluate the prevalence and extent of rotator cuff tears in patients with paraplegia	N/A	MRI (3 observers to interpret results) Scanned patients in supine position with arms adducted and the humerus head in neutral	MRI machine (Gyrosan ACS-2)	No
Gironda, Clark, Neugaard, Nelson 2004	Cross sectional	669	Examine the prevalence and intensity of pain and associated patient characteristics in paraplegia	N/A	Questionnaire of medical history Questionnaire	WUSPI	Yes
Nicholas, Norman, and Ennis 1979	Cross sectional	517		N/A	Postal survey		No
Pentland & Twomey 1994	Cross sectional	52	Describe the effects of longterm paraplegia and wheelchair use on upper limb function	N/A	Physical exam – physical performance and parameters of upper limb function Interview Questionnaire	Upper extremity isokinetic and grip strength, pain and active ROM using KinCom II isokinetic dynamometer	Yes
Pentland & Twomey 1991	Cross sectional	11	To compare upper limb function and pain in wheelchair using women with paraplegia to a matched able bodied sample	N/A	Physical exam – physical performance and parameters of upper limb function Interview Questionnaire	Upper extremity isokinetic and grip strength, pain and active ROM using KinCom II isokinetic dynamometer Smedley's hand held dynamometer	Yes
Samuelsson, Tropp, Gerdle 2004	Cross sectional	56	To describe the consequences of shoulder pain on activity and	N/A	Questionnaire WUSPI Interview	WUSPI Constant Murley Scale Klein and Bell ADL index	Yes

			participation in SCI wheelchair users with paraplegia		Constant Murley Scale Klein and Bell ADL index COPM Physical exam	COPM	
Sie, Waters, Rodney, Adkins, Gellman 1992	Cross sectional	239	To determine the prevalence of upper extremity pain in outpatients with SCI	N/A	Questionnaire Interview Physical exam (Pts offered physical exam following pain)	2 point discrimination and Semmes-Weinstein monofilament testing	No
Silfverskiold and Waters 1991	Cohort	60	To determine the incidence of non-traumatic shoulder pain and associated functional disability during the first 18 months after SCI	18 months	Physical exam following standard protocol at 6 months and then between 6-18 months following this Functional disability questionnaire	Own questionnaire Physical exam	Yes
Subbarao, Klopstein, Turpin 1994	Cross sectional	451	To identify the prevalence of chronic wrist and shoulder pain, to determine which activities caused or exacerbated pain and assess functional and emotional responses and how pain might be reduced.	N/A	Review of medical records Postal survey Physical exam (n=30) Interviewed prior to physical exam Included completing functional tasks transferring, propelling and dressing upper bodies	Own questionnaire previously pilot tested If pain reported in questionnaire participants were interviewed and then physical exam using standardised evaluation sheet	Yes
Van Drongelen, de Groot, Veeger, Angenot, Dallmeijer, Post, van der Woude 2006	Cohort	169	To study MSK UE pain during and after rehabilitation in wheelchair using participants with SCI and its relationship with lesion characteristics, muscle strength and functional outcome	1 year	4 test occasions Physical exam MSK pain questionnaire Manual muscle testing (MMT)	Lesion and personal characteristics assessed by physician Used standardised questionnaire MMT conducted in standardised positions Muscle force measured subjectively by research assist. FIM	Yes

Legend

ROM = Range of Movement; FIM = Functional Index Measure; CHART = Craig Handicap Assessment and Reporting Technique; MRI = Magnetic Resonance Imaging; RCT = Rotator Cuff Tear; AP = Anteroposterior; UE = Upper Extremity; ADLs = Activities of Daily Living; SRQ = Shoulder Rating Questionnaire; PASIPD = Physical Activity Scale for Individuals with Physical Disabilities; SIP68 = Sickness Impact Scale; WUSPI = Wheelchair Users Shoulder Pain Index; SCI = Spinal Cord Injury; COPM = Canadian Occupational Performance Measure; MSK = Musculoskeletal; MMT = Manual Muscle Testing

Appendix 1B: Outcome Measures characteristics

Author & year	N=	Method	Outcome measures	Prevalence	Association with SCI duration/age	Functional association
Aljure, Etorai, Bradley, Lin, Johnson 1985	47 (91 hands)	Electro physiological studies of the median and ulnar nerves Physical exam	Standardised protocol for conducting tests according to Johnson 1980	63% electrical abnormalities confirming CTS with 44.7% ulnar nerve neuropathy also	Incidence of CTS increases with length of time since injury; 27% 1-10 years, 54% 11-20 and 2-30 years, 90% 31 years + since injury	Not assessed
Ballinger, Rintala, Hart 2000	89	Radiographic assessment of shoulders in anteroposterior position Questionnaires Physical exam	FIM CHaRT	30% shoulder pain 22% shoulder ROM issues	Males with shoulder pain were 4 years longer as wheelchair users than those without pain	Men with shoulder pain scored lower CHaRT and FIM scores however unrelated to functional limitations
Boninger, Towers, Cooper, Dicianno, Munin 2001	28	MRI X-ray Questionnaire Physical exam	MRI clinical protocol for identification of rotator cuff tears (RCT) X-rayed in AP, scapular AP and supraspinatus position	32% reported shoulder pain 54% abnormal phys exam 41% subacromial spur 37% rotator cuff enthesitis 30% AC joint DJD 19% distal clavicle osteolysis 1 participant full RCT	No relationship between pain and imaging abnormalities but significant relationship between imaging abnormalities and BMI	Not assessed
Dalyan, Cardenas, Gerard	130	Postal questionnaire	Non-validated questionnaire	58.5% reported UE pain Shoulder = 71%	Significant relationship	Pain interfered with transfers in

1999				Wrist = 53% Hand = 43% Elbow = 35%	between age and pain. No significance between pain and sex, level of injury, para vs tetra.	65%. Pain associated with pressure relief lifts and wheelchair mobility
El Essi, El-Shafie, Al Hawamdah, I Zaquot 2012	80	Interview Questionnaires	WUSPI Shoulder Rating Questionnaire (SRQ)	62% shoulder pain	No significance	Significant relationship between pain and wheelchair propulsion;
Eriks-Hoogland, de Groot, Snoek, Stucki, Post, van der Woude 2016	138	Questionnaire Physical exam 3 wheelchair related tests	Passive ROM test FIM motor score Wheelchair skills test Transferring oneself Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) 2 subscales from the sickness Impact Profile 68 (SIP68) (mobility range and social behaviour scales)	39% shoulder pain 32% shoulder ROM issues	Not assessed	Limitations of shoulder ROM significantly associated with ability to transfer, FIM motor scores and return to work
Escobedo, Hunter, Hollister, Patten, Goldstein 1997	37	MRI (3 observers to interpret results) Scanned patients in supine position with arms adducted and the humerus head in neutral	MRI machine (Gyrosan ACS-2)	70% symptomatic of RCT 73% showed RCT on MRI 62% showed full thickness tears 12% showed partial RCTs	Prevalence and severity of RCTs significantly associated with age and time since injury	Not assessed
Gironda, Clark, Neugaard, Nelson	669	Questionnaire of medical history	WUSPI	81% ongoing unspecified UL pain	Significant association between	Not assessed

2004		Questionnaire		69% current UL pain	pain and level of injury No significance between pain and completeness of injury	
Pentland & Twomey 1994	52	Physical exam – physical performance and parameters of upper limb function Interview Questionnaire	Upper extremity isokinetic and grip strength, pain and active ROM using KinCom II isokinetic dynamometer	39% shoulder 31% elbow 40% wrist/hand	Shoulder pain was significantly associated with duration of injury but not age	Not formally assessed however tasks most impeded by pain were work/school, sleep, wheelchair transfers, outdoor wheeling, driving
Pentland & Twomey 1991	11	Physical exam – physical performance and parameters of upper limb function Interview Questionnaire	Upper extremity isokinetic and grip strength, pain and active ROM using KinCom II isokinetic dynamometer Smedley's hand held dynamometer	73% shoulder 9% elbow 55% wrist 45% hand	Development of pain is significantly associated with paraplegia compared to able bodied persons	Not formally investigated, pain most common when outdoor wheeling
Samuelsson, Tropp, Gerdle 2004	56	Questionnaire WUSPI Interview Constant Murley Scale Klein and Bell ADL index COPM Physical exam	WUSPI Constant Murley Scale Klein and Bell ADL index COPM	Shoulder 37.5%	No correlation between age or level of injury	No significant association with ADLs but 52 issues from COPM impacted by pain
Sie, Waters, Rodney, Adkins, Gellman 1992	239	Questionnaire Interview Physical exam (Pts offered physical exam following pain)	2-point discrimination and Semmes-Weinstein monofilament testing	<i>Quad results:</i> 55% reported UE pain 40% reported pain in more than one region 46% shoulder	Not assessed	Not assessed

				15% elbow 15% wrist 15% hand <i>Para results:</i> 64% reported UE pain 33% pain in more than one region 36% shoulder 16% elbow 13% wrist 11% hand 66% CTS		
Silfverskiold and Waters 1991	60	Physical exam following standard protocol at 6 months and then between 6-18 months following this Functional disability questionnaire	Own questionnaire Physical exam	78% quads and 35% pain in first 6 months 33% quads and 35% paras pain at 18months follow up	Significant reduction in % of sample with pain at second assessment	Not assessed
Subbarao, Klopstein, Turpin 1994	451	Review of medical records Postal survey Physical exam (n=30) Interviewed prior to physical exam Included completing functional tasks transferring, propelling and dressing upper bodies	Own questionnaire previously pilot tested If pain reported in questionnaire participants were interviewed and then physical exam using standardised evaluation sheet	72.7% reported pain in one or more areas of UE 35.6% shoulder 6.6% wrist 57.8% both wrist and shoulder	Time since injury but not age significantly associated with UL pain	Not formally assessed
Van Drongelen, de Groot, Veeger, Angenot, Dallmeijer, Post, van der Woude 2006	169	4 test occasions Physical exam MSK pain questionnaire Manual muscle testing (MMT)	Lesion and personal characteristics assessed by physician Used standardised questionnaire	UE pain decreased by 30% over time Tetra more pain than paras (no stat)	Significant relationship between shoulder pain and level of	UL pain and shoulder pain significantly related to

			MMT conducted in standardised positions Muscle force measured subjectively by research assist. FIM		injury (tetras at greater risk)	functional outcome
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Legend

ROM = Range of Movement; FIM = Functional Index Measure; CHART = Craig Handicap Assessment and Reporting Technique; MRI = Magnetic Resonance Imaging; RCT = Rotator Cuff Tear; AP = Anteroposterior; UE = Upper Extremity; ADLs = Activities of Daily Living; SRQ = Shoulder Rating Questionnaire; PASIPD = Physical Activity Scale for Individuals with Physical Disabilities; SIP68 = Sickness Impact Scale; WUSPI = Wheelchair Users Shoulder Pain Index; SCI = Spinal Cord Injury; COPM = Canadian Occupational Performance Measure; MSK = Musculoskeletal; MMT = Manual Muscle Testing; UL = Upper limb; CTS = Carpel Tunnel Syndrome; AC = Acromioclavicular; DJD = Degenerative Joint Disease; BMI = Body Mass Index; Stat = Statistic; Para = Paraplegia; Tetra = Tetraplegia

Appendix 1C: Causation of injuries and treatments sought

Author & year	Causation of injuries	Treatments sought	Recommendations
Aljure, Eltorai, Bradley, Lin, Johnson 1985	The high incidence of CTS in patients with paraplegia is directly related to the excessive use of hands to compensate for disability; direct relationship between length of injury and development of CTS	N/A	Early testing of median and ulnar nerve function even in asymptomatic patients within first 5 years after SCI and periodically reassessed for early identification of injuries
Ballinger, Rintala, Hart 2000	The shoulder becomes a weight bearing joint during weight shifts and transfers therefore suffers more stress during ADLs compared to able bodied population. Length of time since injury was related to shoulder pain and ROM attributable to the effects of ageing with a SCI	N/A	Rehabilitation professionals should actively seek innovative therapies to alleviate shoulder pain, design new assistive devices to make transferring less stressful and devise new methods of retraining muscles to perform ADLs
Boninger, Towers, Cooper, Dicianno, Munin 2001	Increased BMI may potentially be a causative factor of developing shoulder injuries however more research needed.	N/A	Longitudinal studies required to provide insight if increased BMI is a risk factor for developing shoulder pain
Dalyan, Cardenas, Gerard 1999	Pain is associated with more activity and the resulting overuse of the upper limb	63% sought medical treatment for pain and of those 90% received either physio, pharmacological treatment or massage. Only 27% had home modifications or joint protection education but 26.6% and 63.6% respectively found these very or extremely helpful	There is a need for the implementation of upper limb pain prevention and management programmes both in early rehabilitation and ongoing care even for decades. Wheelchair skills training to educate patients on the overuse of joints and principles on avoiding damaging patterns. Education and training in endurance and balanced strengthening of muscles to achieve normal alignment of shoulder structures

El Essi, El-Shafie, Al Hawamdah, I Zaquot 2012	Activities that exacerbated pain the most were pushing the wheelchair for 10 minutes or more, propulsion up ramps outdoors, performing ADLs at work or school, DADLs, transfers	N/A	Studies are needed on QoL in SCI population. Environmental adaptations need to be made more suitable for wheelchair users. More research required on treatment options and if psychological factors have any effect on shoulder pain and treatment
Eriks-Hoogland, de Groot, Snoek, Stucki, Post, van der Woude 2016	The questionnaire attempted to distinguish between neuropathic pain and MSK pain but cannot completely rule out some participants couldn't distinguish between the two.	N/A	A uniform assessment of pain would be beneficial to ensure study results can be compared
Escobedo, Hunter, Hollister, Patten, Goldstein 1997	The posterior locations of RCT tears in paraplegia may be related to extreme loading of the posterior cuff muscles, muscle imbalance or repetitive strain	N/A	MR imaging is useful in evaluating the shoulder in paraplegia
Gironda, Clark, Neugaard, Nelson 2004	Severity of upper limb pain is associated with functional impact however concluded that prolonged wheelchair related use of the ULs alone is an insufficient explanation for the development of pain	43% used opiate medications daily providing only moderate relief	Development, persistence and exacerbation of UL pain is a multidimensional process that may be best understood in the context of a comprehensive theoretic model that integrates existing empirical literature
Pentland & Twomey 1994	Tasks most commonly reported to elicit upper limb pain were work/school, transfers, outdoor wheeling and driving	Many participants felt medical interventions would be invasive such as steroid injections, surgery, hospital admission or rest. They were fearful of the former and felt rest was unobtainable	The significant influence of duration of SCI on shoulder pain suggests that even at a relatively young age persons with paraplegia should be watched closely for the development of overuse issues

Pentland & Twomey 1991	Women with paraplegia and their development of upper extremity problems secondary to years of wheelchair use is one of the late complications of long term disability. Upper limb pain was most reported in relation to work, outdoor wheeling, DADLs, child care	N/A	Participants would benefit from education on joint protection and upper extremity conditioning techniques of the muscles of the upper limb
Samuelsson, Tropp, Gerdle 2004	SCI patients tend to sit in a kyphotic posture during wheelchair propulsion therefore placing additional stress on the shoulder joint, depressing the acromial process and changing the facing of the glenoid fossa	N/A	The seating posture of the participant must be addressed for ultimate success in pain relief for wheelchair users
Sie, Waters, Rodney, Adkins, Gellman 1992	The structures of the upper limb are designed for prehensile activities. Upper limb in mobility of SCI patients are used more frequently and are subject to increased stresses compared to able bodied persons	30% reported significant pain requiring medication	Further research required on the development of strategies for treatment of pain syndromes
Silfverskiold & Waters 1991	As a younger sample age demographic was used in this study, shoulder pain could be attributed to abnormal glenohumeral motion during active or passive ROM	N/A	Appropriately treated, shoulder pain occurring in new SCI patients will be relieved without any remaining functional limitations in most patients
Subbarao, Klopstein, Turpin 1994	A bimodal incidence of pain was noted where there may be different mechanisms for pain occurring in SCI population. Perhaps acute trauma causes early pain and cumulative trauma late onset pain	N/A	Future research should be focused upon new methods of wheelchair propulsion and transfer techniques that lessen stress and cumulative trauma of the wrist and shoulders

Van Drongelen, de Groot, Veeger, Angenot, Dallmeijer, Post, van der Woude 2006	Tried to distinguish between neurogenic pain however it is not always possible to distinguish between the two and therefore MSK pain reports may include neurogenic pain reports	N/A	Overload of the upper limb should be avoided at initial inpatient rehabilitation. Training should focus on balanced training of the upper limb to strengthen muscles
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Legend

CTS = Carpel Tunnel Syndrome; ADLs = Activities of Daily Living; ROM = Range of Movement; SCI = Spinal Cord Injury; BMI = Body Mass Index; Physio = Physiotherapy; DADLs = Domestic Activities of Daily Living; MR = Magnetic Resonance; UL = Upper Limb; RCT = Rotator Cuff Tear; MSK = Musculoskeletal

Appendix 2A: Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies



Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies

Criteria	Yes	No	Other (CD, NR, NA)*
1. Was the research question or objective in this paper clearly stated?			
2. Was the study population clearly specified and defined?			
3. Was the participation rate of eligible persons at least 50%?			
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?			
5. Was a sample size justification, power description, or variance and effect estimates provided?			
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?			
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?			
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?			
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
10. Was the exposure(s) assessed more than once over time?			
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
12. Were the outcome assessors blinded to the exposure status of participants?			
13. Was loss to follow-up after baseline 20% or less?			
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?			

Appendix 2B: Quality appraisal tables

Author & year	1	2	3	4	5	6	7	8	9	10	11	12	13	14	Total
Aljure et al. 1985	Y	N	CT	Y	N	N	N/A	N/A	N/A	N/A	N	N	N/A	CT	2/9
Ballinger et al. 2000	Y	Y	CT	Y	N	N	N/A	N/A	N/A	N/A	Y	Y	N/A	CT	5/9
Boninger et al. 2001	Y	Y	CT	Y	Y	N	Y	Y	N/A	Y	N	N	N	CT	12/13
Dalyan et al. 1999	Y	N	Y	Y	N	N	N/A	N/A	N/A	N/A	N	N/A	N/A	CT	3/8
El Essi et al. 2012	Y	Y	Y	Y	N	N	N/A	N/A	N/A	N/A	Y	N/A	N/A	CT	5/8
Eriks-Hoogland et al. 2016	Y	Y	CT	Y	N	N	N/A	N/A	N/A	N/A	Y	Y	N/A	CT	5/9
Escobedo et al. 1997	Y	Y	CT	Y	N	N	N/A	N/A	N/A	N/A	N	N	N/A	CT	3/9
Gironda et al. 2004	Y	Y	N	Y	N	N	N/A	N/A	N/A	N/A	Y	N/A	N/A	CT	4/8
Pentland & Twomey 1994	Y	Y	CT	Y	N	N	N/A	N/A	N/A	N/A	N	N	N/A	CT	3/9
Pentland & Twomey 1991	Y	Y	CT	Y	N	N	N/A	N/A	N/A	N/A	N	N	N/A	CT	3/9
Samuelsson, et al. 2004	Y	Y	Y	Y	N	N	N/A	N/A	N/A	N/A	Y	N/A	N/A	CT	5/8
Sie et al. 1992	Y	Y	CT	Y	N	N	N/A	N/A	N/A	N/A	N	N/A	N/A	CT	3/8
Silfverskiold & Waters	Y	Y	CT	Y	N	N	Y	N/A	Y	Y	N	N	N/A	CT	6/12

1991															
Subbarao et al. 1994	Y	Y	Y	Y	N	N	N/A	N/A	N/A	N/A	N	N	N/A	CT	4/9
Van Drongelen et al. 2006	Y	Y	CT	Y	N	N	Y	N/A	Y	Y	Y	N	N	Y	8/13

Legend:

Y = Yes

N= No

CT = Can't tell

N/A = Not applicable

Appendix 3A: Study protocol

Title: Perception of impact of secondary upper limb injuries sustained by manual wheelchair SCI users

Chief Investigator: Dr Mary Hannon-Fletcher (Head of School of Health Sciences, Ulster University)

Academic supervisor: Dr Danny Kerr (Associate Postgraduate Tutor & Lecturer in Physiotherapy, Ulster University)

Co-Researcher: Jackie Casey (Lecturer in Occupational Therapy, Ulster University)

PhD Researcher: Adrienne McCann (BSc Occupational therapy)

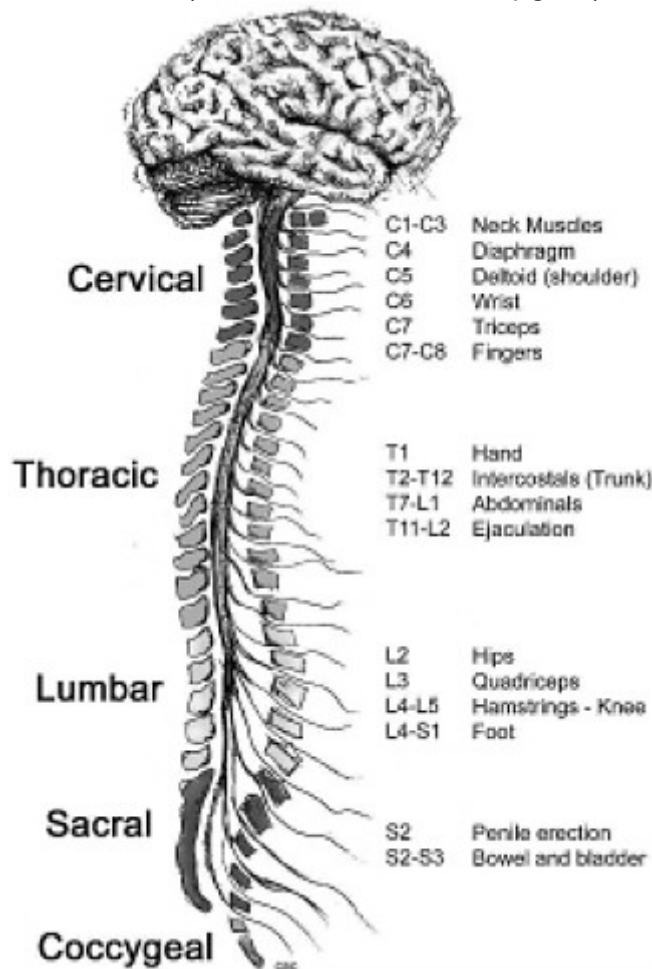
Local Collaborator: Dr Suzanne Maguire (Rehabilitation consultant Spinal Injuries Unit Musgrave Park Hospital).

Background

The spinal cord consists of nerve bundles connecting the brain to the peripheral nervous system and the rest of the body. The spinal cord is made up of the cervical, thoracic, lumbar and sacral vertebrae. Each division is sub-divided as detailed in Figure 1, where the sub-division relates to the function of the specific area of the body. The spinal cord itself is responsible for relaying messages from the brain regarding functions such as movement, pain and temperature to name just a few. A spinal cord injury (SCI) can be defined as complete or incomplete, with the resulting paralysis dependent on the level of injury and sensory and motor neuron involvement (Waters et al., 1991).

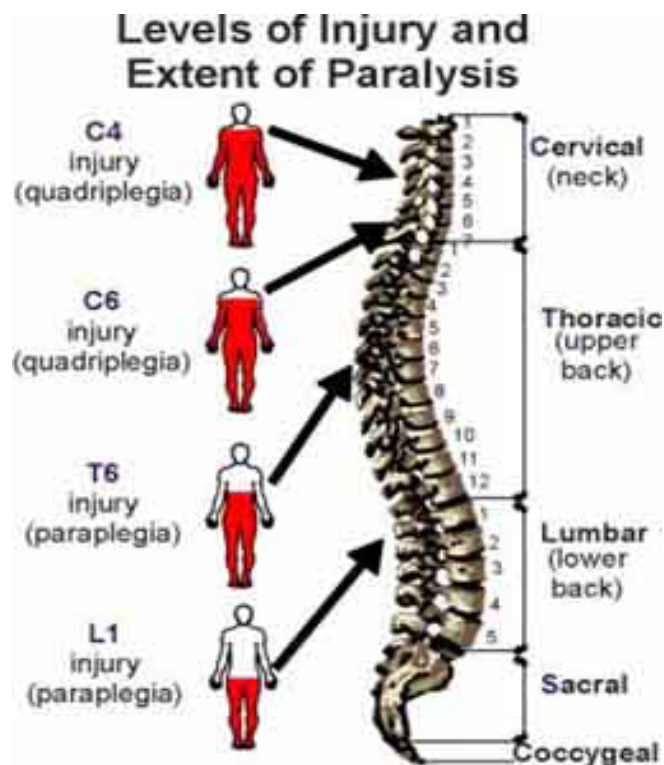
Approximately 1,000 people suffer a SCI each year in the United Kingdom (UK) and Ireland; the highest prevalence of injury occurring between the ages of 15-38 years (Spinal Research, 2011). The most common causes of SCI are road traffic collisions, followed by falls, trauma and sporting injuries (Chen et al., 2013). The American Spinal Injury Association (ASIA) classifies spinal cord injuries based on the level at which the injury occurs. Spinal injuries are classified as either complete or incomplete depending on the level of sensation and muscle movement post injury. A complete SCI involves no voluntary motor or conscious sensory function below the injury site. In comparison, an incomplete SCI is the presence of function several segments below the injury site but the absence of function below a given level (Wyendale, 2006). The level of injury and the extent of the associated paralysis can be seen in Figure 2. Paraplegia can be defined as impairment or loss of motor or sensory function in areas of the body served by the thoracic, lumbar, or sacral neurological segments owing to damage of neural elements in those parts of the spinal column; in comparison to quadriplegia where paralysis is present in all four limbs as a result of injury to the cervical segments of the spinal column (Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health, 2016). Life expectancy in the SCI population has increased with improved healthcare. Le et al., (1981) reported the mean length of survival post initial SCI in 1955 was 4 years 4.8 months, which increased to 9 years 2.5 months by 1963.

Figure 1: Functions controlled by nerves at different levels of the spine.
 Damage at a particular level usually impairs the functions controlled by all nerves at lower levels (Liverman et al., 2005, pg 34)



Strauss et al. (2006), reports the age at which injury occurs is a crucial factor in estimating life expectancy within the SCI population. Today, the estimated life expectancy of a person injured at age 25 years with a non-violent, low level and low grade injury as measured on American Spinal Injury Association scale (Kirshblum et al., 2011) is 69.7 years (+/- 6.8 years dependent on complete/incomplete injury). This increase in life expectancy means the possibility to live long and healthy lives for the 1,000 people injured with a SCI in the UK and Ireland per year is very obtainable.

Figure 2: Levels of injury and extent of paralysis, (Spinal Life Australia, 2009.) *



*Note in the above figure quadriplegia also refers to tetraplegia.

Rationale

Over half (approximately 56%) of SCI wheelchair users are paraplegic meaning the injury is typically at or below the T1 level of the spinal cord (Noonan et al., 2012). The use of a manually propelled wheelchair is therefore most prevalent in paraplegic wheelchair users. For people with SCI who use a manual wheelchair as their primary means of mobility, their ability to perform manual wheelchair skills is associated with higher community participation and life satisfaction (Hosseini et al., 2012). Wheelchair skills comprise the basic elements of activities used daily including: transferring, lifting and propulsion. These may often be incorrectly adopted by wheelchair users (Finley & Rogers, 2004; Nash et al., 2007). This combined with the constant use of the upper limb for functional mobility may place excess or cumulative strain on the upper limbs, resulting in pain in the shoulders, elbows, wrists, and fingers (Jain et al., 2010). Over time, the repetitive nature of these activities may result in secondary upper limb injuries, including rotator cuff tears, carpal tunnel syndrome and muscular strains (Borgens et al., 2012). Several authors (Pentland, 1994; Alm, 2008 and Requejo, 2008) express the repetitive nature of propulsion and transferring as the primary contributing factors in upper limb injury in the SCI population. The associated pain and decreased range of movement, may contribute to an overall reduction in performance in Activities of Daily Living (ADL's). Dalyan et al., (1999) determined that of SCI

patients experiencing upper limb pain, 26% required additional help with functional activities and 28% reported limitations of independence. Research literature highlights that these injuries occur throughout the life span of wheelchair users, particularly in those whose wheelchair use has spanned decades (Asheghan et al., 2015); with increased life expectancy this is likely to be a more common occurrence in this population if power assist add-ons are not sought.

There is a substantial amount of literature in the area documenting the prevalence of these conditions. Injuries such as shoulder, neck and back pain resulting from poor wheeling practice in the long-term are documented in both those who began wheeling as adults or as children (van Drongelen et al., 2006; Kennedy et al. 2006; Rice et al. 2009). Between 49% and 73% of SCI manual wheelchair users develop carpal tunnel syndrome and between 31% and 71% report shoulder pain (Toosi et al., 2010). This may have serious implications for functional mobility, sleep and living life independently (Widerstrom-Noga et al., 2001). Unfortunately, there is no literature directly related to the client's perspective of how the injury affects their day-to-day lives. In planning for the future, SCI patients are encouraged by staff involved in their care to protect their joints and use correct technique in wheeling and transfers (Goldstein et al., 1997). Management of an upper limb injury may prove difficult due to the nature of the treatment. Relative rest is required in order for the upper limb to recover however this may prove problematic as the upper extremity is used for mobility on a daily basis (Alm et al., 2008). In February 2016 The National Institute for Health and Care (NICE) published guidance on spinal injury assessment and early management, however there are currently no evidence based-practice guidelines relating to the *treatment* of upper limb injuries associated with SCI. Rice et al., (2013) investigated a strict protocol – "Preservation of Upper Limb Function Following Spinal Cord Injury (2005)", addressing the impact of an education protocol on transfer skills and wheelchair propulsion in the SCI population. The protocol was part of a review recognizing the different healthcare needs for the SCI population. Recommendations from the report highlighted a lack of research in the area of upper limb injury and a need for further research to understand the basic mechanisms of musculoskeletal upper limb injuries in SCI and investigation into the benefits of management (Connolly et al., 2014).

The objective measurement of health is no longer satisfactory in assessing patient's needs as a whole (Sullivan, 2003). The International Classification of Functioning, Disability and Health, also known as ICF (WHO & World Health Organisation, 2007), is a classification of the health components of functioning and disability, giving consideration to activity, participation and the environment. A client centred approach will be central to this study using the ICF as a framework to establish, how the upper limb injury affects SCI participants and to identify the occupational and social barriers experienced by SCI participants (Van der Woude et al., 2005). The ICF framework is used in this study as an approach to highlight the importance of understanding the person as a whole – encompassing leisure activities, ADL's and environmental factors. The most complete research in current health care now generally assesses the client as a whole, including personal, occupational and environmental aspects. The patient

perspective is crucial in understanding the condition as a whole, and aligns the objective symptoms with their subjective responses in order to create a full picture of how the client and their disease/injury interact together. It is the patient who has the authority to judge their quality of life not the health care professional, therefore the patient's role in communicating their experience with the injury is critical (Robinson et al., 2008). As of yet there is no research directly related to the client's perspective of how their upper limb injury impacts on their day to day lives, yet services are being provided (or not) based on medical observations only. The purpose of this study is to combine objective reporting of injuries from medical notes with the perspective of the patient and health care professional involved in their care, to understand the overall impact of upper limb injuries sustained, specifically from manual wheelchair use.

Aim:

An investigation of upper limb musculoskeletal injury in Spinal Cord Injured participants using manual wheelchairs.

Objectives:

- To carry out a mixed method (quantitative and qualitative) study to determine the rate of occurrence and time-line after SCI of upper limb injury.
- To understand the prevalence and nature of secondary upper limb injuries experienced by people living with spinal cord injury.
- To identify the medical and rehabilitation approaches to their treatment.
- To conduct a qualitative exploration of SCI manual wheelchair users' experience and SCI clinician's opinions of secondary upper limb injuries relating to the injury and treatment.

This study will be carried out in collaboration with the Spinal Cord Injury Unit Musgrave Hospital (SCIU MPH) to establish exactly how many SCI patients are reporting upper limb pain and/or injury and gather demographic information relating to those identified, as this data is not presently collated anywhere in the SCIU records. The investigation will consider the various treatments available (and availed of by the participants) and determine the most common time post-SCI that injuries occur (and when intervention is required). The study will take a holistic view of the person, exploring their personal, social and vocational domains and the psychosocial impact this injury may or may not have on their lives. In addition, this study will seek to establish whether service users feel their needs are being met; the impact of day-to-day living in a wheelchair is having on their personal lives and what they feel can be done to better support them. This will be investigated in the second element of the study - employing focus groups and questionnaires to capture service user and clinician views. This is an emerging area for research and will be invaluable to design future services for SCI patients. It is anticipated that the opinions and experiences of those with SCI can help shape and

develop services for future care. It is, therefore, essential that this gap in knowledge be addressed.

This study will combine qualitative and quantitative research in the form of viewpoints, data collection and analysis; therefore, a mixed methods theoretical approach will be taken to guide the study. A mixed methods approach is an orientation toward social inquiry that actively invites us to participate in dialogue about multiple ways of seeing and hearing, and making sense of the social world. The research team will adhere to strict rigour to ensure credibility and validity of the research findings.

Rigour of study

The following steps have been adapted and implemented by the research team to ensure the credibility and rigour of the research findings.

1. Bracketing has taken place where all members of the research team have outlined and stated their prior experiences/views of SCI or working with those with an SCI. Bracketing will occur throughout the data collection and analysis process in the form of a reflective journal. The feelings and thoughts provoked during the focus groups/one-to-one interviews will be recorded and reflected on prior to analysing the data. This process ensures that the research team leaves any preconceived ideas to the side and can conduct the study in an ethical and fair manner (Lea & Peter, 2012).
2. Acknowledging biases in sampling and ongoing critical reflection of methods to ensure sufficient depth and relevance of data collection and analysis. Recruitment of SCI participants will be completed via purposive sampling. Due to the nature of our recruitment method that not all invitees will accept to participate in the study, the research team acknowledge that the results and findings of the study will not be an exact accurate reflection of the SCI population with an upper limb injury. Recruitment of staff will be conducted via Dr Maguire of MPH SCIU. Dr Maguire will also be involved in the process of bracketing and will be encouraged to record any biases she may have from working in the department with the staff participants. The research team will continually record and acknowledge each of these biases.
3. Meticulous record keeping, demonstrating a clear decision trail and ensuring interpretations of data are consistent and transparent will be completed by all members of the research team.
4. Rich and thick verbatim descriptions of participants' accounts will be used to support findings.
5. The research team will demonstrate clarity in terms of thought processes during data analysis and subsequent interpretations. Analysis will be conducted by two members of the research team independently and they will then meet to compare for consistency for rigour.

6. Member Checking: participants will be invited to comment on the interview transcript and interpretations, and whether they feel the final themes and concepts created adequately reflect their comments.

The research team is referred to as below:

The focus group moderator/one-to-one interviewer – PhD student Adrienne McCann (AMC)

The local collaborator – Dr Suzanne Maguire (SM)

The note taker – Dr Mary Hannon-Fletcher (MHF)/Dr Danny Kerr (DK)

Independent qualitative researcher – Jackie Casey (JC)

Methods:

The study is a mixed methods research project investigating the occurrence of upper limb musculoskeletal (MSK) injuries in manual wheelchair users and the perceived long-term effects of these injuries in the SCI population.

The three components consist of:

Phase A: An identification process of SCI patients who have reported an upper limb injury. The retrospective analysis of data will be conducted to identify the number and type of procedures (both surgical and conservative management) for secondary upper limb injury management in SCI patients. A participant information sheet, consent form and a questionnaire will be posted to participants to gather initial data on their upper limb injury, with a stamped addressed envelope to be returned to the PhD researcher.

Phase B: Focus groups and one-to-one interviews with SCI participants. These will be conducted either on the grounds of Musgrave Park Hospital or Ulster University Jordanstown dependent on the patient's preference.

Phase C: Questionnaires and one-to-one interviews with members of the SCI healthcare team of MPH SCIU. These will be conducted on the grounds of Musgrave Park Hospital at a time suitable to the members of staff. The groups will include SCI clinicians, orthopaedic surgeons, Allied Health Professional's (AHP's) and nursing staff.

Phase A- Questionnaire with SCI participants and identification process

Study Design

Recruitment of patients

As the databases within SCIU MPH are not unique to SCI participants alone and include confidential information non-accessible to the researcher, recruitment will be in the form of a proforma (Appendix 1) posted out to all patients on the SCIU patient list by SCUI consultant. Dr Suzanne Maguire (Consultant in Rehabilitation SCIU MPH), (local collaborator) will identify participants and add each patient's address to the envelopes, to ensure patient details remain confidential, and post on our behalf. A participant information sheet (PIS) (Appendix 2) outlining the project, inclusion and

exclusion criteria, a questionnaire (Appendix 3), and a consent form (Appendix 4) will be posted to potential participants and will include a stamped addressed envelope to assist return to the PhD Researcher (AMC). Potential participants will be asked to answer a series of questions to ensure they meet the criteria for example:

1. Do you have an SCI?
2. Are you minimum 6 months' post SCI?
3. Do you use a manually propelled wheelchair or have you used a manual wheelchair in the past but changed due to the strenuous requirements of a manual wheelchair?

Participants will signal their intent to be included in the study by returning the signed consent form along with the completed questionnaire included in the pack to the PhD researcher (AMC). Potential participants will be asked if they consent to allow the researcher to access their notes in line with ethical and Trust procedures to obtain data relating to the types of treatment they have undergone for their upper limb injury. The data extraction form (Appendix 5) will be used to collect this information from the medical notes for this specific purpose only. The PIS advises that no participant name or contact details will be recorded to protect anonymity. Participants will also be asked to give informed consent to the researcher to contact them in relation to the follow-on study of focus groups and one-to-one interviews. A cooling off period to allow for participants to consider consenting will be in place, with the researcher not contacting participants for two weeks after receiving the consent form.

Once participants return their consent form the researcher will liaise with the local collaborator to identify the patients who have reported upper limb injuries. The local collaborator (SM) will access and identify the participants' notes for review. Data collection will be carried out onsite at MPH using a specifically designed data extraction form by the PhD Researcher (AMC), strictly gathering only the information required for this research. The data extraction form allows the information required to be tailored specifically to meet the needs of the study. These data extraction forms will be anonymised using unique identifier numbers (linked to the patient notes only by the local collaborator) thereby maintaining anonymity of participants, and then analysed at Ulster University by the PhD researcher and research team. The flow chart (Figure 3), demonstrates each stage of the recruitment process for both SCI participants and staff.

In the case that not enough participants are recruited the following back up measures have been decided by the research team.

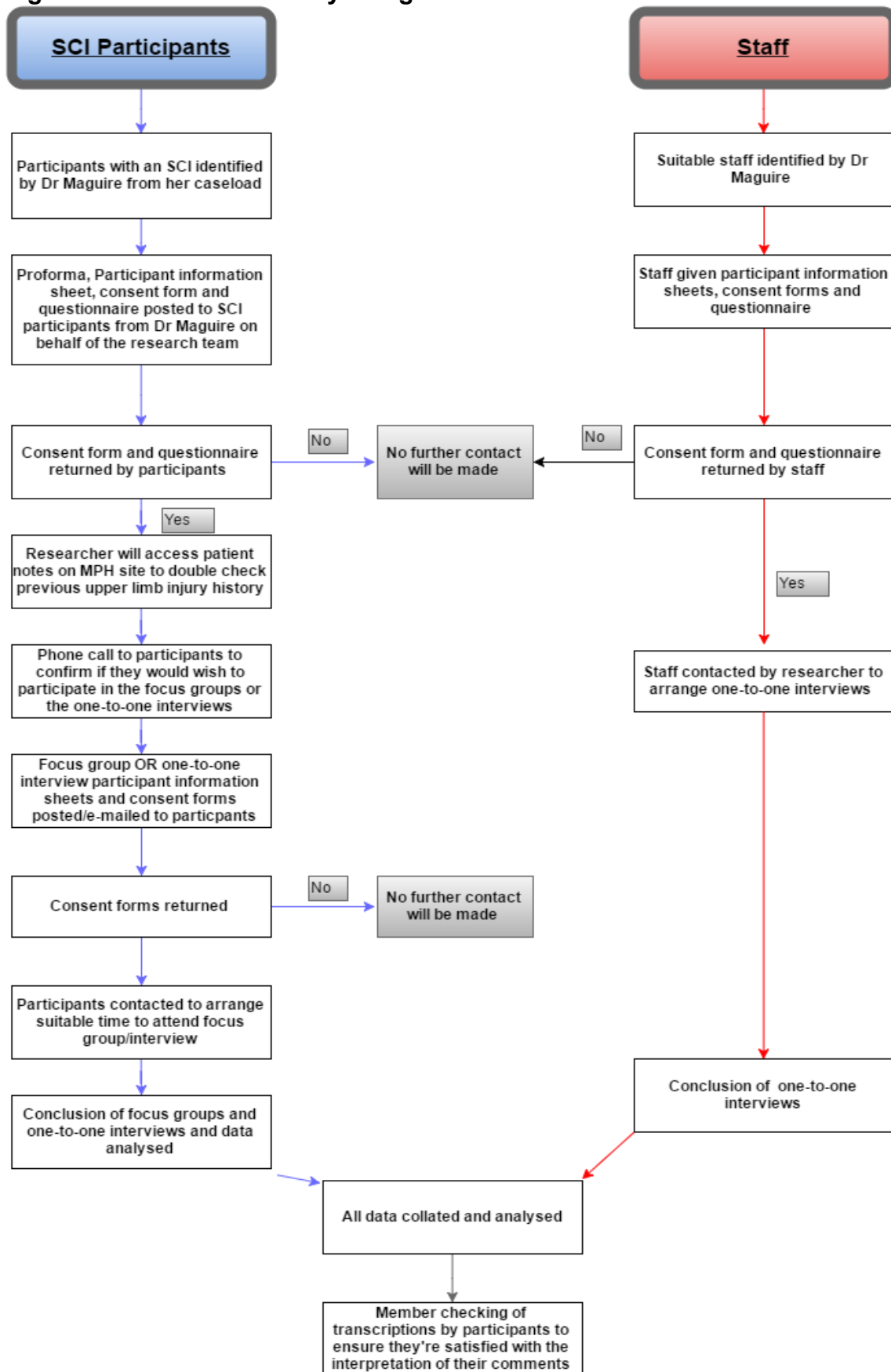
1. A poster has been included (Appendix 6) to post in SCIU MPH advertising the project. Any person who feels they meet the criteria can phone the researcher or Dr Maguire whose numbers will be listed on the poster for further information.
2. Championing – participants who have already agreed to be included will be asked whether any of their peers or friends who have an SCI would be

interested in participating and if they could pass on the information inviting them to participate.

3. Members of the steering committee who reviewed the documentation are also members of “Aspire” – a charity who provide help to those injured with an SCI. It is envisaged that if not enough participants are recruited an advertisement in Aspire’s newsletter may be able to reach out to further participants who may meet the criteria.

Alternatively, in the case that the number of participants wanting to participate exceeds our limits the following will apply. Sampling will be by means of purposive sampling. Participants will be accepted into the study on the basis they meet all the criteria outlined. Thereafter participants will be accepted on a first come first served basis. All participants will be subsequently notified if they have been included in the proposed study and whether they are available to attend the focus group/interview. The number of participants per focus group will vary however it is estimated that there will be approximately five to eight participants per group in line with research in the area. The researcher will aim to recruit ten participants per group in the case that a participant is unable to attend on the day allowing for drop-outs. Therefore, the number of participants for focus groups will be capped at 50 on reaching this quota. The number of one-to-one interviews may vary. The researcher will continue to conduct interviews until data saturation has occurred. The PhD researcher will complete a minimum of three one-to-one interviews. Data analysis will be continual throughout the interviewing stage and the PhD researcher will identify any new or emerging themes. Data saturation refers to the stage where no new emerging themes are noted and it is at this point when interviews will cease.

Figure 3: Flowchart of study design



Procedure

Phase A is a paper-based study, which involves recording reports of upper limb pain, injury or discomfort within the SCI population and the return of consent forms and questionnaires. The PhD researcher will seek a placement contract with the Trust following ethical approval. Ethical approval will be sought from all relevant bodies including the Institute of Nursing and Health Research Governance Filter Committee, Ulster University; Office of Research Ethics NI and the Belfast HSC Trust. Contact with members of the SCI medical team has already been made and these healthcare professionals are keen to participate and for the project to proceed.

On receiving favourable ethical approval, the PhD researcher will obtain training in relation to Trust procedures and policies in accessing patient notes. This will be done under the supervision of a member of the healthcare team to ensure the Trust's relevant data protection procedures and patient confidentiality measures are maintained. This will be completed on obtaining the placement contract from Belfast HSCT.

Data analysis

The quantitative data obtained from the review of medical notes will be entered into Microsoft excel under participant identifier numbers. This will be analysed using descriptive statistics and presented in tabular or graphic form. The findings of this study will inform phase B and C of the study that will investigate personal perspectives and those of health care staff of secondary upper limb injuries via focus groups, one-to-one interviews and questionnaires. Data triangulation will be used to link the results from questionnaires with thematic data obtained from focus groups and one-to-one interviews.

Participant Involvement in phase A

Participant involvement during the identification process will be minimal where we ask for the return of consent forms and questionnaires as outlined in the study design. The use of unique identifier numbers and collection of numerical data and types of treatment only ensures this will not affect patient care. The Trust's data protection and confidentiality policies will be enforced.

A service user group has been established where individuals with a SCI were invited to review the documentation and provide any comments or feedback they have on what they would like included/excluded in the study, and phrasing of questions on the questionnaire. Their suggestions have been included in this draft, version 1.4.

Local collaborator involvement

The local collaborator will be asked to provide minimal support to the researcher. This will be in the form of providing the relevant policies and procedures in order to ensure confidentiality and that all ethical requirements are observed. The local collaborator will add patient's addresses to the information packs provided by the research team, to ensure patient's details remain confidential prior to participation in the study. The

local collaborator will identify patient's notes for the PhD researcher to screen once informed consent has been provided. The study will be organised in such a way to incur minimal disruption to the local collaborator.

Ethical issues

The primary concern is the confidential handling of participant data, treating each participant with respect and ensuring requirements of ORECNI are maintained. As outlined in the design process above, measures will be taken to ensure the anonymised recording of data. Patient names will not be identifiable and each data set will be assigned a unique identifier number while on MPH. The researcher will have access to the data sets on the physical site only. All saved data will be anonymised and transported to Ulster University Jordanstown campus using password protected and encrypted files and folders and securely stored for 10 years. Ethical approval will be sought Office of Research Ethics, NI and submission through HSC governance procedures.

Phase B – SCI participants

Study Design - Focus groups and one-to-one interviews.

A qualitative approach will be taken to elicit patient perspectives of their upper limb injury to address the aims and objectives of the study. Interviews and focus groups were selected as the main components of data collection to gather patient perspectives. Qualitative methods of investigation have been found to be especially useful during the discovery phase of research, where questions are explored and hypotheses created (Morgan, 1998; Litosseliti, 2003; Barbour, 2008). Focus groups are intended to help the researcher better understand a situation and to gain insights into the subjective experiences of those from a targeted population (Morgan, 1988; Litosseliti, 2003; Barbour, 2008). Focus groups are an effective way to get a greater understanding of people's thoughts and experiences of living with a condition or injury. Focus groups can encourage participants to consider the ways in which they are both similar to and different from each other, through group interaction (Morgan, 1998; Zhi, 2006; Krueger and Casey, 2009), and can help to stimulate exploration of the phenomenon in question. In addition, hearing how participants react to hearing others views whether it be agreeing or disagreeing with others can highlight to the researcher the sentiments and range of attitudes expressed by the participants (Morgan, 1998; Kamberelis and Dimitriadis, 2008; Flick, 2009). Focus groups are a popular approach in health research; as they offer an ideal method for exploring an individual's personal perceptions of health and illness and contribute to the medical assessment of a patient only (Wilkinson, 1998; Rabiee, 2004; Wong, 2008). As such, it could be argued that focus groups are an essential method of data collection when the research aim is not to reach a consensus, instead to encourage a wide range of responses to provide powerful insights and a greater understanding of the research issue (Lehoux et al., 2006; Kamberelis & Dimitriadis, 2008; Flick, 2009; Jayasekara et al., 2012).

Client group

The focus groups and interviews will be videotaped and the PhD researcher and a note taker (MHF or DK) will also be present.

- Focus groups – participants will be posted a participant information sheet for those who are comfortable speaking in a group setting. This will be to elicit personal perspectives of how their upper limb injury has affected their lives as a whole and the dynamic of how they have balanced family, life and work commitments.
- One-to-one interviews – for those who may not feel comfortable speaking in a group setting and would prefer to speak alone to the researcher, one-to-one interviews will be offered to participants. These will be audio recorded. One-to-one interviews provide the researcher an opportunity to further delve into the themes expressed in the focus groups and enhance the quality of data obtained, and to identify detailed perceptions, opinions, beliefs, and attitudes.

SCI participant recruitment

SCI Participants will be identified from Phase A of the study from those who signalled their intent in participating in the follow on study. The following inclusion and exclusion criteria will be applied on screening the respondents:

Inclusion and Exclusion criteria

Inclusion Criteria

- Have a complete traumatic spinal cord injury
- Aged 18 years or older
- Minimum of six months' post SCI
- Powered wheelchair users who previously used a manual wheelchair

Exclusion criteria

- Life time powered wheelchair users
- Patients with a cognitive impairment, pre-existing comorbidity* or similar that would prevent them from participating in a focus group/interview**
- Patients who are taking medication that may impact on their ability to participate**

*Pre-existing comorbidities may include (but not limited to): Polymyalgia Rheumatica, Rheumatoid Arthritis, Multiple Sclerosis, Fibromyalgia, Cancer and Polymyositis. On screening of the medical notes, the researcher will identify those with an upper limb injury whose causation may be different to that of an overuse injury. Consultation with the research team will be conducted prior to any participant being excluded on this basis.

**Participants medical notes will be screened and will state whether there is an existing cognitive impairment or medications administered which may prevent them from participating. This can be checked with the consultant, Dr Maguire, as required.

Sample size

The number of participants included per focus group will vary between five to eight participants in line with other research in the area (Biering-Sorensen et al. 2006; Henwood et al. 2004; Kirchberger et al. 2010). Focus groups will be analysed in a sequential manner and concluded once the research team are satisfied that enough information has been collected for data saturation to occur and new themes to emerge. A minimum of three one-to-one interviews will be completed (dependent on recruitment of participants) until data saturation has occurred.

Procedure

Once the participant (patient) has signed the consent form to be contacted by the researcher, the researcher will phone participants and explain the follow-on study. Participants will be asked if they would like to be included in the focus groups or one-to-one interviews and will be posted or e-mailed (dependent on preference) further information dependant on their choice. The information pack will include a participant information sheet (Appendix 7) and one of two consent forms, focus groups (Appendix 8) or one-to-one interviews (Appendix 9) with a stamped addressed envelope. On accepting to take part in the study, participants will be given the option to attend either Musgrave Park Hospital or Ulster University Jordanstown at a date and time that suits the majority of invitees. Participants will be offered flexible times to suit travel to and from the interviews/focus groups. Refreshments will be provided and site parking covered by the research team. On attendance, the facilitator will advise the participants of the objective of the focus group and the overall study and a consent form will be circulated. Participants will be asked to complete the consent form in duplicate for both focus groups and interviews – one copy for the participant and one for the moderator. Participants will be advised that they are not obliged to attend the group, that they may withdraw from the group at any time and this will not affect the level of care they receive as normal. Confidentiality will be explained and written consent to participate and video-recording will be sought. Although every attempt will be made to anonymise the data, comments may be reported as anonymous or with pseudonyms. Participants will be informed at the beginning of each focus group that the discussion should remain confidential, however the moderator has no way of ensuring this. A flip chart will be used to agree some ground rules, which the group deem appropriate for the setting, including the need for confidentiality between attendees.

Focus groups will be facilitated by the moderator (AMC) and recorded using a video tape recorder. The researcher has undergone qualitative training courses specifically focusing on 1:1 interviews, 1:2 interviews (dyads) and focus groups. A topic guide (Appendix 10) will be used to ensure the focus group flows and is relevant to the research question. A note taker will also be present to record any observations, non-verbal behaviour and minor details, which may be missed using the tape only. This

will then be matched with the transcription of the focus group. After each focus group session, the researcher and note taker will reflect on the session and any observations noted including atmosphere and observations noted (de-brief). A reflective research diary will be kept to note researcher thoughts, and any emerging themes as further groups take place, which can be added to the topic guide. A summary of the topics/issues raised will be shared with the participants on completion of data analysis to confirm accuracy and that all members are satisfied with the interpretation of their comments from both focus groups and interviews.

Phase C – Healthcare Professionals

Health care professionals involved in the care of SCI patients with upper limb injuries, within SCIU MPH – (consultants, orthopaedic surgeons, allied health professionals)

One-to-one interviews and questionnaires – these will be conducted with staff members of the SCIU MPH as and when their schedule allows. This client group may prove difficult to recruit due to the high demands of their jobs and schedules. The administration of a questionnaire allows staff to provide their opinion without the pressure of making time for an interview. Staff members who feel they could allocate the time to a short interview (20-30 minutes approximately) will be invited to speak confidentially to the researcher on issues they observe which may not be highlighted by the SCI participants themselves. The interviews will be conducted face to face or as a fall back, staff will be offered to complete the interview via telephone or skype. Furthermore, they may be able to provide detail relating to the current care pathway and services available to SCI patients in Northern Ireland, noting that there may be differences according to which area/ Healthcare Trust the patient resides in.

Recruitment

Recruitment of staff will be completed via purposive sampling. On liaising with Dr Maguire we will identify staff members who may be the most insightful and beneficial to contact for the study.

Members of multidisciplinary team we wish to contact:

- Orthopaedic surgeons
- Occupational Therapists
- Physiotherapists
- Nursing staff

Questionnaire and one-to-one interview criteria

Inclusion criteria

- Any clinical professional involved in the care of the SCI patient

Exclusion criteria

- Less than 3 months experience working in SCIU

Procedure

The researcher will request staff to complete a questionnaire (Appendix 11) relating to the numbers of SCI patients with an upper limb injury and the types of treatments or interventions these patients may have been prescribed. A participant information sheet (Appendix 12) will be presented to staff members once identified, explaining the layout of the interview and the purpose of their involvement. The participant information sheet will include information regarding the questionnaire and the one-to-one interviews. Two separate consent forms for the questionnaire (Appendix 13) and interview (Appendix 14) will also be provided and staff will be asked to complete a questionnaire initially. The consent form will also ask staff to indicate whether they wish to be contacted by the researcher to participate in a one-to-one interview with the researcher to further delve into the topic, and whether they consent to being audiotaped to ensure the research team gathers all information correctly. The PhD student will leave the information sheet, consent forms and questionnaire with the staff to complete in their own time and will collect these at a later date. From this, the researcher will be able to identify from the questionnaires any staff who may be interested in completing a one-to-one interview. A topic guide will be used for completion of the interview (Appendix 15) and will last for approximately 20-30 minutes. The researcher will then contact said staff members to arrange a suitable date and time for the interview to go ahead. Consent will also be sought for staff to be audiotaped. On attendance at the interview, staff will be asked to complete another consent form in duplicate – one copy for the participant and one for the moderator.

Phase B & C Data Analysis

Transcription of recordings

Transcription of the audio and video tapes will be completed by the PhD researcher (AMC). These will be typed into Microsoft Word and will be cross-checked by members of the research team to ensure the transcriptions are accurate. Transcriptions will then be imported into NVivo (qualitative data management software) for coding and analysis by the researcher.

Data Analysis

Two members of the research team will analyse the data independently and meet to compare and agree initial coding and theme generation. Data will be inputted into NVivo software and coded after each focus group. This will allow the researcher to draw out the most common themes observed. A reflective diary will also be used which allows observation of any common threads, which may have been missed in the recordings, and acknowledgement of researcher's attitudes, thoughts and values. Once the early transcripts have been inputted to NVivo, any emerging ideas or themes that have not been included in the original topic guide can then be added after consultation with the research team. This is to ensure all members are satisfied with the interpretation of their comments. Data triangulation will be used as a "method of cross-checking data from multiple sources to search for regularities in the research

data" O'Donoghue and Punch (2003). Using this technique will ensure that the interpretation of the data is rich, robust, comprehensive and well-developed.

Data Management

Data for all elements of the study will be stored and protected in line with Ulster University's data protection regulations. Research project data, whether electronic or hard copy, will be accessible only to those people who have a legitimate purpose, including members of the project team, internal and external auditors and representatives of regulatory bodies.

1. All data collection forms will be stored in the data storage room located in Ulster University Jordanstown Campus, in Block 1 Level F. Technical partners and members of the research team will have access to the anonymous data only. Data will be stored for up to 10 years after the project has been completed.
2. All audio and video files will be deleted once transcription has been completed and cross-checked.
3. All typed files will be encrypted and stored on a password protected memory stick, which will be stored in the data storage room located in in Ulster University Jordanstown Campus, in Block 1 Level F. All transcribed documents will be formatted in the same layout for ease of analysis; this will include participant identifier numbers recorded for each member.
4. Consent forms will be stored in a locked filing cabinet onsite at Ulster University (within a locked office space).
5. All research team staff will have completed the Good clinical practice training to ensure practices are current.

Withdrawal of participants

A participant can withdraw at any time from the project and this will not in way adversely impact on their service experience, and do not need to give a reason. We will check with the participants at each stage if they wish to proceed. If some data has been collected from the participants this will be included as part of the data set, unless they do not wish this data to be used.

Handling distressing situations and 'what if' scenarios

Each participant will receive participant information sheets outlining what is expected of their involvement in order to ensure informed consent is obtained. All participants will be briefed on regulations surrounding disclosure of any information and be aware that in the case that a participant discloses sensitive information such as being a victim (or perpetrator) of a crime or if the researcher deems the participant to be at risk of harm, the researcher is obliged to disclose this information to the relevant authorities. There is a possibility of poor practice being identified during focus groups/interviews with SCI participants or staff. In this case the participants will be directed to the NHS's patient's complaints procedure in line with NHS policy (www.nidirect.gov.uk/articles/make-complaint-against-health-service). This website

discusses the step by step procedure for making a complaint and the relevant contact details for making a complaint in each Trust. In the case that a staff member raises an issue of poor practice of another colleague, (s)he will be instructed that the protocol for reporting misconduct in the work place instructs the person to speak to their line manager initially. If the person is not satisfied they can be directed to the “Raising concerns at work guidance” which can be found at (www.wbhelpline.org.uk/resources/raising-concerns-at-work)

In the case that a participant becomes upset or distressed during the focus group or interview, the researcher will be on hand to assess the situation. A distress protocol has been included (Appendix 16) and will be followed. The research team will review the situation afterwards to ensure that participant distress could not have been avoided. Contact numbers for counselling services at MPH SCUI and the Samaritans will also be available.

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Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)

Perception of impact of secondary upper limb injuries SCI

1. Is your project research?

Yes No

2. Select one category from the list below:

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank
- Research database

If your work does not fit any of these categories, select the option below:

Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? Yes No
- b) Will you be taking new human tissue samples (or other human biological samples)? Yes No
- c) Will you be using existing human tissue samples (or other human biological samples)? Yes No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

- England
- Scotland

- Wales
 Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- England
 Scotland
 Wales
 Northern Ireland
 This study does not involve the NHS

4. Which applications do you require?

IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.

- IRAS Form
 NHS/HSC Research and Development offices
 Research Ethics Committee
 Confidentiality Advisory Group (CAG)
 National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.

For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.

5. Will any research sites in this study be NHS organisations?

- Yes No

6. Do you plan to include any participants who are children?

- Yes No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- Yes No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

- Yes No

9. Is the study or any part of it being undertaken as an educational project?

Yes No

Please describe briefly the involvement of the student(s):

The project is part of a larger scale PhD study

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

Yes No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

Yes No

Integrated Research Application System
Application Form for Research administering questionnaires/interviews for quantitative analysis or mixed methodology study



Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
 Perception of impact of secondary upper limb injuries SCI

Please complete these details after you have booked the REC application for review.

REC Name:

REC Reference Number: **Submission date:**

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:
 Perception of impact of secondary upper limb injuries sustained by manual wheelchair SCI users.

A2-1. Educational projects

Name and contact details of student(s):

Student 1	
	Title Forename/Initials Surname Ms Adrienne McCann
Address	Block 1 Level F Ulster university
Post Code	BT370QB
E-mail	mccann-a18@email.ulster.ac.uk
Telephone	
Fax	

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

PhD: A qualitative study into upper-limb musculoskeletal overuse and injury in Spinal Cord Injury: the long-term impact of manual wheelchair usage.

Name of educational establishment:

Ulster University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title Forename/Initials Surname
	Dr Mary Hannon-Fletcher
Address	Room 01B120 University of Ulster Jordanstown campus Shore Road Newtownabbey
Post Code	BT37 0QB
E-mail	mp.hannon@ulster.ac.uk
Telephone	+44 28 90366914
Fax	

Academic supervisor 2

	Title Forename/Initials Surname
	Dr Danny Kerr
Address	Room 01F110 University of Ulster Jordanstown campus Shore Road Newtownabbey
Post Code	BT37 0QB
E-mail	dp.kerr@ulster.ac.uk
Telephone	+44 28 90366462
Fax	

Please state which academic supervisor(s) has responsibility for which student(s):

Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Ms Adrienne McCann	<input type="checkbox"/> Dr Mary Hannon-Fletcher <input type="checkbox"/> Dr Danny Kerr

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- Student
- Academic supervisor
- Other

A3-1. Chief Investigator:

	Title Forename/Initials Surname
	Dr Mary Hannon-Fletcher
Post	Head of School of Health Sciences Nursing & Health Research
	Level 2 Award in Team Leading, Institute of Leadership and Management (ILM)
	Registered Biomedical Scientist.
Qualifications	Chartered Scientist
	Postgraduate Certificate in Higher Education Teaching (PgCHET)
	DPhil (Biomedical Sciences),
	B.Sc. (Hons) Biomedical Science
ORCID ID	
Employer	Ulster University
Work Address	Room 01B120
	Ulster University Jordanstown
	Belfast
Post Code	BT370QB
Work E-mail	mp.hannon@ulster.ac.uk
* Personal E-mail	
Work Telephone	+44 28 90366914
* Personal Telephone/Mobile	
Fax	

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*

A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?

This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname
	Mr Nick Curry
Address	Room 26A17
	Research & Innovation
	University of Ulster Jordanstown campus
Post Code	BT37 0QB
E-mail	n.curry@ulster.ac.uk
Telephone	+44 28 90366629
Fax	

A5-1. Research reference numbers. Please give any relevant references for your study:

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version:

Protocol Date:

Funder's reference number:

Project
website:

Additional reference number(s):

Ref.Number	Description	Reference Number
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Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

Yes No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

The aim of this study is to investigate upper limb injuries spinal cord injured (SCI) patients have suffered as a result of using their manual wheelchair. Over 1,000 people per year are injured with an SCI and 26-28% report upper limb pain that inhibits them from living their lives to their full potential. The project aims to investigate the number of those reporting upper limb pain in Northern Ireland, the psychological effects it has on aspects of their lives and the treatment and management of their condition. The study will be split into three elements - an identification process of SCI patients who have reported an upper limb injury, and then following on from this focus groups and one-to-one interviews with SCI participants, and one-to-one interview with the staff involved in their care. The study is a mixed methods study aiming to elicit patient and staff perspectives of living with a secondary upper limb injury and understand the medical and rehabilitation approaches to their treatment.

In summary, this study will seek to establish whether SCI service users feel their needs are being met; the impact of day-to-day living in a wheelchair is having on their personal lives and what they feel can be done to better support them.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

The primary ethical concern is the accessing of patient's notes by the researcher and the confidential handling of participant data, treating each participant with respect and ensuring requirements of ORECNI are maintained. Dr Maguire (local collaborator) will assist in identifying participants on our behalf. The researcher will prepare information packs and Dr Maguire will add each patients address to the envelope and post on our behalf. The information pack will include participant information sheets and consent forms to ensure the patient can make an informed decision. The researcher will not have access to any patient details until informed consent is obtained.

Measures will be taken to ensure the anonymised recording of data. Patient names will not be identifiable and each data set will be assigned a unique identifier number while on MPH. The researcher will have access to the data sets on the physical site only. All saved data will be anonymised and transported to Ulster University Jordanstown campus in password protected and encrypted files and folders and securely stored for 10 years in line with Ulster University's data protection policy.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. Please tick all that apply:

- Case series/ case note review
- Case control
- Cohort observation
- Controlled trial without randomisation
- Cross-sectional study
- Database analysis
- Epidemiology
- Feasibility/ pilot study
- Laboratory study
- Metanalysis
- Qualitative research
- Questionnaire, interview or observation study
- Randomised controlled trial
- Other (please specify)

Mixed methods design

A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.

Aim:

An investigation of upper limb musculoskeletal injury in Spinal Cord Injured participants sustained from manual wheelchair use.

A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.

Objectives:

- To carry out a mixed method (quantitative and qualitative) study to determine the rate of occurrence and time-line after SCI of upper limb injury.
- To understand the prevalence and nature of secondary upper limb injuries experienced by people living with spinal cord injury.
- To identify the medical and rehabilitation approaches to their treatment.
- To conduct a qualitative exploration of SCI manual wheelchair users' experience and SCI clinician's opinions of secondary upper limb injuries relating to the injury and treatment

A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.

Over half (approximately 56%) of SCI wheelchair users are paraplegic (paralysed below the waist) (Noonan et al, 2012). The use of a manually propelled wheelchair is therefore most common in paraplegic wheelchair users. For people with an SCI who use a manual wheelchair as their main means of mobility, their ability to use their chair efficiently is associated with higher community participation and life satisfaction (Hosseini et al, 2012). The constant use of the upper limb for mobility such as wheeling their chair or transferring in/out of their chair, may place excess strain on the upper limbs, resulting in pain in the shoulders, elbows, wrists, and fingers (Jain et al, 2010). Over time, the repetition of these activities may result in secondary upper limb injuries, including rotator cuff tears, carpal tunnel syndrome and muscular strains (Borgens et al, 2012). Several authors (Pentland, 1994; Alm, 2008 and Requejo, 2008) state the repetitive nature of wheeling and transferring as the main contributing factors of upper limb injury in the SCI population. The associated pain and decreased range of movement, may contribute to an overall reduction in performance in Activities of Daily Living (ADL's). Dalyan et al (1999) noted, that of SCI patients experiencing upper limb pain, 26% required additional help with daily activities and 28% reported limitations of independence. Research literature highlights that these injuries occur throughout the life span of wheelchair users, particularly in those whose wheelchair use has spanned decades (Asheghan et al, 2015); with increased life expectancy this is likely to be a more

common occurrence in this population.

The study will take a holistic view of the person, exploring their personal, social and vocational circles and the impact this injury may or may not have on their lives. In addition, this study will seek to establish whether service users feel their needs are being met; the impact of day-to-day living in a wheelchair is having on their personal lives and what they feel can be done to better support them.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

The study is split into three components; Phase A - consists of identifying SCI participants via Dr Maguire of Musgrave Park Hospital (MPH), Phase B - a qualitative exploration of secondary upper limb injuries with SCI participants via focus groups and one-to-one interviews and Phase C- one-to-one interviews with staff

Phase A - The researcher has prepared participant information packs including an invitation letter, participant information sheet, consent form, questionnaire and stamped addressed envelope. Information packs will be posted to all patients on the caseload of Dr Maguire and Dr Hillen from the Spinal Cord Injury Unit at MPH. Participants can signal their intent to be included in the study by returning the questionnaire and consent forms. The consent form also asks for permission for the researcher to access their notes on site at MPH to double check their medical history relating to their upper limb injury.

Phase B - SCI participants. On identifying SCI participants who meet the inclusion and exclusion criteria via a retrospective review of notes, participants will be contacted if they wish to participate in the follow on focus groups and one-to-one interviews. If agreeable, further participant information sheets and consent forms will be posted out to participants for their consideration. On obtaining informed consent, the researcher will arrange focus groups and interviews at a time convenient to the majority of invitees at MPH or Ulster University dependent on their choice. A topic guide has been developed to ensure all topics are covered and ensure flow of the groups/interviews. Focus groups will be video recorded and interviews audio recorded and then analysed for emerging themes to add to the topic guides.

Phase C - Staff. Recruitment for staff will be conducted via purposive sampling. Dr Maguire will identify suitable staff involved in the care of SCI participants and participant information sheets, consent forms and a questionnaire will be distributed to staff. On obtaining informed consent staff will be contacted to attend an interview. A topic guide will be used for guidance and interviews will be audio recorded.

All data will then be collated and analysed.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- Design of the research
- Management of the research
- Undertaking the research
- Analysis of results
- Dissemination of findings
- None of the above

Give details of involvement, or if none please justify the absence of involvement.

A steering group consisting of two SCI patients has been established. Both attendees attended a meeting in Ulster University where the study documentation was reviewed and feedback was given. The feedback was taken on board and changes were made to the protocol and participant information sheets.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

Phase B - SCI Participants:
Have a complete traumatic spinal cord injury
Aged 18 years or older

Minimum of six months' post SCI
 Powered wheelchair users who previously used a manual wheelchair

Phase C - Staff
 Any clinical professional involved in the care of the SCI patient

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Phase B - SCI Participants
 Life time powered wheelchair users
 Patients with a cognitive impairment, pre-existing comorbidity or similar that would prevent them from participating in a focus group/interview
 Patients who are taking medication that may impact on their ability to participate

Phase C - Staff
 Staff must have a minimum of 3 months experience working in MPH SCIU

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Participants are posted participant information pack and asked to complete questionnaire and consent form and return	2	0	30 minutes	Posted by Dr Maguire, participants are asked to complete in their own time at home.
Participants contacted and asked to consider documentation and if they consent to be included in focus group/interview	1	0	30minutes	The researcher will contact participants via post with participant information sheet and consent form for focus group/interview
Participants return consent form for focus group/interview	1	0	10minutes	Participants return consent form to attend focus group/interview
Participants will be contacted to arrange a suitable time to attend focus group/interview	1	0	10minutes	The researcher will contact via post/telephone to arrange time
Participant will attend focus group/interview	1	0	90minutes	Participants will attend MPH for focus group/interview
Staff will be asked to complete questionnaire and consent form and the PhD student will collect from MPH	1	0	15 minutes	Staff will be asked to complete questionnaire
One-to-one interviews will be conducted with staff at a time suitable to them on site at MPH	1	0	30minutes	The PhD researcher will conduct the interviews on site at MPH

A21. How long do you expect each participant to be in the study in total?

SCI participants will be contacted when informed consent is received. Questionnaires will take a maximum of 30 minutes to complete. The focus groups/interviews will take maximum 90 minutes each. From review to completion of all focus groups the involvement of participants will take a maximum of 7 months.

Staff involved in care of SCI patients will be asked to complete a questionnaire which should take a maximum of 15

minutes to complete. Interviews will be no longer than 30 minutes.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Research participants are advised they do not have to participate if they do not wish and the current care they receive will not be affected. As an SCI can be a life changing event, speaking about their injuries may be a sensitive subject for some participants. The researcher is trained in chairing focus groups and administering interviews and a distress protocol has been included in the case a participant is distressed or feels they cannot continue.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

Yes No

If Yes, please give details of procedures in place to deal with these issues:

The researcher has completed research training on conducting focus groups and interviews and is a trained health care professional (occupational therapist). In the case that a participant becomes distressed or feels they cannot continue a distress protocol will be acted on to ensure the participant is comforted and reassured. Participants will be aware as stated in the participant information sheets that in the case a participant discloses information of a crime or the researcher feels they may be at risk to themselves, that the researcher is obliged to contact the relevant authorities and services. In the case that a participant does become upset/distressed, a distress protocol has been included and will be implemented if required. In the case that a participant identifies malpractice, they will be sign posted as to how to make a complaint or how to take the issue further.

A24. What is the potential for benefit to research participants?

There is no monetary incentive for participants however parking costs will be covered and refreshments provided. It is anticipated the responses from the focus groups and interviews will listen to patients needs and help shape future services for SCI patients.

A26. What are the potential risks for the researchers themselves? (if any)

There are no risks for the researcher.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).

Phase A - SCI participants

SCI participants will be recruited via a convenience sample. An invitation letter and participant information pack will be posted to all SCI patients on the case load of Dr Maguire and Dr Hillen at MPH on our behalf. The information pack is paper based and includes a participant information sheet, consent form, questionnaire and stamped addressed envelope for ease of return. Dr Maguire and Dr Hillen have both been involved in the early design stages of the project and are agreeable to assisting and for the project to proceed.

Phase B - SCI participants

Participants who consented to be contacted by the researcher will be posted further information relating to the qualitative exploration of their secondary upper limb injury. A participant information sheet and consent form will be posted to participants and a suitable time will be arranged on receiving informed consent.

Phase C - Staff

Dr Maguire has agreed to identify suitable staff on our behalf. Staff will be provided with a similar information pack including a participant information sheet, consent form and questionnaire. The researcher will collect the returned consent forms and questionnaire from MPH. Staff will be asked at the end of the questionnaire whether they wish to be included in a one-to-one interview with the PhD researcher and can signal their intent to do so by ticking yes.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

Yes No

Please give details below:

On obtaining informed consent the researcher will access patients notes onsite at MPH to double check participants history of upper limb injury. Participants will be asked whether they consent to the researcher accessing their notes via a consent form. The notes will be accessed on site at MPH and a specific data collection form will be used to collect only the information required for this study.

A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?

Yes No

A27-5. Has prior consent been obtained or will it be obtained for access to identifiable personal information?

Yes No

If Yes, please give details below.

A consent form posted out to all SCI patients will include a consent form asking patients whether they consent to allow the researcher to access their notes. A participant information sheet is also included to ensure the patient can make an informed decision.

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

Yes No

If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).

In the case that not enough participants are recruited a poster will be posted in the SCIU department at MPH with further information and contact details should they wish to find out more information about being included in the study.

A29. How and by whom will potential participants first be approached?

Potential participants will be contacted by Dr Maguire on our behalf. The PhD researcher will put together information packs for Dr Maguire to add patient's addresses to and will then be posted out. Both Dr Maguire and the researcher's contact details will be listed if participants have any further questions or queries relating to the study. Participants may signal their intent to participate by completing the consent form and questionnaire. A stamped addressed envelope will be included for ease of return.

A30-1. Will you obtain informed consent from or on behalf of research participants?

Yes No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Informed consent will be obtained via a written consent form which will be posted to potential participants alongside a participant information sheet and letter from Dr Maguire. This will be done by Dr Maguire on our behalf. Consent will also be sought for part 2 of the study for focus groups and interviews via a participant information sheet and consent form as above. Verbal consent will also be sought on the day of the focus groups/interviews and participants will be advised they can leave at any time without any adverse effects on the current care they receive.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

Yes No

A31. How long will you allow potential participants to decide whether or not to take part?

Participants will have a 2 week cooling off period to decide if they wish to take part prior to the initiation of focus groups/interviews.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)

Unfortunately due to the nature of focus groups and interviews, those with a cognitive impairment or illness which may impact their ability to participate in a focus group/interview setting have been excluded.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

- The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- The participant would continue to be included in the study.
- Not applicable – informed consent will not be sought from any participants in this research.
- Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

Participants are advised in the participant information sheet that they may withdraw from the study at any time and any data that has been previously collected will be included in the data collection if useful. this is also included on the consent form.

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick as appropriate)*

- Access to medical records by those outside the direct healthcare team
- Access to social care records by those outside the direct social care team
- Electronic transfer by magnetic or optical media, email or computer networks
- Sharing of personal data with other organisations
- Export of personal data outside the EEA
- Use of personal addresses, postcodes, faxes, emails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
 - Manual files (includes paper or film)
 - NHS computers
 - Social Care Service computers
 - Home or other personal computers
 - University computers
 - Private company computers
 - Laptop computers

Further details:

Data for both elements of the study will be stored and protected in line with Ulster University's data protection regulations. Research project data, whether electronic or hard copy, will be accessible only to those people who have a legitimate purpose, including members of the project team, internal and external auditors and representatives of regulatory bodies

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

All data collection forms and questionnaires are coded with unique identifier numbers (a number assigned to each participant's name so as they are not identifiable) to ensure confidentiality. Although every attempt will be made to anonymise the data obtained from focus groups, the researcher cannot guarantee members of the focus group will keep confidentiality. Members will be advised of this in the participant information sheet and will be asked to keep confidentiality prior to the focus group beginning.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

The researcher will seek consent via a consent form posted to participants by Dr Maguire. The researcher will access participants notes for the purpose of double checking their history of upper limb injury.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- Less than 3 months
- 3 – 6 months

- 6 – 12 months
 12 months – 3 years
 Over 3 years

If longer than 12 months, please justify:

In line with Ulster University's data protection policy, all data will be stored for 10 years on site at Ulster University Jordanstown in a locked data storage room.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

- Yes No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined. Participants will have their parking costs covered and refreshments provided by the research team.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

- Yes No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

- Yes No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

- Yes No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

- Yes No

Please give details, or justify if not registering the research.

Yes the research will be registered on INVOLVE - a database of published and unpublished research projects in the field of health, that have actively involved members of the public in the research process.

Registration of research studies is encouraged wherever possible.

You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have

entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- Peer reviewed scientific journals
- Internal report
- Conference presentation
- Publication on website
- Other publication
- Submission to regulatory authorities
- Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- No plans to report or disseminate the results
- Other (please specify)

PhD thesis

A53. Will you inform participants of the results?

- Yes No

Please give details of how you will inform participants or justify if not doing so.

Participants will be given a summary of the focus groups/interviews to ensure they are satisfied with the interpretation of their comments.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? Tick as appropriate:

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Review within the Chief Investigator's institution or host organisation
- Review within the research team
- Review by educational supervisor
- Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

Ethical approval will be sought via two peer reviews within Ulster University, the Institute of Nursing and Health Research Governance Filter Committee, Ulster University; Office of Research Ethics NI and the Belfast HSC Trust.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A56. How have the statistical aspects of the research been reviewed? Tick as appropriate:

- Review by independent statistician commissioned by funder or sponsor
- Other review by independent statistician
- Review by company statistician

- Review by a statistician within the Chief Investigator's institution
- Review by a statistician within the research team or multi-centre group
- Review by educational supervisor
- Other review by individual with relevant statistical expertise
- No review necessary as only frequencies and associations will be assessed – details of statistical input not required

In all cases please give details below of the individual responsible for reviewing the statistical aspects. If advice has been provided in confidence, give details of the department and institution concerned.

	Title Forename/Initials Surname
	Dr Mary Hannon Fletcher
Department	
Institution	Institute of Nursing and Health Research
Work Address	Room 01B120 School of Health Sciences Ulster University Jordanstown Shore Road Newtownabbey
Post Code	BT370QB
Telephone	+442890366914
Fax	
Mobile	+442890366914
E-mail	mp.hannon@ulster.ac.uk

Please enclose a copy of any available comments or reports from a statistician.

A57. What is the primary outcome measure for the study?

To carry out a mixed method (quantitative and qualitative) study to determine the rate of occurrence and time-line after SCI of upper limb injury.

A58. What are the secondary outcome measures?(if any)

Nil

A59. What is the sample size for the research? How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.

Total UK sample size: 700

Total international sample size (including UK):

Total in European Economic Area:

Further details:

Phase A & B - SCI participants

As there are no definite figures relating to numbers of SCI patients in Northern Ireland, we have opted for a sample of convenience. Dr Maguire and Dr Hillen are the two primary consultants of SCI in the only hospital in Northern Ireland that treats patients with an SCI. They have estimated they have approximately 700 patients on their caseload with an SCI although not all will have a traumatic SCI whom we are aiming to recruit. We therefore will recruit whoever identifies themselves as meeting our inclusion and exclusion criteria and consent to be involved in the study.

Phase C - Staff

MPH has a small staff number involved with SCI participants and we anticipate we may recruit 10 - 12 members of staff.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

A sample size calculation based on the identification procedure outlined in Part A will be completed. The number of participants included per focus group will vary between five to eight participants in line with other research in the area (Biering-Sorensen et al, 2006; Henwood et al, 2004; Kirchberger et al, 2010). Focus groups will be analysed in a sequential manner and concluded once the researcher is satisfied that enough information has been collected for data saturation to occur and new themes to emerge.

A61. Will participants be allocated to groups at random?

Yes No

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

This study will combine qualitative and quantitative research methods in the form of viewpoints, data collection and analysis; therefore, a mixed methods theoretical approach will be taken to guide the study. A mixed methods approach is an orientation toward social inquiry that actively invites us to participate in dialogue about multiple ways of seeing and hearing. The research team will adhere to strict rigour to ensure credibility and validity of the research findings.

Data from Phase A will be analysed using descriptive statistics and presented in tabular or graphic form.

Data from Phase B will be inputted into NVivo software after each focus group and analysed. This will allow the researcher to draw out the most common themes observed. A reflective diary will also be used to include bracketing of the research team - any emotions or prior experience which may bias the data analysis. A de-brief with the moderator (PhD student) and note taker post focus groups/interviews will be recorded which allows observation of any common threads, which may have been missed in the recordings. Once the early transcripts have been inputted to NVivo, any emerging ideas or themes that have not been included in the original topic guide can then be added after consultation with the research team. Quantitative data obtained from the review of medical notes will be entered into Microsoft excel under participant identifier numbers.

Data triangulation will be used to integrate the quantitative data obtained from questionnaires and thematic data obtained from focus groups/one-to-one interviews for both SCI and staff participants.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title Forename/Initials Surname
	Dr Suzanne Maguire
Post	Consultant in Rehabilitation
Qualifications	M.B., B.Ch., B.A.O., (N.U.I.) (Hons.) M.R.C.P. (Edinburgh) June 1993 M.D. (Queen's University, Belfast) December 1997 FRCP (Edinburgh) July 2004
Employer	Belfast Health and Social Care Trust
Work Address	Spinal Cord Injuries Unit Musgrave Park Hospital Belfast
Post Code	BT9 7JB
Telephone	02895049250
Fax	
Mobile	
Work Email	Suzanne.Maguire@belfasttrust.hscni.net

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status: NHS or HSC care organisation Academic Pharmaceutical industry Medical device industry Local Authority Other social care provider (including voluntary sector or private organisation) Other

Commercial status:

If Other, please specify:

Contact person

Name of organisation Ulster University

Given name Nick

Family name Curry

Address Ulster University Jordanstown campus, Shore Road, Newtownabbey

Town/city Co. Antrim

Post code BT370QB

Country UNITED KINGDOM

Telephone +44 28 90366629

Fax

E-mail n.curry@ulster.ac.uk

Is the sponsor based outside the UK?

 Yes No*Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.*

A65. Has external funding for the research been secured?

 Funding secured from one or more funders External funding application to one or more funders in progress No application for external funding will be made

What type of research project is this?

 Standalone project

- Project that is part of a programme grant
 Project that is part of a Centre grant
 Project that is part of a fellowship/ personal award/ research training award
 Other

Other – please state:
Part of a PhD

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

- Yes No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title Forename/Initials Surname
	Ms Alison Murphy
Organisation	Research Governance Belfast Health and Social Care Trust
Address	King Edward Building
	Belfast Health and Social Care Trust
	Royal Victoria Hospital Site Grosvenor Road
Post Code	BT12 6BA
Work Email	Alison.murphy@belfasttrust.hscni.net
Telephone	028 9063 6349
Fax	
Mobile	

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/05/2017

Planned end date: 01/10/2017

Total duration:

Years: 0 Months: 5 Days: 1

A71-2. Where will the research take place? (Tick as appropriate)

- England
 Scotland
 Wales
 Northern Ireland
 Other countries in European Economic Area

Total UK sites in study 2

Does this trial involve countries outside the EU?

Yes No

A72. Which organisations in the UK will host the research? Please indicate the type of organisation by ticking the box and give approximate numbers if known:

- NHS organisations in England
- NHS organisations in Wales
- NHS organisations in Scotland
- HSC organisations in Northern Ireland 1
- GP practices in England
- GP practices in Wales
- GP practices in Scotland
- GP practices in Northern Ireland
- Joint health and social care agencies (eg community mental health teams)
- Local authorities
- Phase 1 trial units
- Prison establishments
- Probation areas
- Independent (private or voluntary sector) organisations
- Educational establishments 1
- Independent research units
- Other (give details)
- Total UK sites in study: 2

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (NHS sponsors only)
- Other insurance or indemnity arrangements will apply (give details below)

The University's normal indemnity arrangements will apply

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (protocol authors with NHS contracts only)
- Other insurance or indemnity arrangements will apply (give details below)

The University's normal indemnity arrangements will apply

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

The University's normal indemnity arrangements will apply

Please enclose a copy of relevant documents.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

Research site	Investigator/ Collaborator/ Contact		
Institution name	Musgrave Park Hospital	Title	Dr
Department name	Spinal Cord Injury Unit	First name/ Initials	Suzanne
Street address	Stockmans Lane	Surname	Maguire
Town/city	Belfast		
Post Code	BT97JB		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
 - ◊ Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
 - ◊ May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
 - ◊ May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
 - ◊ Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
 - ◊ May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication *(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

Chief Investigator

- Sponsor
- Study co-ordinator
- Student
- Other – please give details
- None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Mary P.A. Hannon-Fletcher on 13/03/2017 22:18.

Job Title/Post: Head of School
Organisation: Ulster University
Email: MP.hannon@ulster.ac.uk

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

Please note: The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by Mr Nick Curry on 13/03/2017 11:40.

Job Title/Post: Research Governance
Organisation: Ulster University
Email: n.curry@ulster.ac.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Dr Daniel Kerr on 13/03/2017 11:32.

Job Title/Post: Lecturer
Organisation: Ulster University
Email: dp.kerr@ulster.ac.uk

Academic supervisor 2

This section was signed electronically by Mary P.A. Hannon-Fletcher on 13/03/2017 22:19.

Job Title/Post: Head of School
Organisation: Ulster University
Email: MP.hannon@ulster.ac.uk

Customer Care & Performance Directorate

Unit 4, Lissue Industrial Estate West
Rathdown Walk
Moir Road
Lisburn
BT28 2RF
Tel: 028 95361400
www.orecni.hscni.net

HSC REC A

04 April 2017

Dr Mary Hannon-Fletcher
Ulster University
Room 01B120, Jordanstown campus
Shore Road Newtownabbey
Co Londonderry
BT37 0QB

Dear Dr Hannon-Fletcher

Study title: Perception of impact of secondary upper limb injuries sustained by manual wheelchair SCI users.
REC reference: 17/NI/0062
IRAS project ID: 210512

Thank you for your letter, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a **favourable ethical opinion** for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.



Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Recruitment poster]	1.4	21 November 2016
Covering letter on headed paper [Cover letter rebuttal]	1.0	30 March 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Letter of sponsorship & indemnity from Ulster University]		16 March 2017
Interview schedules or topic guides for participants [Focus group/1:1 interview topic guide SCI Participants]	1.4	21 November 2016

Interview schedules or topic guides for participants [Topic guide 1 to 1 interviews staff]	1.0	21 November 2016
IRAS Checklist XML [Checklist_14032017]		14 March 2017
IRAS Checklist XML [Checklist_04042017]		04 April 2017
Letters of invitation to participant [Letter of invitation to SCI participants clean]	1.5	30 March 2017
Letters of invitation to participant [Letter of invitation to SCI participants highlighted]	1.5	30 March 2017
Non-validated questionnaire [Healthcare professionals questionnaire]	1.4	21 November 2016
Non-validated questionnaire [SCI participant's questionnaire clean]	1.5	30 March 2017
Non-validated questionnaire [SCI participants questionnaire highlighted]	1.5	30 March 2017
Other [Distress protocol]	1.2	21 November 2016
Other [Data Collection Review of notes Version 1.4 21.11.16]	1.4	21 November 2016
Participant consent form [Consent form SCI participants focus groups]	1.4	21 November 2016
Participant consent form [Consent form 1 to 1 interviews SCI participants]	1.4	21 November 2016
Participant consent form [Consent form staff questionnaire]	1.4	21 November 2016
Participant consent form [Consent form staff 1 to 1 interviews]	1.4	21 November 2016
Participant consent form [Consent Form for participation in questionnaire for SCI participants clean]	1.5	30 March 2017
Participant consent form [Consent Form for participation in questionnaire for SCI participants highlighted]	1.5	30 March 2017
Participant information sheet (PIS) [PIS SCI participants clean]	1.5	30 March 2017
Participant information sheet (PIS) [Participant information sheet SCI participants highlighted]	1.5	30 March 2017
Participant information sheet (PIS) [Participant information sheet SCI participants focus groups and interviews clean]	1.5	30 March 2017
Participant information sheet (PIS) [Participant information sheet SCI participants focus groups and interviews highlighted]	1.5	30 March 2017
Participant information sheet (PIS) [Participant information sheet staff questionnaire and interviews clean]	1.5	30 March 2017
Participant information sheet (PIS) [Participant information sheet staff questionnaire and interviews highlighted]	1.5	30 March 2017
REC Application Form [REC_Form_14032017]		14 March 2017
Referee's report or other scientific critique report [Peer review 1]	1.0	16 July 2016
Referee's report or other scientific critique report [Peer review 2]	1.0	30 July 2016
Referee's report or other scientific critique report [RG3 filter committee]	1.0	24 November 2016
Research protocol or project proposal [Protocol]	1.4	21 November 2016
Summary CV for Chief Investigator (CI) [Chief Investigator MHF CV]	1.0	26 January 2017
Summary CV for student [PhD student CV]	1.0	26 January 2017
Summary CV for supervisor (student research) [D Kerr CV]		25 January 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flowchart of study design]	1.4	21 November 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

17/NI/0062	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



pp Dr Catherine Hack
Chair
Email: RECA@hscni.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Mr Nick Curry, Ulster University*
Ms Alison Murphy, Research Governance Belfast Health and Social Care Trust

HSC REC A

Dr Mary Hannon-Fletcher
Ulster University
Room 01B120
University of Ulster Jordanstown campus
Shore Road Newtownabbey
Co Londonderry
BT37 0QB

Dear Dr Hannon-Fletcher

Study title: Perception of impact of secondary upper limb injuries sustained by manual wheelchair SCI users.
REC reference: 17/NI/0062
Amendment number: 1.5 04.08.17
Amendment date: 08 August 2017
IRAS project ID: 210512

The above amendment was reviewed at the meeting of the Sub-Committee held on 07 September 2017 in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Recruitment Poster]	1.5	04 August 2017
Interview schedules or topic guides for participants [One-to-one interview topic guide/outline]	1.0	04 August 2017
Letters of invitation to participant [Invitation letter to all SCI patients on database]	1.6	04 August 2017
Notice of Substantial Amendment (non-CTIMP) ["Perception of impact of secondary upper limb injuries SCI" (IRAS id 210512 REC Ref 17/NI/0062)]	1.5 04.08.17	08 August 2017

Other [Email Cover]		16 August 2017
Participant consent form [Consent Form for participation in questionnaire for SCI participants]	1.6	04 August 2017
Participant information sheet (PIS) [PIS for SCI participants for one-to-one interviews study]	1.6	04 August 2017
Participant information sheet (PIS) [Participant information sheet SCI participants questionnaire]	1.6	04 August 2017
Research protocol or project proposal [Study Protocol]	1.5	04 August 2017

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

17/NI/0062:

Please quote this number on all correspondence

Yours sincerely

Denise Nesbitt

P.P

Tamla Meredith
REC A Manager

E-mail: RECA@hscni.net

Enclosures: List of names and professions of members who took part in the review

*Copy to: Ms Alison Murphy, Research Governance Belfast Health and Social Care Trust
Mr Nick Curry, Ulster University*

HSC REC A

Attendance at Sub-Committee of the REC meeting on 07 September 2017

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Catherine Hack (Chair)	Consultant in Academic Practice (STEM)	Yes	
Dr Toni McAloon	Nurse Lecturer	No	
Mrs Tamla Meredith	REC Manager	Yes	
Dr Charles Mullan	Consultant Radiologist	Yes	

Appendix 4A: Invitation Letter



Dear Patient

I am contacting you on behalf of researchers from Ulster University who are conducting a study on upper limb injuries sustained from manual wheelchair use. The project aims to record personal perspectives and opinions of how your upper limb pain/discomfort/injury has affected you and your personal life and any adverse effects you may have undergone as a result. We are contacting you today to invite you to participate in the study to help further research in the area which will contribute to shaping services and addressing the needs of spinal cord injured (SCI) patients with an upper limb injury in the future.

The research project is split into three elements. The first element includes contacting you and inviting you to complete a questionnaire. The questionnaire is to identify those who have experienced upper limb pain and also to record the number of participants who have not experienced upper limb pain. The questionnaire asks some general demographic questions which we would encourage all participants to complete even if they do not have an upper limb injury, as we are also interested in how many participants do not report this. The remainder of the questionnaire asks you some general questions about upper limb injuries and how you manage your day to day tasks and activities with upper limb pain. We would like you to complete the questionnaire included in this pack and the enclosed consent form. If no upper limb pain is reported, we would ask you to complete the consent form and the first page of the questionnaire only, and return to the researcher. The consent form also asks if you would like to be included in some discussions with other participants who also have upper limb pain as a result of using their wheelchair at a later stage. These discussions will be in the form of focus groups and one-to-one interviews.

The second and third elements of the study will involve focus groups and one-to-one interviews with those who have suffered with upper limb pain as a result of wheelchair use. These will be held in Musgrave Park Hospital (MPH) or Ulster University Jordanstown (your choice) and will consist of some general questions about your injury and the type of pain you have experienced, and treatment you have underwent.

For the research study to take place, we are requesting your permission for the researcher (Adrienne McCann), to access your patient notes and use a specifically designed data collection form to record your previous upper limb

injuries as recorded in your medical notes. This will be completed under Belfast Health and Social Care Trust's policies and procedures and under the guidance of Dr Maguire. This study is entirely optional and will not affect your care if you do not wish to participate.

Should you wish to participate in the focus groups/interview, the researcher will contact you with further information regarding the study, including topic outlines for the focus groups, interviews and questionnaire.

If you think you may be interested, please read the attached information sheet and consent form that outlines the criteria we would require you to meet, prior to inclusion. A stamped addressed envelope has been included for your ease.

If you have any queries, please contact Dr Maguire on her below details or alternatively the chief investigator or researcher who can provide further information:

Dr Maguire's contact details:

Dr Suzanne Maguire
Consultant in Rehabilitation
Spinal Cord Injuries Unit
Musgrave Park Hospital
Belfast BT9 7JB
02895041808 (Ward)
02895049250 (Secretary)

Chief Investigator
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Researcher:
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Email: mccann-a18@email.ulster.ac.uk

Appendix 4B: Participant Information Sheet (PIS) for patients with an SCI

Title of study: Perception of impact of secondary upper limb injuries sustained by manual wheelchair SCI users

What is involved in the study?

My name is Adrienne McCann; I am an occupational therapist currently completing my PhD as part of my doctoral studies in Ulster University. We are contacting you to invite you to be involved in a study we are completing focusing on upper limb injuries that have occurred as a result of you using your wheelchair. The purpose of this study is to gain an insight into the lives of those with a spinal cord injury (SCI) who may have had an injury to their neck, shoulder, elbow, wrist, hand or fingers as a result of using their chair. The type of injury we hope to target is that which has happened possibly by overuse or strain from transferring in and out of your wheelchair or propelling your wheelchair over time to name just a few. This study has received ethical approval from the Institute of Nursing and Health Research Governance Filter Committee, Ulster University; Office of Research Ethics NI and the Belfast HSC Trust. It is reported that over 50% of SCI patients admit to shoulder pain, which can be arm, elbow, hand, wrist, or finger pain, general muscle fatigue and pain on transfers, propelling and activities of daily living. There is a substantial amount of literature in the area documenting the prevalence of these conditions however there is nothing directly related to you and your perspective of how the injury affects you. We hope to encompass elements of your personal, social and leisure activities to gain a greater understanding of the injury and the impact this may or may not have on your life as a whole. This is a new emerging area for research and it is anticipated that the opinions and experiences of those with SCI can help shape and develop services for future care.

What is involved?

We hope to gain as much information about you and your injury but prior to this we would like to make sure you are well informed about the project and can make an informed decision. The project is split into three elements – first we will need to calculate how many manual wheelchair users with an SCI are affected by upper limb injuries. To do this we have posted this information pack to all patients with an SCI in the hope they will return the questionnaire enclosed. We are also seeking your consent for the researcher (Adrienne McCann) to access your medical notes on site at Musgrave Park Hospital. This will be done in line with Belfast Health and Social Care policies and procedures and under the guidance of Dr Maguire. This is to record the number of upper limb injuries you have reported and the type and quantity of treatment you received. If you consent, we will allocate a participant identifier number (a number given to you for confidentiality rather than using your name) to each record to ensure that your personal details are not identifiable.

The second part of the study includes one-to-one interviews. This includes discussing your upper limb injury which may take approximately one hour of your time. This element of the study will be conducted at a later stage however we are also requesting your consent to be contacted by the researcher with further information regarding these interviews. It is hoped your opinions on the impact of your upper limb injury and experience of various treatments can help shape services, which are central to your needs. If you wish to be involved in these in future, there is a tick box on the consent form, which will signal to the researcher to send further information to you about these.

Do I have to take part?

No, it is up to you whether you wish to participate. If you do, you are still free to withdraw at any time.

What happens to the information?

We will give you a unique identifier code that will be used instead of your name on completion of the questionnaire. At no point, will your name be identifiable. Consent forms will be stored in a locked filing cabinet onsite at Ulster University (within a locked office space). Research project data, whether electronic or hard-copy, will only be accessible only to those people who have a legitimate purpose, including members of the project team, internal and external auditors and representatives of regulatory bodies. All data will be stored securely and subsequently destroyed in accordance with Ulster University's data protection policy after ten-years. Please be aware that in the case that a participant discloses sensitive information as being a victim of an unlawful act or if the researcher deems the person to be at risk of harm, the researcher is obliged to disclose this information to the relevant authorities.

Complaints procedure

Any complaints will be taken seriously and should be made, in the first place, to the Chief Investigator, contact details are below. Following this, the research office can also provide additional guidance, contact details below.

The University is insured for its staff and students to carry out research involving people. The University knows about this research project and has given permission for it to proceed. Further details can be found in the University's research indemnity statement which is available on request.

What happens next?

If you are willing to participate, please read the questions listed below. If you answer yes to all the below questions, please proceed to the questionnaire enclosed which will ask you questions specific to your upper limb injury(s). A consent form has been enclosed which will need to be returned alongside the questionnaire and a stamped addressed envelope for your ease.

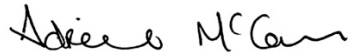
We have some criteria listed below we would like you to answer before completing the questionnaire to ensure all the participants are eligible for the study.

1. Do you have a traumatic SCI?
2. Are you minimum 6 months' post SCI?
3. Do you use a manually propelled wheelchair or have you used a manual wheelchair in the past but changed due to the strenuous requirements of a manual wheelchair?
4. Did you attend Musgrave Park hospital for medical treatment of your SCI?

If you have answered yes to the above questions, please proceed to the questionnaire enclosed. If you have answered no to any of the above questions, unfortunately you are not eligible for the study and can disregard this and enclosed documentation.

Thank you for reading this information sheet and considering participating in this study.
Please contact me on the details below should you have any queries.

Yours sincerely



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Ulster University Jordanstown
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028 903 66736

Chief Investigator:

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Appendix 4C: Upper limb Injury Identifying Questionnaire

Upper limb injury identifying questionnaire

Dear

The following questionnaire is designed to help identify any ache, pain or injury to your upper limb, which has resulted from use of your chair.

If you have not had any upper limb pain, we would be grateful if you completed the first page of this questionnaire and return to the researcher –as this will provide us with valuable information.

Participant name:	
Participant Identification number:	
Age:	
Gender:	
Level of spinal injury:	
Date of spinal injury:	____/____/____
Type of SCI (<i>please circle</i>):	Complete OR incomplete
Which best describes your employment status (<i>please tick</i>):	<ul style="list-style-type: none"> • Student • Employed, working 35 or more hours per week • Employed, working 1-34 hours per week • Not employed, looking for work • Not employed, NOT looking for work • Retired • Unable to work • Other (please specify) <p>_____</p>
What sector do you work in:	<p>_____</p> <p>_____</p> <p>_____</p>
Do you use a computer during the day for work/leisure? (Not including smartphone use)	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p>If so for how long per day would you spend sitting at your computer?</p> <p>_____</p> <p>_____</p>

Although you may have many aches and pains, we are focusing on the injuries you have sustained from your chair rather than a once off injury which you may have sustained from another activity. For example, we would like to know if your shoulder hurts when you transfer in and out of your car, however if this was an injury sustained during, for example, tennis, that would not be related to our questionnaire.

Health Screening Questions:

Do you suffer with any upper limb pain including back, neck, shoulder, elbow, wrist or finger pain?

- Yes
- No

If you have ticked 'No' above, you are not required to complete the remainder of the questionnaire. Thank you for taking the time to complete this questionnaire, please return to the researcher.

Please tick yes/no for each of the statements	YES	NO
This is a new pain (pain in a new location or pain that has new characteristics)		
This is a significant flare up (or worsening) of an existing pain		
There has been a recent decrease in my muscle strength or function		
There has been an increase in my muscle spasms		

Please circle the location of any type of pain or ache you have experienced which was as a result of using your chair

- (a) Neck
- (b) Back
- (c) Shoulder
- (d) Elbow
- (e) Wrist
- (f) Fingers
- (g) Other _____

How would you describe the pain experienced? Please circle all that are relevant:

- (a) Dull
- (b) Prickly
- (c) Throbbing
- (d) Moves from place to place
- (e) Comes and goes
- (f) Severe pain that can be pin-pointed
- (g) Pain that spreads over a large area

Have you had any pain during the last 30 days including today? *	<p style="text-align: center;">Yes</p> <p style="text-align: center;">(Please continue with questionnaire)</p>	<p style="text-align: center;">No</p> <p style="text-align: center;">(You are not required to complete the remainder of this questionnaire however please return to the researcher)</p>
--	---	--

Please circle on the accompanying scale your pain levels in relation to each question

In general, how much has pain interfered with your day to-day activities in the last week? *	<p>0 - 10 VAS Numeric Pain Distress Scale</p> <p>No pain Moderate pain Unbearable pain</p> <p style="text-align: center;">0 1 2 3 4 5 6 7 8 9 10</p>
--	---

In general, how much has pain interfered with your overall mood in the last week? *	<p>0 - 10 VAS Numeric Pain Distress Scale</p> <p>No pain Moderate pain Unbearable pain</p> <p style="text-align: center;">0 1 2 3 4 5 6 7 8 9 10</p>
---	---

In general, how much has pain interfered with your ability to get a good night's sleep? *	<p>0 - 10 VAS Numeric Pain Distress Scale</p> <p>No pain Moderate pain Unbearable pain</p> <p style="text-align: center;">0 1 2 3 4 5 6 7 8 9 10</p>
---	---

Average pain intensity in the past week?	<p>0 - 10 VAS Numeric Pain Distress Scale</p> <p>No pain Moderate pain Unbearable pain</p> <p style="text-align: center;">0 1 2 3 4 5 6 7 8 9 10</p>
--	---

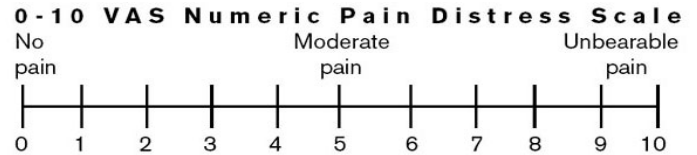
How many different pain locations do you have?*	<p>1 2 3 4 ≥ 5</p>
---	--------------------------------

Please circle if applicable and use the scale to describe the level of pain associated with each of the following:

1. Washing/dressing/grooming

I can dress myself independently with

- a) No pain
- b) Minimal pain
- c) Severe pain
- d) I cannot dress independently



2. Leisure

a) My pain prevents me from completing physical activity

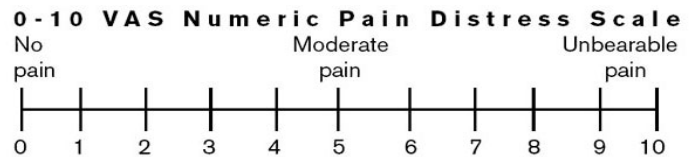
- Occasionally
- All the time

b) I do minimal physical activity

c) I participate in sport/physical activity regularly

d) What sport do you play (if any)?

e) How many hours per week do you play sport? _____

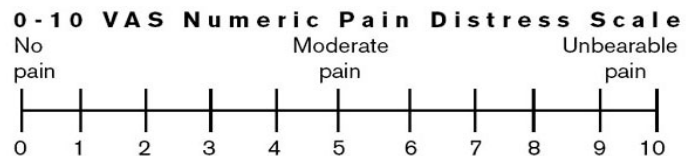


3. Social

a) I regularly participate in social activities

b) My pain prevents me from participating in social activities

c) Occasionally my pain prevents me from participating social activities



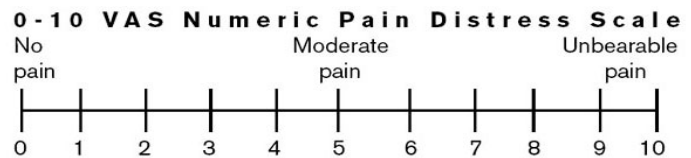
4. Home care/commitments

a) I complete house work independently

b) I have minimal pain completing housework

c) I have a lot of pain completing housework

d) I do not complete housework



5. Family

- Do you have family commitments YES NO

If so:

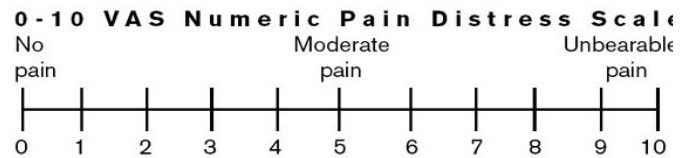
- a) I have young children
- b) I care for an older relative
- c) Other _____

6. Work

- a) I work/volunteer full time
- b) I work/volunteer part time
- c) I do not work

If you partake in work/volunteering please circle:

- i) I have no pain during work/volunteering
- ii) I have minimal pain during work/volunteering
- iii) I have constant pain during work /volunteering

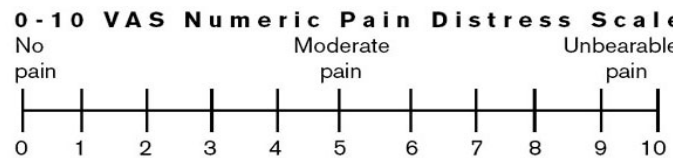


7. Driving

Do you drive YES NO

If you circled yes:

- a) How long do you spend in your car per day _____?
- b) Do you use a roof box to store your wheelchair YES NO
- c) Do you have pain while driving?
- d) If so how would you rate this pain



8. Treatment

If you reported pain at any stage, what type of treatment did you receive:

- a) Rest
- b) Medication
- c) Attend a physiotherapist/occupational therapist/massage/acupuncture
- d) I have undergone surgery for the pain
- e) Other _____

Of these treatments which did you find worked best?

Please provide further detail on how you feel your upper limb injury limits you in daily life:

*Questions from the International Spinal Cord Injury Pain Basic Data Set: Version 2 (Widerstrom-Noga et al. 2014)

** Questions to help identify SCI Pain Type - International Spinal Cord Injury Pain Classification (Bryce et al 2012)

Permission to adapt and use both questionnaires has been obtained from the relevant authors.

Appendix 4D: Participant information sheet (PIS) for one-to-one interviews

Title of study: Perception of impact of secondary upper limb injuries sustained by manual wheelchair SCI users.

Introduction:

We are contacting you to invite you to be involved in a study we are running focusing on upper limb injuries sustained by people such as you as a result of manual wheelchair use. This would include injuries to the neck, shoulder, arm, elbow, wrist, hand or fingers. The purpose of this study is to gain an insight into the lives of those suffering with an upper limb injury. It is reported that over 50% of SCI patients admit to shoulder pain which can be arm, elbow, hand, wrist or finger pain, general muscle fatigue and pain on transfers, propelling and activities of daily living. There is a substantial amount of literature in the area documenting the prevalence of these conditions however there is nothing directly related to you and your perspective of how the injury affects you. We hope include elements of your personal, social and leisure activities to gain a greater understanding of the effect the injury may or may not have on your life. This is a new emerging area for research and it is anticipated that the opinions and experiences of those with SCI can help shape and develop services for future care.

We hope to run some one-to-one interviews for you to speak about your experience with your upper limb injury.

One-to-one interviews

The aim of the interview is to let you speak freely about your experience of your upper limb injury and how it has affected your life. The researcher (Adrienne McCann) will lead the interview and will ask some general questions about your experiences, however overall it is your opinions that will guide the topic of the conversation. You do not have to speak about anything you do not wish to share and you are welcome to leave the interview at any stage if you feel uncomfortable. The interviews will last approximately one hour and will also be audio taped so as no information is forgotten.

What we will ask:

We would like you to be as open and honest about your upper limb injuries however you do not have to contribute any information you do not feel comfortable sharing. We will talk about various aspects of your personal life such as work, your family, how you manage using your wheelchair daily, sleep patterns, and any other topics you feel comfortable sharing.

What will happen if I consent?

If you agree to take part in the study, you will be invited to participate in an interview at Musgrave Park hospital or Ulster University Jordanstown or via telephone/skype

interview. Participants will be advised that they are not obliged to attend, that they may withdraw at any time and this will not affect their care. Confidentiality and anonymity will be explained and written consent to participate and recorded on tape will be sought.

Do I have to take part?

No, it is up to you whether or not you wish to participate. If you do, you are still free to withdraw at any time. You may withdraw at any time and this will not in any way adversely impact on the services you receive as normal. Please be aware that in the case you do withdraw from the focus group or interview, the research team will use the data obtained up to this point if relevant, as per consent form.

What happens to the information?

We will give you a unique identifier code (a number used instead of your name so your personal details are not identifiable) that will be used instead of your name to the completion of the study. After participating in the interview, the researcher will compile all the information and contact you to ensure you are happy with the interpretation of your comments made prior to reporting any results. Any data obtained from the interview will be coded with your unique identifier number to ensure comments are reported anonymously.

Consent forms will be stored in a locked filing cabinet onsite at Ulster University (within a locked office space). Members of the research team only will have access to the computer anonymous data for each participant. All data will be stored securely and subsequently destroyed in accordance with Ulster University's data protection policy after ten-years.

Please be aware that in the case that a participant discloses sensitive information as being a victim of an unlawful act or if the researcher deems the person to be at risk of harm, the researcher is obliged to disclose this information to the relevant authorities. In the case that you are unhappy with any aspect of treatment or procedure associated with the study, the Chief Investigator (lead on study) and member of ethical guidance staff at Ulster University, contact details have been included below.

Complaints procedure

Any complaints will be taken seriously and should be made, in the first place, to the Chief Investigator, contact details are below. Following this, the research office can also provide additional guidance, contact details below.

The University is insured for its staff and students to carry out research involving people. The University knows about this research project and has given permission for it to proceed. Further details can be found in the University's research indemnity statement which is available on request.

What happens next?

If you are willing to participate, please sign and return the consent form. A stamped addressed envelope has been provided for your ease. We will then be in contact to arrange suitable times and dates for the interview.

Thank you for reading this information sheet and considering participating in this study. Please contact me on the details below should you have any queries.

Yours sincerely



Adrienne McCann (PhD Student)

Email: mccann-a18@email.ulster.ac.uk

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Mary Hannon-Fletcher
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Email: mp.hannon@ulster.ac.uk*

Senior Administrative Officer:
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Tel: 028 903 66736
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Appendix 4E: Consent form for participation in questionnaire

Title of Study: Perception of impact of secondary upper limb injuries sustained by manual wheelchair SCI users.

Chief Investigator: Dr Mary Hannon Fletcher
Principal Investigator: Adrienne McCann
Supervisors: Dr Mary Hannon-Fletcher; Dr Daniel Kerr

Please initial

- I confirm that
 - a) I have a traumatic spinal cord injury
 - b) I am aged 18 years or older
 - c) I am minimum six months post initial SCI
 - d) I use/have previously used a manually propelled wheelchair for mobility purposes.
 - e) I have attended Musgrave Park Hospital for medical treatment of my SCI
- I consent for the researcher to access my medical notes under the guidance of Dr Maguire and in line with Belfast Health and Social Care Trust's policies and procedures, to access information relating to my upper limb injury and demographic details about me and my spinal injury.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights being affected in any way.
- I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law) and I give permission for the researchers to hold relevant personal data.
- I give permission for the research team to use my data even if I withdraw from the study, if useful.
- I would like to be contacted by the research team with further information relating to the next elements of the research study.

_____	_____	_____
Name of participant	Signature	Date
_____	_____	_____
Name of researcher	Signature	Date

In the case that you are unhappy with any aspect of treatment or procedure associated with the study, the Chief Investigator (lead on study) and member of ethical guidance staff UU, contact details have been included below

Chief Investigator:

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Tel: +44 28 90366914

Email: mp.hannon@ulster.ac.uk

Senior Administrative Officer:

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Researcher:

Adrienne McCann

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Tel: 028 903 66736

Email: mccann-a18@email.ulster.ac.uk

Appendix 4F – Consent form for one-to-one interviews

Title of Study: Perception of impact of secondary upper limb injuries sustained by manual wheelchair SCI users.

Chief Investigator: Dr Mary Hannon Fletcher
Supervisors: Dr Mary Hannon-Fletcher; Dr Danny Kerr
Principal Investigator: Adrienne McCann

Please initial

- I confirm that I have been given and have read and understood the information sheet for the above study and have asked and received answers to any questions raised.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights being affected in any way
- I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law) and I give permission for the researchers to hold relevant personal data
- I give permission for the research team to use my data even if I withdraw from the study if useful.
- I consent to be audiotaped for the purpose of this interview so as no information is lost.
- I agree to take part in the one-to-one interview

Name of participant

Signature

Date

Name of researcher

Signature

Date

In the case that you are unhappy with any aspect of treatment or procedure associated with the study, the Chief Investigator (lead on study) and member of ethical guidance staff UU, contact details have been included below.

Chief Investigator:

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Tel: 028 903 66736

Email: mccann-a18@email.ulster.ac.uk

Appendix 5: Data extraction form for review of medical notes

Data Collection form review of notes

Participant identifier number:	
Gender:	
Age:	
Age at spinal cord injury:	
Diagnosis:	
Level of injury:	
Date of injury:	
Reports of upper limb discomfort, injury or pain? (Please circle):	Yes No
Location of discomfort, injury or pain:	
Nature of upper limb injury/pain and how it occurred: e.g. over time, sudden injury, overuse injury, situational, specific activity pain from transfers:	
Type of treatment used:	
Number of hospital admissions/GP attendance recorded due to upper limb injury:	
Has patient attended Occupational therapy/physiotherapy? How many referrals?	
Has patient recorded an improvement in symptoms post treatment:	
Cognitive impairment reported?	Yes No
Medications prescribed/taken:	

Appendix 6: Topic Guide for one-to-one interviews with patients with an SCI

One-to-one interview topic guide/outline

Research goals of the interviews:

- ✓ To gain a greater insight into the prevalence of upper limb injuries, how this impacts on leisure, social, vocational and physical aspects of life as a wheelchair user.

1. What type of pain do you experience and where is it located?
2. How often do you experience this pain on a daily basis and how would you describe the type of pain e.g. prickly, throbbing, dull ache etc.
3. Do you know of any “triggers” or activities that bring on this pain more so than others?
4. Talk me through a regular day for you, how does this affect your daily routine?
5. Do you have family, work or other commitments – young children, live alone, carer for a parent/sick child etc. Do you think these impacts on your interaction with them? If so how?
6. Does the injury impact on how you get around on a day to day basis, are you less likely to meet friends/go to the shops etc. if you are in pain?
7. How does pain impact on your:
 - Personal care
 - Domestic tasks in the home
 - Work/Volunteering
 - Leisure/sport
 - Social activities
8. What coping mechanisms do you find have worked best to manage your upper limb pain?
9. Do you take medication to manage pain or inflammation?
10. Have you ever been referred to Occupational therapy or Physiotherapy? What type of treatments did you under go, for how long did you attend, did you find it beneficial?
 - Explore pros/cons of each
11. Have you ever undergone surgery for your injury – what was the recovery time like, had you to take time off work, other sacrifices?
12. What strategies were put in place by you or by healthcare staff during your rehab/ recovery from surgery to enable you to continue with day to day life?
13. Have you participated in wheelchair skills training? If so did you find it beneficial?

Appendix 7: Overview of thematic analysis aligned with the “Comprehensive ICF Core Set for Spinal Cord Injury – Chronic Situation”

Codes	Quotes	ICF category and code
Theme 1: Consequences of pain		
<p>Pain</p> <p>type of pain, triggers, transfers, sleep, environment, physical activity, social activities, ADLs driving</p>	<p><i>“the upper limb pain that I would have would most definitely be most sort of acute or prompt in the shoulders. Mainly my right shoulder and I feel that pain mainly in the front of it and it does run right down, sort of like a sickening ache, does run right down into the front of the elbow. Occasionally the back of the shoulders get sore as well but it’s mainly the front of the shoulders and I think it’s because we’re kind of pushing the one way all the time.”</i></p> <p><i>“For me I have to use my arms to lift myself across from the wheelchair and its kind of lift and hope that I get there okay but it can be initially a wee bit sort of painful. Then as the day goes on, I kind of, as my muscles sort of waken up and get more used to moving about it’s not so bad”</i></p> <p><i>“yeah it does it does sort of interfere at certain times of the day, mainly at night when I’m lying down and I’m trying to find a position to sort of leaving in just the way I’m sort of lying keeping on my side or something. The shoulder if an injury, it would hurt whenever I’m lifting things a certain way. If I was lifting sort of straight up with my arms straight out things you’ve to sort or manoeuvre it’s a bit differently with different things”</i></p> <p><i>“You know, certainly about 6 weeks ago when I did something to my shoulder I wouldn’t have been able to go out. That was more that happens occasionally, it wouldn’t happen an awful lot but just whenever I’ve done something to my shoulder, I’m never quite sure what but it’s a bit like back pain. If you’ve done something at the time you don’t realise until the next day”</i></p>	<p>Body functions and structures:</p> <p>Sleep functions – b134</p> <p>Emotional functions – b152</p> <p>Pain in upper limb – b28014</p> <p>Pain in joints – b28016</p> <p>Exercise tolerance functions – b455</p> <p>Muscle power functions – b730</p> <p>Activities and participation</p> <p>Lying down – d4100</p> <p>Sitting – d4103</p> <p>Transferring oneself – d420</p> <p>Lifting and carrying objects – d430</p> <p>Moving around outside the home and other buildings – d4602</p>

	<p><i>“There’s always housework to do so there is and you know, if I’ve hurt my shoulders it would certainly curtail what I could do about the house. I would take things easier”</i></p> <p><i>“I wouldn’t go to restaurants maybe where there’s a pile of steps or something you know so something fairly accessible but you know you would notice even pushing around the town even slopes and cubes and things you do notice the shoulder discomfort but as I’ve said keep saying to you, you just have to get on with it you can’t let it stop you or you do nothing.”</i></p> <p><i>“I would notice a constant discomfort there all the time but whenever you’re out and about and you’re pushing around and maybe do a few hills or you go and play sport like wheelchair tennis it definitely, you notice the pain even more, the discomfort even after it”</i></p>	<p>Moving around using equipment – d465</p> <p>Driving – d475</p> <p>Washing oneself – d510</p> <p>Dressing – d540</p> <p>Preparing meals – d630</p> <p>Doing housework – d640</p> <p>Remunerative employment – d850</p> <p>Recreation and leisure – d920</p> <p>Environmental factors</p> <p>Immediate family – e310</p> <p>Friends – e320</p> <p>Acquaintances, peers, colleagues, neighbours and community members – e325</p>
Theme 2: Medical and rehabilitation input		
<p>Treatment: medication, rest, injections, exercise, benefits. Consultant input</p>	<p><i>“If it’s really bad – pain killers. But that would be the height of it. Who do you go and see?”</i></p> <p><i>“The best thing I found so far is a certain level of exercise to help my shoulders. I don’t think painkillers were really, they just numb the pain”</i></p> <p><i>“so that’s been my sort of way of dealing with pain over the years, distraction for want of a better word really rather than medication</i></p>	<p>Body function</p> <p>Emotional functions – b152</p> <p>Exercise tolerance functions – b455</p> <p>Muscle power functions – b730</p>

<p>GP input</p> <p>OT Input</p> <p>Physio input</p>	<p><i>and different tablets which I would've done back in the early days whenever I first came out of hospital. Back then I would have been on all sorts, the like of amitriptyline's and different things to deal with the pain but I mean there was no quality of life with those sorts of meds so it's just been get on with it really"</i></p> <p><i>"Getting from a to b short distances is fine but do you what I mean there's times I'd see myself up and down here and being wrecked by the time you get to where you're going so rest that way yeah, and like if I'm sitting at the desk here, do you know what I mean, I would try and put the arm up a certain way to try and take the strain off or find a position that's suitable even like a cushion on the desk so you know what I mean so"</i></p> <p><i>"they'd spoken about putting an injection in and different things but I couldn't have done that because I use the arm too much you would have needed to rest it so that was out."</i></p> <p><i>"But as you said it's hard to actually always rest it but if you can't get the injection, you can't rest it you're always using it"</i></p> <p><i>"I had tennis elbow a few years ago and I got a cortisone injection, I was heading off for a competition and I had my arm in a sling for 2 days and it was a nightmare. You know trying to transfer trying to do all the things everybody else does in their everyday life was extremely difficult and I would be very independent, very proud so you know I don't like taking help with anything so like that there so no"</i></p> <p><i>"the acupuncture kept the pain away for a couple of months and the exercises maybe kept the pain away for maybe two or three months somewhat"</i></p> <p><i>"it was more short term, sort of realised that the injury will probably be there do you know what I mean for the long term so</i></p>	<p>Environmental factors</p> <p>Individual attitudes of health professionals – e410</p> <p>Health professionals - e355</p> <p>Personal care providers - e340</p> <p>Activities and participation</p> <p>Moving around outside the home and other buildings – d4602</p>
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it's just a matter of managing it putting up with it really, that way"
(physio)

"No, I think the last time I saw the, (consultants name), would be my consultant. It must be 10 maybe plus years since I've seen her... And that over the years has dwindled away and now it doesn't happen and now unless I did something myself it wouldn't. Now touch wood my health is fairly good I don't have many problems apart from the bit of pain every now and again and any time I do have problems I would go to my local GP to see it or the treatment room."

"I'm supposed to see her once a year and the last time I was with her I was having a few problems and she said she would need to see me back in 6 months but that was getting on toward 18months ago now I would say. I don't know whether it's the consultant or whether it's the secretary but appointments are like gold dust in that place in the spinal injury they're really hard to see anybody at all."

"I was told that if I had any problems at all regardless of what it is don't go to the GP don't go to A&E go straight to the spinal injury which I did and they were more than helpful on many occasions. But the last few years there that policy has completely changed and now it's nearly impossible for a former patient to get in to the spinal unit. Now I don't know what the setup is in the UK whether they're using the same system or not but I find it hard to believe that they would actually because when you go to any other department they haven't got the first idea how to look after a paraplegic, they really don't"

"well you know (hospital name) I really dislike. I felt it was a formality, they asked you how you were doing they ticked a few boxes and it was always the same right up until this year. "I know you've chronic neuropathic pain but I know you can do nothing

	<p><i>about it” and that was it really. And if you said there was anything else wrong with you, I may have mentioned the shoulders, probably didn’t, but as I said it was so insignificant compared to the neuropathic pain you just went in, you got your boxes ticked and then you went out again”</i></p>	
<p>Theme 3: Coping with pain and self-management</p>		
<p>Exercise: positive light, coping strategy, limitations</p> <p>Support: family, friends Dependents Carers</p> <p>Treatment: lack of services, barriers, short term relief, recovery time concerns</p> <p>Lack of specialised knowledge</p>	<p><i>“I mean most of the time I’ve got anything done is after one of these meetings where I’ve mentioned it. You tend not to go to the GP a) because it’s a real pain trying to go through the effort to get there, and the GPs don’t understand anything really about spinal injury. You know there occasionally I have to rely on them but I wouldn’t if I had a real problem that I thought was connected I wouldn’t go to my GP.”</i></p> <p><i>“you know whatever he could fit in to an hour session, he would put tape on as well and sometimes it would have had more affect than others. Not a very long lasting or obvious effect”</i></p> <p><i>“yes, I have thought about it but I haven’t really done anything about it because I know other people in wheelchairs who have had to have arm surgery and you’re talking about your arm in a sling for something like 12 weeks and that just makes life so difficult. I mean talk about running out of limbs you’re going from 4 limbs down to 1 then you know (laughs) you’d end up just pushing around in circles you know so unless it gets to the stage where I just have to have it, I’ll probably just go with it and keep going because the thought of being down to one arms for a few weeks is just.”</i></p> <p><i>“yeah, the acupuncture was sort of short term so it kept it away for about a month or less but when I went to the gym and built up the muscles the other muscles in my left shoulder then that really kept the pain away for a good few months, that was it worked, it kept the pain away for longer than the acupuncture”</i></p>	<p>Body function</p> <p>Emotional functions – b152</p> <p>Exercise tolerance functions – b455</p> <p>Muscle power functions – b730</p> <p>Activities and participation</p> <p>Remunerative employment – d850</p> <p>Recreation and leisure – d920</p>

	<p><i>“well I have a wife and two daughters but I tend to do everything kind of by, you know all kinds of chores and things I would do all by myself and I don’t normally ask for assistance you know. I mean my wife would do 99% of the cooking that sort of thing but the sort of manly chores around the place and what needs done around the house I just get on and do that myself.”</i></p> <p><i>“I get carers 3 times a week... I get a bit of help from the carers they, that’s why they, they call three times a week” (washing and dressing)</i></p> <p><i>“well my son would (inaudible) help me. Things whether they need done or not I just can’t do them... cleaning windows”</i></p> <p><i>“I mean my wife Maureen is you may hear her in the background (laughs) I’m more reliant now on her mainly things like the getting on/off the loo just to make sure the chair doesn’t move or getting me the board and helping me”</i></p>	
Theme 4: Resilience and pride		
<p>Attitude – deal with it independently, asking for help, putting up with pain</p>	<p><i>“I have the heart of a lion really (laughs). If I, I wouldn’t let something like that there stop me going places or to some sort of event so I’m lucky it’s not an extreme pain. At times its ridiculous pain. It can be annoying over long periods of time but it wouldn’t stop me from going out”</i></p> <p><i>“I ended up just putting up with the pain every now and then when it came along instead.”</i></p> <p><i>“but it was really on discussing with people who well you got wear and tear and I mean I’ve been using this chair now since my accident in the 70s so they say yes they do but not entirely happy that I’ve had to do because I find that if you stop doing things after a while you lose the ability to do them anyways.”</i></p>	<p>Body function and structures</p> <p>Emotional functions – b152</p> <p>Temperament and personality functions – b126</p> <p>Activities and participation</p> <p>Carrying out daily routine – d230</p> <p>Handling stress and other psychological demands – d240</p>

	<p><i>“at the end of a day it’d be very tight and tired do you know what I mean but I’d just sort of soldier on through you know, I’d just be stuck in bed all the time unless I’m really, really bad and really need to lie down but most of the time I’d just get on with it and do you know what I mean”</i></p> <p><i>“You know trying to transfer trying to do all the things everybody else does in their everyday life was extremely difficult and I would be very independent, very proud so you know I don’t like taking help with anything so like that there so no”</i></p> <p><i>“yeah well, I think they would if I asked them but I suppose a bit of male pride thing you just get on with it yourself... I mean anything that I couldn’t do would be too heavy for ladies anyway so I probably wouldn’t annoy them really”</i></p> <p><i>“my brother, he is my carer, he gets the carers allowance and he does quite a bit of the DIY, cuts the grass and things like that. My wife she wouldn’t do an awful lot know with the pregnancy and she was very sick but we were away on holidays there and she did the most of the stuff. But I help out as much as I could. My daughter now she’s 8 and she’s getting into the swing of things, my oldest daughter I mean she’s starting to get very helpful as well she’s good support.”</i></p> <p><i>“well for example until recent years I would have happily gone off to England on my own or somewhere you know getting on a plane and going somewhere. I’ll probably not do that anymore. I mean my wife Maureen is you may hear her in the background (laughs) I’m more reliant now on her mainly things like the getting on/off the loo just to make sure the chair doesn’t move or getting me the board and helping me.”</i></p>	<p>Individual attitudes of</p> <p>Environmental factors</p> <p>Acquaintances, peers, colleagues, neighbours and community members – e425</p>
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	<p><i>“It’s a big ramp there’s no rail at the minute so I’ve said look get a rail in so they are going to get one in. But this past while it’s been going past and waiting for someone to walk past and give me a push up that ramp cause, do you know what I mean. I wouldn’t be afraid of asking do you know what I mean like I wouldn’t be embarrassed to ask say “jump on the back there mate give us a push up” so I’ll take the help where I can get it”</i></p>	
<p>Theme 5: Looking towards the future</p>		
<p>Future concerns Low on priority list Smart drive Powered wheelchairs</p>	<p><i>“Leading to a certain amount of concern on my behalf that, you know, as I get older, will this get worse. I’ve been told in the past by consultants that I will have shoulder problems in the future but now it seems to be becoming... Prevalent yes. A bit more obvious”</i></p> <p><i>“there’s the more gradual one (pain) that seems to be coming from, I don’t know whether from age or wear and tear but this is the one that kind of I’m keeping an eye on at the minute, lifting myself. I think I’m weaker as I’m getting older but lifting myself from the bed on to the wheelchair, in and out of the car or they would be the main occurrences. It’s that one I’m keeping an eye on to see, over the next few years how that develops”</i></p> <p><i>“I mean I’m 57 I do wonder whether I’ll be doing this in my sixties I don’t know. At the moment, I might take a moments breather after I’ve done all that because you’ve also got the palaver of getting the chair in the right place and then setting it back up again and stuff.”</i></p> <p><i>“I’m thinking later in life when I need to get around, but I also like the exercise as well you know, even if it does half kill me (laughs) you know but I still like the exercise and getting up and round and I think that... but you know 10 years’ time how much pushing will be left in me I don’t know (laughs)”</i></p>	<p>Body function and structure</p> <p>Emotional functions – b152</p> <p>Pain in upper limb – b28014</p> <p>Activities and participation</p> <p>Moving around using equipment – d465</p> <p>Driving – d475</p> <p>Recreation and leisure – d920</p> <p>Environmental factors</p> <p>Acquaintances, peers, colleagues, neighbours and community members – e425</p> <p>Immediate family – e310</p>

“yeah and like it gets harder over the years, like there’s some days you are aching but a lot of my other pains come more from muscle spasms in the legs in stuff and id recurrent sort of urine infections, kidney infections over the years so they would cause a lot of spasms, headaches, back pain just a general sense of being run down by those. They’re very hard to shift so they would be above my shoulder and upper limb pain so they would sort of put that pain down the list its these other pains that are doing me in”

“I may not be a great case for this (researchers name) because I was so used to living at a level of chronic pain, every day for 27 years that the arms and shoulders may be more annoying to other people than me because the neuropathic pain that I have because of my spinal injury, way exceeded any sort of pain you could have. Like it was kind of labelled as an 8/10 every day and I had an operation in February of this year which brought it down to about a 2/10... so whenever you’ve had that and you’ve lived with that, things like shoulder pain and arm pain which are an inconvenience you know, it’s pretty insignificant it’s not nice and it’s sickening at times but compared to having like 5 times worse that a tooth ache every day and you know”

“Smart drive is the first thing I can sort of manage on my own but even it for me it’s an awkward thing to get on and off. I can get it off quite easily, getting it on is more problematic but I can do it. And for me that immediately limits what is the practical range of choices you have and probably then you’d say I should just put up with the shoulder pain (laughs). “

“it’s not that practical or desirable to be honest because you are kind of giving a degree of your independence because you’re going to have to look at an entirely other way at getting in and out of a car because you’re not going to lift up one of those things and put it in the back seat”

	<p><i>“all those things are expense, and also, they change the way you do things and probably for me, always the biggest goal is to maintain the flexibility and not to constrain my choice about where I go, when I go, you know not to have to be relying on people getting the chair in and out of the car. So that period for me, now I know these guys have these sorts of wheelchairs with the battery motors in the wheels, even them they’re just too heavy to do what I do with my wheelchair.”</i></p>	
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Appendix 7B: Frequency of codes

	Code	ULS001	ULS002	ULS004	ULS005	ULS006	ULS007	ULS009
Pain	Pain – type of pain	X	X	X	X	X	X	X
	Pain - triggers		X			X	X	X
	Pain - transfers	X	X	X	X	X	X	X
	Pain – sleep	X		X	X		X	X
	Pain - environment				X	X	X	X
	Pain – exercise/physical activity	X	X	X	X			
	Pain – social activities		X		X			X
	Pain – barrier to ADL’s		X	X	X	X		X
Exercise	Exercise - positive light	X	X	X	X		X	X
	Exercise - coping strategy	X	X				X	X
	Exercise - limitations	X	X					
Treatment	Treatment – medication	X	X			X	X	X
	Treatment – rest	X		X			X	X
	Treatment – injections			X	X			X
	Treatment – concerns	X		X			X	X
	Treatment – benefits	X			X			
	Treatment – exercise		X					X
	Treatment – lack of services	X		X		X		X
	Treatment – barriers		X	X			X	
	Treatment – short term relief	X	X	X	X	X		X
	Treatment – recovery time concerns			X			X	X
Medical team	Consultant input	X	X	X	X	X	X	X
	GP input	X		X		X	X	X
	OT Input			X		X		

	Physio input	X	X	X		X	X	X
	Lack of specialised knowledge			X		X		X
Support network	Support – family	X	X	X		X	X	
	Support - friends	X		X				
	Dependents		X				X	
	Carers				X			
Psychological impact	Attitude – wants to deal with it independently		X	X		X		X
	Attitude – asking for help	X			X		X	
	Attitude – putting up with pain	X	X	X		X	X	X
	Pain on priority list - low	X	X	X	X		X	X
	Future concerns	X	X	X		X	X	X
ADL's	Domestic tasks - pain	X	X		X			
	Domestic tasks – employs own strategies		X		X			
	Driving – pain		X			X	X	
	Driving – employs own strategies		X			X		
	Difficulty implementing changes		X				X	
Assistive technology	Other wheelchairs			X		X		
	Smart drive					X	X	X
	Assistive technology						X	X
	Wheelchair skills				X			
	Powered wheelchairs			X		X		

Appendix 7C: Grouping of codes to produce themes

Code	Theme
Pain – type of pain	Consequences of pain
Pain – triggers	
Pain – transfers	
Pain – sleep	
Pain – environment	
Pain – physical activity	
Pain – social activities	
Pain – ADL's	
Pain – driving	
Treatment – medication	Medical and rehabilitation input
Treatment – rest	
Treatment – injections	
Treatment – exercise	
Treatment – benefits	
Consultant input	
GP input	
OT Input - Wheelchair skills	
Physio input	
Exercise - positive light	Coping with pain and self-management
Exercise - coping strategy	
Exercise - limitations	
Support – family	
Support - friends	
Dependents	
Carers	
Treatment – lack of services	
Treatment – barriers	
Treatment – short term relief	
Treatment – recovery time concerns	
Lack of specialised knowledge	
Attitude – deal with it independently	Resilience and pride
Attitude – asking for help	
Attitude – putting up with pain	
Future concerns	Looking towards the future
Low on priority list	
Smart drive	
Powered wheelchairs	

Appendix 8A: Participant information sheet staff

Title of study: Perception of impact of secondary upper limb injuries sustained by manual wheelchair SCI users.

What is involved in the study:

We are contacting you to invite you to be involved in a study we are running focusing on secondary upper limb injuries sustained as a result of manual wheelchair use in the spinal cord injury (SCI) population. The purpose of this study is to gain an insight into the lives of those suffering with secondary complications, with the focus on upper limb injury.

It is reported that over 50% of SCI patients admit to shoulder pain which can be arm, elbow, hand, wrist or finger pain, general muscle fatigue and pain on transfers, propelling and activities of daily living. We hope to gain an insight into the lives of those living with an SCI who suffer with upper limb pain. We also would like to elicit the perspectives of the multi-disciplinary team who are involved in the care of the patient and the role you play in their treatment.

The study is comprised of two elements – the first stage will involve recruitment of SCI participants who use a manual wheelchair as their primary wheelchair and have an upper limb injury or pain. We will contact these patients via Dr Maguire who is assisting us with the study. We will identify the number of those with an SCI injury and the type of treatment they have undergone. The second and third elements of the study involves speaking to both SCI participants and the staff involved in their treatment to elicit their personal perspectives of the physical and psychosocial impact the injury has on their day to day lives.

We hope to speak to members of the multidisciplinary team including; orthopaedic surgeons, occupational therapists, physiotherapists and nursing staff to gain a greater perspective, not just from the patients but from those who are treating them for their upper limb injury. We would ask you to complete the enclosed questionnaire and consent form at a time that suits you best, and the researcher will return to collect these from Musgrave Park Hospital when completed. The questionnaire should take no longer than ten minutes to complete.

The final question on the questionnaire asks if you would be interested to participate in a one-to-one interview with the researcher to further explore the incident of upper limb injuries in the SCI population. This interview will be conducted at MPH at a time suitable to you and your schedule. The interview will be audiotaped and we will also seek your consent for this. The purpose of audiotaping is to ensure no information is misunderstood by the researcher and that all information recorded is correct.

Do I have to take part?

No, it is up to you whether or not you wish to participate. If you do, you are still free to withdraw at any time. You do not need to give a reason for your withdrawal.

Please be aware that in the case you do withdraw from the interview, the research team will use the data obtained up to this point if relevant, as per consent form.

What happens to the information?

We will give you a unique identifier code that will be used instead of your name on completion of the questionnaire. At no point will your name be identifiable. Consent forms will be stored in a locked filing cabinet onsite at Ulster University (within a locked office space). Research project data, whether electronic or hard-copy, will only be accessible to those people who have a legitimate purpose, including members of the project team, internal and external auditors and representatives of regulatory bodies. All data will be stored securely and subsequently destroyed in accordance with Ulster University's data protection policy after ten-years. Please be aware that in the case that a participant discloses sensitive information as being a victim of an unlawful act or if the researcher deems the person to be at risk of harm, the researcher is obliged to disclose this information to the relevant authorities.

Complaints procedure

Any complaints will be taken seriously and should be made, in the first place, to the Chief Investigator, contact details are below. Following this, the research office can also provide additional guidance, contact details below.

The University is insured for its staff and students to carry out research involving people. The University knows about this research project and has given permission for it to proceed. Further details can be found in the University's research indemnity statement which is available on request.

What happens next?

If you are willing to participate, please complete the consent form and questionnaire. We will then be in contact to arrange collection of the forms and to arrange one-to-one interviews if you wish to participate.

Thank you for reading this information sheet and considering participating in this study. Please contact me on the details below should you have any queries.

Yours sincerely

Adrienne McCann (PhD Student)

Email: mccann-a18@email.ulster.ac.uk

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Mary Hannon-Fletcher

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Appendix 8B: Consent form participation in questionnaire - staff

Title of Study: Perception of impact of secondary upper limb injuries sustained by manual wheelchair SCI users.

Chief Investigator: Dr Mary Hannon Fletcher
Principal Investigator: Adrienne McCann
Supervisors: Dr Mary Hannon-Fletcher; Dr Danny Kerr

Please initial

- I confirm that I have been given and have read and understood the information sheet for the above study and have asked and received answers to any questions raised.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights being affected in any way.
- I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law) and I give permission for the researchers to hold relevant personal data.
- I give permission for the research team to use my data even if I withdraw from the study, if useful.
- I agree to take part in the above questionnaire.

_____	_____	_____
Name of participant	Signature	Date
_____	_____	_____
Name of researcher	Signature	Date

In the case that you are unhappy with any aspect of treatment or procedure associated with the study, the Chief Investigator (lead on study) and member of ethical guidance staff UU, contact details have been included below.

Chief Investigator:
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Appendix 8C: Consent form participation in one-to-one interview - staff

Title of Study: Perception of impact of secondary upper limb injuries sustained by manual wheelchair SCI users.

Chief Investigator: Dr Mary Hannon Fletcher
Principal Investigator: Adrienne McCann
Supervisors: Dr Mary Hannon-Fletcher; Dr Danny Kerr

Please initial

- I confirm that I have been given and have read and understood the information sheet for the above study and have asked and received answers to any questions raised.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights being affected in any way.
- I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law) and I give permission for the researchers to hold relevant personal data.
- I consent to be audiotaped for the purpose of this interview so as no information is lost.
- I give permission for the research team to use my data even if I withdraw from the study, if useful.
- I agree to take part in the above mentioned one-to-one interview.

Name of participant	Signature	Date
Name of researcher	Signature	Date

In the case that you are unhappy with any aspect of treatment or procedure associated with the study, the Chief Investigator (lead on study) and member of ethical guidance staff UU, contact details have been included below.

<p>Chief Investigator: Mary Hannon-Fletcher <i>Room 01B120 School of Health Sciences Ulster University Jordanstown Shore Road Newtownabbey Co. Antrim BT37 0QB</i> Tel: +44 28 90366914 Email: mp.hannon@ulster.ac.uk</p>	<p>Senior Administrative Officer: Nick Curry <i>Room 26A17 Research & Innovation Ulster University Jordanstown Shore Road Newtownabbey Co. Antrim BT37 0QB</i> Tel: +44 28 90366629 Email: n.curry@ulster.ac.uk</p>	<p>Researcher: Adrienne McCann <i>Block 1 Level F School of Health Sciences Ulster University Jordanstown Shore Road Newtownabbey Co. Antrim BT37 0QB</i> Tel: 028 903 66736 Email: mccann-a18@email.ulster.ac.uk</p>
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Appendix 8D – Staff questionnaire

1. What is your profession and where are you based?

2. Do you treat patients with a Spinal Cord Injury who suffer with upper limb discomfort/pain/injury? (Please circle)

Yes/No

If you ticked “Yes” please continue to question 3. If you ticked “No”, unfortunately we do not require your input and you may discard this questionnaire.

3. What do you perceive is the primary cause of upper limb injuries in SCI patients whom you treated/have been involved in their care?

4. What is the primary intervention(s)/treatment(s) you provide/recommend for this injury?

5. Do you feel upper limb injuries are part of SCI progression or preventable?

6. Do you think there is a common age/length of time in chair at which the symptoms of an upper limb injury are most commonly observed? (Please circle)

Yes/No

Please expand on your answer above

7. Do you feel your patients suffer with any psychological or psychosocial issues as a result of their upper limb injury e.g. low mood, loss of motivation, anxiety, depression? (Please circle)

Yes/No

Please expand on your answer above

8. Do you/the multidisciplinary team provide any wheelchair skills training to SCI patients that you are aware of? (Please circle) OR is there any provided externally e.g. through a charity organisation?

Yes/No

9. If so is this provided on a continual basis or a one off on first receiving their wheelchair?

10. Do you feel this level of training is satisfactory?

Yes/No

Please expand on your answer above

11. Do you feel that SCI patients have opted for a power assisted/smart drive/powered wheelchair due to the strains a manual chair has on their upper limbs? (Please circle)

Yes/No

Please expand on your answer above

12. Do you wish to partake in a one-to-one interview with the researcher to answer the above questions in further detail?

Yes/No

If yes, please provide your contact details (name and email address below)

Name: _____

Email address: _____

Appendix 8E: Topic guide for one-to-one interviews - staff

Topic guide for one-to-one interviews with staff:

1. When a patient first presents/referred to you, what do you feel is their primary concern in relation to their personal lives e.g. managing family, work, children/spouse, managing activities of daily living (ADL's), general functioning.
2. Do you feel the level of wheelchair training provided is adequate? How often is it provided and by whom? What does the wheelchair training cover?
3. Do you feel upper limb injury is a common occurrence among SCI patients? What kind of injuries?
4. What do you perceive as the primary cause of upper limb injury?
5. Do you feel it could be prevented at an earlier stage? Split into two – prevent; and sooner/earlier?
6. Do patients adhere to preventative advice given to them to reduce risk of injury?

Appendix 9: Staff open ended questionnaire responses

Staff Questionnaire – open ended responses									
Participant ID	What is your job title	Primary cause of UL pain in SCI	Treatments you recommend for this injury	Are UL injuries preventable	Is there a common age/ time in chair when UL pain occurs	Psychological or psychosocial issues because of UL pain	Is WC skills training provided	Is further training required	Do patients opt for powered chairs due to UL strain
MDT01	OT	Wear and tear in joints from overuse	Splinting, change of wheelchair or transfer technique	Part of progression but can be reduced by lifestyle changes	Yes – not necessarily age related, more regarding time in a wheelchair. 15+ years probably have most significant pain	Yes – pain when self-propelling reduces ability to go out frequently or may make you dependent on having someone with you, therefore more socially isolating	Yes – one off on receiving their wheelchair as there is currently no funding for an outpatient service	Yes – very comprehensive programme established now and we also have links with the BackUp trust for peer led skills sessions x4 per year	Yes – but most do this reluctantly so it means a total change of lifestyle
MDT02	OT	Prolonged dependence on UL's for all ADLs, mobility, transfers	Adaptation of task where possible, ? physiotherapy Ax/Rx, consideration of equipment/ environment	Perhaps not entirely preventable but impact could be reduced in many cases	Not sure – I mostly work with clients in the rehab phase i.e. early after injury	Yes – with SCI, maintaining independence can be a struggle – UL injury compounds this struggle	Yes – we train all users to their optimum ability at time of rehab. BackUp are a charity who also provide training	No – in many cases it is sufficient but often a client's confidence and therefore skill will grow in time as they recommence their lives with SCI post rehab	Yes – I am aware of past patients having to move from manual to power
MDT03	OT	Tetraplegia: weakness/ imbalance in upper limb. Increase tone can cause increase pain. Overuse of certain muscle groups e.g. upper trapezius from functional tasks In pushing wheelchair/ transfers etc	Promote normal movement patterns/ UL strengthening programmes. Teach energy efficient wheelchair skills. Education re positioning of upper limbs, management of tone	Can often be an issue but can be managed/reduced	Yes – I feel that over a length of time in a chair if someone is ++ active with self-propelling, transfers, lifting wheelchairs in and out of cars then there will be wear and tear on some joints - ?10 years+. Equally a client with weak upper limbs initially (ie tetraplegia) may experience injuries earlier. May also	Yes – pain increase can reduce activity leading to decreased mood, difficulties getting around in community can affect integration	Yes – this is offered on a one-to-one basis when a patient receives their wheelchair – intensive wheelchair skills training provided	Yes – I feel the spinal unit offers intensive one-to-one wheelchair skills training to all patients. We also run group wheelchair skills training facilitated by “BackUp”	Yes – on some occasions – patients perhaps with tetraplegia have considered power assist/smart drive devices privately particularly to cover long distances/ outdoor mobility powered wheelchairs have also been sought when ++ difficulties with continuation of a manual chair

					depend on age at onset, previous UL activities undertaken ie manual work?				
MDT04	Physio – rotational	Overuse of UL's to compensate for trunk/ lower limb weakness – muscle imbalance causing malalignment of shoulder joint	Strengthening, postural awareness, stretching programme	Preventable	No	Yes – pain impacts psychological well-being. Our patients are heavily...	Yes – OTs work on this throughout the patient's stay	Yes	No – not aware of this in my experience – usually using power chair due to weakness in UL's or trunk
MDT05	Physio	Central cord patients who develop impingement post-op complications of C3 nerve paralysis brachial plexus injuries. As patients BMI increases the incidence of shoulder/ upper limb injury increases	Physiotherapy – stretching, manual therapy, re-education Of manual movement patterns, acupuncture, hydrotherapy, FFS upper limb cycling, Bioness H200 FES, education and advice	Education of correct stretching and handling can minimise occurrence, although long-term use of wheelchair leads to wear and tear. Incomplete injuries e.g. CCS have issues with muscle imbalance and tone	No – individual dependent	Yes – pain, limitations in function/ ADLs	Yes – during first episode of rehab	Yes	Yes
MDT06	Medical doctor	Wheelchair use – self-propelling. Also, in tetraplegics, the muscle imbalances associated with the shoulder	Adjustment of technique/ rest where necessary	Part of progression but this can be delayed/ reduced	No – depends on patient's spinal injury level, degree of activities, type, body habits and other medical issues	Yes – impacts greatly when threatens transfers/ independence	Yes – mainly one-off during initial rehab period, one off but continuous through inpatient stay	Yes – but it depends again on patient use and biology. Not sufficient for same patient	Yes
MDT07	Medical doctor	Post injury – upper limb pain. Shoulder problems – rotator cuff injuries, bursitis – at outpatient's similar patterns mainly shoulder pain	Pain relief, investigations x-ray/ LISS, intraarticular injections, referral to orthopaedics	Part of SCI	No	Yes – Can affect ability to transfer – loss of independence that they may have built up	Yes – initially during their initial rehab however BackUp do courses several times a year on the ward	Yes	Yes – only occasionally

Appendix 10A: Mapping of response to ICF “Core Set for Rehabilitation” with additional categories from the whole ICF core set

Coding staff interviews: Theme 1: The OT process

Code	Participant	Quote	ICF code	
Transfers	MDT01	<p><i>“we work on transfer technique and that happens in the first day or two because if they’ve come in being hoisted but we think they have the potential to transfer, we’d probably just introduce the board straight away and not hoist or if they’re a low level para we never give them a board. If you start them off with a board it’s very hard for them to get rid of it so from day 1 they don’t get a board they just so either the physio or OT would do the initial mobilisation into the chair so we quite often do that as a double, we go down together and do that jointly.”</i></p> <p><i>“if able we work on transfer technique and that happens in the first day or two because if they’ve come in being hoisted but we think they have the potential to transfer, we’d probably just introduce the board straight away and not hoist or if they’re a low level para we never give them a board. If you start them off with a board it’s very hard for them to get rid of it so from day 1 they don’t get a board they just so either the physio or OT would do the initial mobilisation into the chair so we quite often do that as a double, we go down together and do that jointly.”</i></p>	D420: TRANSFERRING ONESELF	
	MDT02	<p><i>“so we do look at everything that’s down your problem list everything that’s down your AD’s list we would look at personal care, transfers, functional transfers”</i></p>	D230: CARRYING OUT DAILY ROUTINE D510: WASHING ONESELF D540: DRESSING D420: TRANSFERRING ONESELF D520: CARING FOR BODY PARTS	
	MDT03	<p><i>“Physios will normally do the first transfer practice so they will do the wheelchair to plinth and then we would tend to look at the functional transfers so we would look at you know on and off a toilet, on and off a shower chair, in and out of a car, in and out of a driver’s side car, lifting the wheelchair into the car, returning to drive, kitchen assessments, there’s just, everything”</i></p>	D420: TRANSFERRING ONESELF D465: MOVING AROUND USING EQUIPMENT D475: DRIVING	
	Assessment and treatment	MDT01	<p><i>“we also have an upper limb screening assessment that we have to do within 3 working days of admission. So that would be dexterity, sensation, grip strength and then we just have a non-standardised hand function test. Which would be open a pill bottle, operating a remote control, typing a number in a mobile phone, can they press the button the</i></p>	B710: MOBILITY OF JOINT FUNCTIONS E585: EDUCATION AND TRAINING

		<p>nurse call to ask for help so it's a wee checklist can they hold a bit of cutlery, can they fill in their menu card, things like that "</p> <p>"it would be very much heat, or a combination of putting heat and cold on and ranging, trying to maintain the range because a lot of the pain comes from, people with arthritis develop pain and start to lose that full range and if they're restricted in any way and they begin to load the joint incorrectly and that causes more pain."</p> <p>"And there are braces but you know some of the kind of neoprene braces and supports that can be put on for shoulder or elbow or wrists and I think most OT departments can issue them now because there's very little thermoplastic splinting done now for the elbow or shoulder now it's usually an off the shelf splint as opposed to custom made but around the wrist and the hand and the thumb is still done."</p> <p>"I suppose for carpal tunnel it's about rest at night as well so it might be something soft and neoprene or feature brace during the day for a bit of support but maybe at night one night one wrist fully supported in the night resting splint and then the next night the other one, not both of them because they can't do anything"</p>	<p>SERVICES, SYSTEMS AND POLICIES</p> <p>B730: MUSCLE POWER FUNCTIONS</p> <p>B735: MUSCLE TONE FUNCTIONS</p> <p>B134: SLEEP FUNCTIONS</p> <p>E115: PRODUCTS AND TECHNOLOGY FOR PERSONAL USE IN DAILY LIVING</p>
MDT02		<p>"it's always wheelchair seating for our clients not just static seating. So the first port of call for us would be a seating assessment we would go in and do a brief assessment of your patients seating needs... And then we usually go in and meet the client, find out how long they've been sitting, our nurses and doctors will have admitted and clocked them into the wards so well be aware of any skin issues preventing seating assessment. Well do a brief screen on their ranges, their critical measures, we mightn't necessarily go into a full critical measures assessment that first day but we will check that they have appropriate range to get up and seated and then seating will be their first priority."</p> <p>"so we do look at everything that's down your problem list everything that's down your ADLs list we would look at personal care, transfers, functional transfers, a lot of upper limb assessment and therapeutic input to try and improve upper limb function, grip strength, range, splinting, tone is quite a big problem with a lot of our patients, a lot of patients would have very high tone or spasm or clonus that we would need to try and address or measure as it has a big impact on function. We would look as well at home environment, it would take up quite the bulk of our treatment and discharge planning... we would do home visits with almost all of our patients and we would try and do that jointly with the community staff so that the follow through is there, the continuity of care is there and we would be looking at then adaptations and providing the correct equipment, at</p>	<p>D420: TRANSFERRING ONESELF</p> <p>E585: EDUCATION AND TRAINING SERVICES, SYSTEMS AND POLICIES</p> <p>B710: MOBILITY OF JOINT FUNCTIONS</p> <p>B730: MUSCLE POWER FUNCTIONS</p> <p>B735: MUSCLE TONE FUNCTIONS</p> <p>D420: TRANSFERRING ONESELF</p> <p>D475: DRIVING</p> <p>D910: COMMUNITY LIFE</p>

		<p><i>least with the home visit we know what the home environment is, we know what goals the patient really has to achieve in terms of space or heights at home, furniture and things like that."</i></p> <p><i>"We would do look at extended ADLs as well, we are fortunate here to have the time and the scope to go into things like shopping, driving, return to work, we do, we mightn't necessarily follow through with patients the whole way but we go as far as we can, sometimes you do, we have been out in the past in educational settings with patients maybe getting students back into university and linking in with special needs coordinators at schools and things like that."</i></p> <p><i>"we would start off with a comprehensive assessment and we would look at grip strength, sensation, range of movement, coordination and function obviously, functional screening from the start. And then wherever your deficits are so if somebody maybe had very high tone you might be looking at a splinting and a stretching regime for them, if someone had weaker muscle groups then you'd be looking at a strengthening regime for them, so certainly strengthening work, positioning and movement patterns, we would spend quite a bit of time trying to teach more normal movement patterns to clients so you might have some clients who have to use adenitises function for activity in which case so in the case of C5/6 you might be teaching them to use adenitises function. There might be other clients that because of tone or restrictive movement could be using adapted movement patterns and you'd be trying to teach them a more normal movement pattern because they may then have potential to gain a little more recovery or indeed a more normal movement pattern which might prevent wear and tear injuries or other injuries down the line. Splinting, wed have a fair bit of input with splinting but we do try a lot of our upper limb clients would need wrist support for example and you would certainly be supporting the wrist with the aim to improve function but then with the guys with high tone as well you could be looking at splinting and stretching to try manage that tone and prevent the loss of range as well. We also sometimes do more functional splints so splints to help somebody feed or shave or a splint that might hold them more in pronation or supination in order then to feed in to their functional levels."</i></p>	<p>D920: RECREATION AND LEISURE</p> <p>B710: MOBILITY OF JOINT FUNCTIONS</p> <p>B730: MUSCLE POWER FUNCTIONS</p> <p>B735: MUSCLE TONE FUNCTIONS</p> <p>S720: STRUCTURE OF SHOULDER REGION</p> <p>E115: PRODUCTS AND TECHNOLOGY FOR PERSONAL USE IN DAILY LIVING</p>
	MDT03	<p><i>"yeah so day one is going to be assessing for wheelchair whether that is going to be a level 3 tilt in space chair or is it going to be something a bit more basic. Generally, if it's what we refer to as a basic chair it will be something like an Action 3. Very rarely would somebody go in to an active wheelchair on day 1. And also, then we are assessing for pressure relief which would be our big priority for day 1 introduction."</i></p>	<p>S810: STRUCTURE OF AREAS OF SKIN</p>

		<p><i>"It is goal planning every 2 weeks with a patient so that they are involved in the treatment interventions and it can be anything from personal care practice to transfer practice. Physios will normally do the first transfer practice so they will do the wheelchair to plinth and then we would tend to look at the functional transfers so we would look at you know on and off a toilet, on and off a shower chair, in and out of a car, in and out of a driver's side car, lifting the wheelchair into the car, returning to drive, kitchen assessments, there's just, everything"</i></p> <p><i>"... there's weakness there, there's issues with their sensation, it might often be issue that they're over using so people will adopt postures and compensatory techniques. So a lot of our job is to try educate the patient and try to promote normal patterns of movement if there is such a thing but try to optimise their function, looking at their posture so that they're in the best seated posture for them to use their upper limb function because we would see a lot of compensation and that's a lot of... it's very common in spinal injury where there's maybe an imbalance of muscle, strength and power so some muscles are working much harder than others so that is quite common and you know perhaps sometimes with during the period of rehab they maybe haven't presented with a lot of upper limb pain initially. Perhaps as they go through they might develop a little bit and then that's the job for us to look at what may be causing that you know is it maybe something to do with how you know they're pushing the chair or their transfer or have this you know it could be lots of reasons."</i></p>	<p>D155: ACQUIRING SKILLS</p> <p>E115: PRODUCTS AND TECHNOLOGY FOR PERSONAL USE IN DAILY LIVING</p>
Seating	MDT01	<p><i>"So we have a kind of protocol here ourselves that they have to be seen within the first 24 hours after admission and hopefully seated within the first 36 hours so if they're fit to sit up that's usually our first point of contact; getting them a wheelchair and cushion and getting them up to sit. Everybody goes in to a manual chair even if they don't have any potential to push it, because we don't put people straight into power until we've an idea of their cognitive status, how alert they are, how able to follow instructions."</i></p> <p><i>"they have to be seen within the first 24 hours after admission and hopefully seated within the first 36 hours so if they're fit to sit up that's usually our first point of contact; getting them a wheelchair and cushion and getting them up to sit"</i></p>	D465: MOVING AROUND USING EQUIPMENT
	MDT02	<p><i>"Quite often in the acute centre patients would be up and seated but on a chair beside the bed, all of our patients need mobility to come to and from therapy so it's always wheelchair seating for our clients not just static seating... We would know from the file; we would know from the handover from the OTs in the Royal whether they're likely to need tilt</i></p>	D465: MOVING AROUND USING EQUIPMENT

		<p><i>in space for example or whether they're somebody who could manage in a more active wheelchair."</i></p> <p><i>"we don't know for sure if they're going to be wheelchair users long term, mobility is a big go but also seating, posture, pressure relief, they're, it's very important that your client is comfortable above all else. All the technical things, textbook things, we know of the pressure relief, posture and symmetry and even function they don't necessarily, their brain wouldn't be in that place yet but they know that they do need to be comfortable if they're not comfortable they're not going to stay out of bed, if they don't stay out of bed, they're not going to build up their tolerance and they're not going to benefit from therapy"</i></p>	
	MDT03	<p><i>"yeah so day one is going to be assessing for wheelchair whether that is going to be a level 3 tilt in space chair or is it going to be something a bit more basic. Generally, if it's what we refer to as a basic chair it will be something like an Action 3. Very rarely would somebody go in to an active wheelchair on day 1"</i></p> <p><i>"we want to assess the seating and provide a good comfortable posture. Initially our goal may be if that patient can't sit up for 2 hours a day or sit up for 3 hours or 4 hours and sometimes we would do a seating plan so they can monitor how long they can sit for because obviously the risks of somebody sitting up for a long period of time on day 1 can cause a lot of pain discomfort you know. Posture can be compromised if they're sitting up longer and also pressure injuries but primarily as OTs we want to achieve mobility for that person whether that be providing them with a manual wheelchair or if we feel that they don't have the function to operate that or any other reason we would be looking at powered mobility."</i></p>	<p>D465: MOVING AROUND USING EQUIPMENT</p> <p>B810: PROTECTIVE FUNCTIONS OF THE SKIN</p>
Upper limb screening	MDT01	<p><i>"we also have an upper limb screening assessment that we have to do within 3 working days of admission. So that would be dexterity, sensation, grip strength and then we just have a non-standardised hand function test. Which would be open a pill bottle, operating a remote control, typing a number in a mobile phone, can they press the button the nurse call to ask for help so it's a wee checklist can they hold a bit of cutlery, can they fill in their menu card, things like that"</i></p>	<p>D465: MOVING AROUND USING EQUIPMENT</p> <p>B810: PROTECTIVE FUNCTIONS OF THE SKIN</p>
	MDT02	<p><i>" a lot of upper limb assessment and therapeutic input to try and improve upper limb function, grip strength, range, splinting, tone is quite a big problem with a lot of our patients, a lot of patients would have very high tone or spasm or clonus that we would need to try and address or measure as it has a big impact on function."</i></p>	D440:FINE HAND USE
	MDT03	<p><i>"yeah so with our own day to day assessment and treatment of the newly injured is what we see, yes there are lots of patients that present with upper limb injuries due to their</i></p>	B735: MUSCLE TONE FUNCTIONS

		<i>level of injury so if they've got tetraplegic they're going to have weakness and sensory loss in their upper limbs and part of our role is to assess that and treat it... So probably jointly with the physio colleagues we would need to look at that and you know sometimes it might be that we have to increase the assistance that they're needing to do that transfer or we might need to spend a bit more time educating them how to manage functional tasks"</i>	D440: FINE HAND USE D445: HAND AND ARM USE
Wheelchair skills training	MDT01	<i>"oh the full range of skills so I would say the predominant amount of our work would be the kind of level 1 level 2 skills so that's just how to propel efficiently, how to turn the chair, using energy efficient techniques, how to pick things up from the chair and even the basic set up of the chair so they have an awareness of what makes it lighter but if you make it lighter to push it it may be more unstable so can they cope with the instability. We do that when we're going through the prescription for the chair so they end up with a chair that they're comfortable in using and its lightweight and efficient as possible and then we always have a number of active wheelchair users that go on to do all the back wheel balance and steps and stairs."</i>	D465: MOVING AROUND USING EQUIPMENT
	MDT02	<i>"We would do most of the wheelchair skills practice in the treatment room but we do go out and around the grounds, we go over to the wheelchair skills garden over here with different surfaces, different types of curbs. And then back up as I say, backup is over every quarter and as much as we would do a lot of the wheelchair skills training and some clients we do bring them to their potential where others may gain a little more and you really do see the difference when its peer education then." "We would do some overlay with family members as well so not everybody is going to have a high level of independent wheelchair skills but be able to be verbally independent is almost as important so they can direct a carer up and down a curb, so they can direct a carer to help them cross the road or I know sometimes we would have family members in as well so if we thought that family member would benefit from basic stuff, curbs and ramps, cambers and pavements so sometimes we'll go through that with the family member as well."</i>	D465: MOVING AROUND USING EQUIPMENT
			D750: INFORMAL SOCIAL RELATIONSHIPS E585: EDUCATION AND TRAINING SERVICES, SYSTEMS AND POLICIES D760: FAMILY RELATIONSHIPS
MDT03	<i>"So, wheelchair skills day 1 when we get patient in to a manual chair, we automatically run through the basics of how to use the wheelchair. So we use the regional wheelchair skills checklist and we will tick that off so number one thing we would teach is energy efficient push because</i>	D465: MOVING AROUND USING EQUIPMENT	

		<i>most people get in to the chair and do not push it correctly, in day 1 they do the shuffle. So we really try to hone that in on day one and that might only be on the ward environment when we're showing them how to put on and off the brakes and how to remove the armrests we will discuss how to do the energy efficient pushing because I kind of feel like if they don't get it on day 1 then they're going to develop bad habits and that's what we try to say to them. And then we will do a 1 to 1 individual sessions with that patient so that will be individual sessions up here in OT with ourselves and also with our Tl's who are all competent in completing wheelchair skills. And then depending on the person's level of function and ability we can progress that on to level 2, level 3, advanced skills. Again, done on a 1 to 1 basis with the patient so they have a lot of time to practice. It's part of their treatment its part of their goals that we set."</i>	E585: EDUCATION AND TRAINING SERVICES, SYSTEMS AND POLICIES
MDT team input	MDT01	<i>"we have a very good nursing staff and most of the techniques that are reinforced by them as well so it's not as if they come for one hour of OT and then its forgotten about for the rest of the day, so it's very much promoted at ward level and then physio as well and we would do joint working a lot with physio, so we ensure that were telling them the same advice or same techniques"</i>	E585: EDUCATION AND TRAINING SERVICES, SYSTEMS AND POLICIES
	MDT02	<i>"would do home visits with almost all of our patients and we would try and do that jointly with the community staff so that the follow through is there, the continuity of care is there and we would be looking at then adaptations and providing the correct equipment, at least with the home visit we know what the home environment is, we know what goals the patient really has to achieve in terms of space or heights at home, furniture and things like that."</i>	D910: COMMUNITY LIFE
	MDT03	<i>"So probably jointly with the physio colleagues we would need to look at that and you know sometimes it might be that we have to increase the assistance that they're needing to do that transfer or we might need to spend a bit more time educating them how to manage functional tasks" (transfers)</i>	D230: CARRYING OUT DAILY ROUTINE
Education	MDT01	<i>"giving them long term advice and to avoid repetitive strain injuries and lifting and just about their positioning and posture you know in the chair as well that they could do with. I think there's a huge role for OT the whole way along that spectrum"</i>	D410: CHANGING BASIC BODY POSITION E585: EDUCATION AND TRAINING SERVICES, SYSTEMS AND POLICIES

	MDT02	<p><i>“So we do try and educate patients and we do try and make them aware that the reason you’re learning this technique, or the reason you’re learning to move your chair this way is to minimise the risk of further damage”</i></p> <p><i>“we do give as much education we give lots and lots, without frightening, you don’t want to frighten anyone but you do want them to be well warned that this is the safe way of doing it... we do try and promote good habits we do try and encourage them and remind them but it doesn’t always filter through.”</i></p> <p><i>“we do try and cover and backup information in writing as much as possible because you do know people are getting a vast amount of information”</i></p>	<p>B710: MOBILITY OF JOINT FUNCTIONS</p> <p>B730: MUSCLE POWER FUNCTIONS</p> <p>E585: EDUCATION AND TRAINING SERVICES, SYSTEMS AND POLICIES</p> <p>B735: MUSCLE TONE FUNCTIONS</p>
	MDT03	<p><i>“a lot of our job is to try educate the patient and try to promote normal patterns of movement if there is such a thing but try to optimise their function, looking at their posture so that they’re in the best seated posture for them to use their upper limb”</i></p>	<p>E585: EDUCATION AND TRAINING SERVICES, SYSTEMS AND POLICIES</p>

Coding staff interviews – Theme 2: Patient priorities

Code	Participant	Quote	ICF code
Mobility - walking	MDT01	“they all want to walk, they don’t want to, they don’t really care about their hands initially.”	D450: WALKING
	MDT02	“basic mobility would be the big one. And I think once somebody has had a life changing accident or injury mobility tends to be their first concern or their primary concern – will I walk?”	D450: WALKING
	MDT03	“both therapist and patient goal I think initially is mobility, whatever that may be so for ourselves clearly, we want to assess the seating and provide a good comfortable posture. Initially our goal may be if that patient can’t sit up for 2 hours a day or sit up for 3 hours or 4 hours and sometimes we would do a seating plan so they can monitor how long they can sit for because obviously the risks of somebody sitting up for a long period of time on day 1 can cause a lot of pain discomfort you know.	D465: MOVING AROUND USING EQUIPMENT
Para’s vs tetra’s	MDT01	“so if they’ve had any degree of paralysis, they want to get back on their feet and in fact we would find that people who are paraplegic would nearly have a better outcome, you know if they’ve got full upper limb strength but can’t walk, they can still be fully independent from a chair but some of the patients who walk but don’t have good hand function are much more dependent you know on helping assistance as well so.” “and a lot of tetraplegics would say this, they’re more concerned about hand function, their legs don’t matter they just want to be able to feed themselves, wipe their bum or you know (laughs)... so they don’t want to have people doing those intimate jobs”	D450: WALKING
			D440: FINE HAND USE
			D445: HAND AND ARM USE
			D530: TOILETING
			B152: EMOTIONAL FUNCTIONS
	MDT02	“And sometimes for the guys who are complete its very difficult to accept that, for the guys who have incomplete injuries it makes things maybe even more difficult in some ways because right now were dealing with how they are today we don’t know how they’ll be in the afterwards so sometimes you have to say to people this is the way were working with you were going to discharge you with this level of mobility we cannot say that it will improve further, we cannot say that it won’t improve further so” “the tetras would always say they didn’t realise how much they needed their hands until they could no longer use them. And for somebody who might only have limited upper limb	D465: MOVING AROUND USING EQUIPMENT
			D155: ACQUIRING SKILLS
			B152: EMOTIONAL FUNCTIONS
			B152: EMOTIONAL FUNCTIONS
			D440: FINE HAND USE

		movement, to lose a little bit is magnified for them, they lose a whole lot more as a result so they if they've only lost a little bit of range or a little bit of power it almost has a magnifying effect on their life."	
	MDT03	nil	
Neuropathic pain	MDT01	"if someone is experiencing quite a lot of neuropathic pain, then they'll identify it to you as a problem. But if they're not then no. They're more focused on can I get home for Christmas, can I get to my daughters 21 st birthday."	B280: SENSATION OF PAIN B152: EMOTIONAL FUNCTIONS
	MDT02	Nil	
	MDT03	Nil	
Not thinking long term	MDT01	"So we'd someone who was admitted there last week and their goal was to watch the Karl Frampton fight there on Saturday so a lot of the time they're still thinking of the wee immediate goals of will I sit up again, will I get out of my house, will I see my dog, they're not really thinking long term"	B152: EMOTIONAL FUNCTIONS D420: TRANSFERRING ONESELF
	MDT02	"upper limb function in the tetraplegic patients, most of the tetras would tell you that even if they didn't walk they'd like a return of upper limb function and it quite often takes a wee while for that to be realised for clients...sooner or later they realise that their upper limb function you use more than your lower limb function so. It's not always the first thing patients complain about but it is quite often one of the most difficult things they have difficulty accepting that they might need help to feed or help to shave or dress or wash or reach for their phone for example."	D440: FINE HAND USE D445: HAND AND ARM USE D230: CARRYING OUT DAILY ROUTINE D240: CHANDLING STRESS AND OTHER PSYCHOLOGICAL DEMANDS
	MDT03	Nil	
Acceptance of injury	MDT01	"they haven't really accepted it to be honest most of the guys as well. It's usually a period of realisation whenever they're here, obviously some will get a really good recovery and if they're incompletes, may walk out of here and that's great but there are other who will have to come to the fact that they won't walk again and the loss of lower limb appears to annoy them more."	D240: CHANDLING STRESS AND OTHER PSYCHOLOGICAL DEMANDS D450: WALKING
	MDT02	"And sometimes for the guys who are complete its very difficult to accept that, for the guys who have incomplete injuries it makes things maybe even more difficult in some ways because right now were dealing with how they are today we	D240: CHANDLING STRESS AND OTHER PSYCHOLOGICAL DEMANDS

		don't know how they'll be in the afterwards so sometimes you have to say to people this is the way were working with you were going to discharge you with this level of mobility we cannot say that it will improve further, we cannot say that it won't improve further so"	
	MDT03	Nil	
Continence	MDT01	"and a lot of tetraplegics would say this, they're more concerned about hand function, their legs don't matter they just want to be able to feed themselves, wipe their bum or you know (laughs)... so they don't want to have people doing those intimate jobs"	D440: FINE HAND USE D445: HAND AND ARM USE
	MDT02	"And then in our ward one of the big pressing issues which is not strictly therapy is more the nurses that would deal with continence, bowel and bladder function overlays everything else. If a reliable regime can be established where somebody can be continent throughout the day it then allows them to realise their previous life roles, it allows them to parent better, it allows them to return to work it allows them to think about driving. And even on a basic early level, if continence is a problem they can't even participate in therapy they might come up and have an accident and have to return and the same patient might go to physio 4 or 5 days in a row but not actually get a physio session started so yes mobility, personal care, continence would be a big one in the early stages"	B620: URINATION FUNCTIONS D475: DRIVING
	MDT03	"for our spinal patients its toileting, its bladder, its bowel everything needs to be looked at"	B620: URINATION FUNCTIONS
Comfort over function	MDT01	"We do that when we're going through the prescription for the chair so they end up with a chair that they're comfortable in using and its lightweight and efficient as possible and then we always have a number of active wheelchair users that go on to do all the back wheel balance and steps and stairs."	D465: MOVING AROUND USING EQUIPMENT
	MDT02	"you still want them to be motivated enough to make the most of their therapy. So certainly mobility is a big one, for the guys that aren't incomplete and the guys that aren't going to be, we don't know for sure if they're going to be wheelchair users long term, mobility is a big go but also seating, posture, pressure relief, they're, it's very important that your client is comfortable above all else."	D465: MOVING AROUND USING EQUIPMENT B810: PROTECTIVE FUNCTIONS OF THE SKIN

		“their brain wouldn’t be in that place yet but they know that they do need to be comfortable if they’re not comfortable they’re not going to stay out of bed, if they don’t stay out of bed, they’re not going to build up their tolerance and they’re not going to benefit from therapy.”	
	MDT03	“yeah primarily our, both therapist and patient goal I think initially is mobility, whatever that may be so for ourselves clearly, we want to assess the seating and provide a good comfortable posture... obviously the risks of somebody sitting up for a long period of time on day 1 can cause a lot of pain discomfort you know. Posture can be compromised if they’re sitting up longer and also pressure injuries”	D465: MOVING AROUND USING EQUIPMENT B810: PROTECTIVE FUNCTIONS OF THE SKIN
Previous life roles	MDT01	“at the employment clinics we used to do a little bit more with disabled employment advisors about returning to work through patients are so fast at the minute that they’re all gone home really quickly they’re not really ready for work when they’re leaving us but we don’t see them maybe 10 weeks later when they would be yeah”	D845: ACQUIRING, KEEPING AND TERMINATING A JOB D910: COMMUNITY LIFE
	MDT02	“Life roles, previous life roles would be a big issue for clients but not something necessarily they would present themselves with in the early days. Certainly the parents, if somebody’s in and they’re a parent you know that that’s a pressing concern. For most people employment might be in the back of their minds but it’s only when you start to ask questions you realise how big a concern it might be. And with that you’ve got finances and future planning and things as well”	D910: COMMUNITY LIFE D920: RECREATION AND LEISURE D240: CHANDLING STRESS AND OTHER PSYCHOLOGICAL DEMANDS
	MDT03	Nil	
Goal setting	MDT01	“So we’d someone who was admitted there last week and their goal was to watch the Karl Frampton fight there on Saturday so a lot of the time they’re still thinking of the wee immediate goals of will I sit up again, will I get out of my house, will I see my dog, they’re not really thinking long term”	D240: CHANDLING STRESS AND OTHER PSYCHOLOGICAL DEMANDS
	MDT02	nil	
	MDT03	“It is goal planning every 2 weeks with a patient so that they are involved in the treatment interventions and it can be anything from personal care practice to transfer practice” “we will do a 1 to 1 individual sessions with that patient so that will be individual sessions up here in OT with ourselves and also with our TI’s	D465: MOVING AROUND USING EQUIPMENT E585: EDUCATION AND TRAINING SERVICES, SYSTEMS AND POLICIES

		who are all competent in completing wheelchair skills. And then depending on the person's level of function and ability we can progress that on to level 2, level 3, advanced skills. Again, done on a 1 to 1 basis with the patient so they have a lot of time to practice. It's part of their treatment, it's part of their goals that we set"	

Coding staff interviews: theme 3 - Barriers

Code	Participant	Quote	ICF code
Lack of specialised knowledge in community	MDT01	<i>"I suppose if we've got a bit of hand pain or kind of symptoms, like they tend to go back through hand injuries or rheumatology so sometimes the rheumatology ones will phone up and say we've been asked to make resting splints for this person but they're not rheumatology they're spinal and we just tell them you know it's not a standard night resting splint it's a "prosay" we talk them through, we send them the information and they do it"</i>	D440: FINE HAND USE D445: HAND AND ARM USE E115: PRODUCTS AND TECHNOLOGY FOR PERSONAL USE IN DAILY LIVING
	MDT02	<i>"Now there are community services out there, there are community physios and community OTs and there's domiciliary OTs and there are rehab teams out there but coming from a spinal injury background we might be better placed to look at the technique and more specialised transfers. Particularly the functional transfers when it comes to transferring in and out of the car or a shower chair or you know a lot of the patients it would have been 3 years ago and would have been using a different technique to what we're teaching now and they might benefit from learning new transfer techniques."</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
	MDT03	<i>"We're equally getting so many incomplete injuries through as well and there's no time for you to treat them forever. And maybe you don't need to see them every day because their changes start to become so small, but it would be so nice to see what they're functioning at, you know, if it was once a week you could review them but I mean we just don't have that service here and it's a huge issue because it's very, very difficult to get outpatient hand therapy or upper limb therapy in the community so there's lots of functional rehab therapists that can look at how you're managing to wash and dress yourself but there's nobody there that can sort of instruct you of an upper limb hand therapy programme" "I think there's a huge role there for OTs and especially for OTs that are working in spinal injuries where a lot of that might be passed on to community staff who don't know the staff as what we do."</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
Lack of access to UL clinics SCI	MDT01	<i>"we're lucky that Mr Mahwhinney as a hand therapist or upper limb surgeon wants us there as well and his own OTs have identified that they don't have capacity you know to see those clients...The only clinics that there is none at are the spinal ones, and it's probably the area that he feels less confident with so and were not able to help out there. And he would be very supportive of having us there as well... he would be</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES

		<i>very keen not to undertake a major tendon transfer or shoulder replacement or something like that without having the powered chair set up or the care package set up or advice for what the person is going to do with regards transfers for 6 weeks after or how they're going to dress so he's quite keen to have us involved in that and were quite keen to be there as well."</i>	
	MDT02	<i>"you'd be better chatting to the medics. The medics would see the clients when they come back in to clinic and they would, our physios have an outpatients service, were not currently funded to have an outpatient service"</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
	MDT03	<i>"all of our patients are medically reviewed initially at 6 weeks post discharge and then at 6 months and then they're seen every year for life or until as long as they're needing something and some patients also get referred to physio for ongoing, and quite often they can actually see the patients at the medical review. So were not funded for any outpatients here at all so were not involved at any of the medical reviews. Sometimes if Dr Maguire or Dr Glackin or Dr Hillan are doing a review with a patient and something comes up that they deem as much as urgent in terms of OT is needed but if something like a roho cushion is, if Dr Maguire and the consultants are very clued in to seating and our accessories they might think that a cushion is overinflated or underinflated and if this person has a history of pressure injury then they might ring us and say look can you come down or something"</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
			E115: PRODUCTS AND TECHNOLOGY FOR PERSONAL USE IN DAILY LIVING
			B810: PROTECTIVE FUNCTIONS OF THE SKIN
Unable to follow up due to no out patient service	MDT01	<i>"I always now because I've been here so long come back and ask me a question and I don't mind answering because its sometimes genuinely a quick question that I can solve. I have a few patients out there that can shave themselves with like a shaving strap that I've made for them. You can't buy them, community OTs don't make them but if they didn't get it they'd be dependent on someone to come in and shave them, so I'll get the odd wee call of my feeding strap or my shaving strap is broken could you make me a splint and I'll pop up and make them a splint and I'll go away and nobody would ever know that they were here... actual face to face contact we're technically not supposed to do it."</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
			D520: CARING FOR BODY PARTS
			E115: PRODUCTS AND TECHNOLOGY FOR PERSONAL USE IN DAILY LIVING
	MDT02	<i>"in my experience here we've only taken a handful of old patients back in for another shot of rehab and it might be someone who's functional level has really changed so I'm trying to think of the last guy, it's</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES

		<i>going back a few years before the last guy that I had, had to learn to do his transfers differently, again his upper limbs like that had become, the function of his upper limbs had changed due to wear and tear injuries and he wasn't able to do what he had been able to do before so he had to relearn things but it's not commonly done. It is something actually maybe that could be considered more, maybe could be offered more."</i>	D420: TRANSFERRING ONESELF D445: HAND AND ARM USE
	MDT03	<i>"we don't have an outpatient service but we really do feel that there is an unmet need there... we're not funded for any outpatients here at all so were not involved at any of the medical reviews... So, in the past we have seen some (outpatients) but it depends on our own staffing and we can't prioritise our own patients over the outpatients, so for whatever reason if we had a limited number of inpatients for whatever reason which doesn't happen very often and hasn't happened in a while to be honest, sometimes we might try squeeze one in at the end of the day and that's ringing the patient and making an appointment to come up. Or on some occasions the patient might ring themselves so we can't just accept a referral like that we have to have it in writing from Dr Maguire" "sometimes I feel the real rehab starts whenever they go home and its getting used to a new environment and they're having to do an awful lot more so they're having to be more active at home. And I think it would be good to have a review of that of each patient to see how things are going"</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES B730: MUSCLE POWER FUNCTIONS D420: TRANSFERRING ONESELF
Shorter hospital stays	MDT01	<i>"we used to do a little bit more with disabled employment advisors about returning to work through patients are so fast at the minute that they're all gone home really quickly they're not really ready for work when they're leaving us but we don't see them maybe 10 weeks later when they would be, yeah so and again giving them long term advice and to avoid repetitive strain injuries and lifting and just about their positioning and posture you know in the chair as well that they could do with. I think there's a huge role for OT the whole way along that spectrum"</i>	D845: ACQUIRING, KEEPING AND TERMINATING A JOB E580: HEALTH SERVICES, SYSTEMS AND POLICIES
	MDT02	<i>"yes so we do feel a bit of a responsibility to maximise somebody's potential before they leave here because you're painfully aware the next time they're out on a busy street, it's on their own or with their family member."</i>	D420: TRANSFERRING ONESELF
	MDT03	<i>"ideally we probably all as a team would probably love to be able to review patients I just think a general length of stay is getting shorter overall and you know patients are being discharged and there's a huge,</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES

		<i>there's a lot of community rehab schemes there and patients are getting referred to community rehab schemes and it would be nice to catch up and see how things are progressing."</i>	
Lack of planning post-op	MDT01	<i>"would love to be there at source seeing the people that are coming in and then if he's making that decision then to have surgery I think we could make it a much better transition for the patient because we would know what they were like pre-op, if we needed to order a chair in or something we could have all of that done in advance rather than it being a scramble at the end for whatever is free it would be better planned for them, if they needed a care package or something then definitely we would help coordinate that and we could do, get an idea of their strength first of all as well and sometimes you're just attending transfers and it would be a good idea to see what the joint was like beforehand and how well it was supported, how strong it was instead of just seeing them when they're at their worst post op. and then to be able to bring them back and offer them that ongoing rehab would be great"</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES B730: MUSCLE POWER FUNCTIONS D420: TRANSFERRING ONESELF
	MDT02	<i>nil</i>	
	MDT03	<i>"I'm just thinking of a particular gentleman who used a manual chair for many years who was admitted for surgery to his shoulder for whatever reason... anyways he was having huge problems and was admitted for upper limb surgery on his shoulder...it hadn't been picked up in the community for whatever reason. I think he had maybe been upstairs in Musgrave and then hold on this man can't be discharged he can't push his chair, he can't transfer, he has no equipment at home so personally I feel if we had of been involved at that pre-assessment perhaps there could have been a bit of better planning</i>	D230: CARRYING OUT DAILY ROUTINE D240: CHANDLING STRESS AND OTHER PSYCHOLOGICAL DEMANDS E580: HEALTH SERVICES, SYSTEMS AND POLICIES
Advice not adhered to by patients or families	MDT01	<i>"we would do handover to family as well and sometimes we'll say we would recommend you use a sliding sheet not just the board because I don't think you have the strength to lift your full body weight it would be much more efficient to slide and the person might ignore that and then the family might try, maybe the car transfer and say I can't manage it and then you'll say well we were recommending the sliding sheet but you felt you didn't need it, and then they're like why didn't you use the sliding sheet (laughs) so"</i>	D760: FAMILY RELATIONSHIPS D660: ASSISSTING OTHERS E585: EDUCATION AND TRAINING SERVICES, SYSTEMS AND POLICIES
	MDT02	<i>"on a day to day level if they need to move across the room to reach their cup of tea or their tooth brush,</i>	E585: EDUCATION

		<i>they're going to do it in the quickest way possible, not necessarily the best way. So they don't adhere to everything, we do while they're in rehab, we do try and promote good habits, we do try and encourage them and remind them but it doesn't always filter through."</i>	AND TRAINING SERVICES, SYSTEMS AND POLICIES
	MDT03	<i>"there's no doubt and I just think when they come in here for rehab it's so intensive and they're thrown so much information and they're expected to take it all in and to go home and you it'll be you really should be reviewing them at a certain stage even just in terms have they, do they remember all the advice you've given them about pressure relief, because they're still occurring so what's going on"</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES B810: PROTECTIVE FUNCTIONS OF THE SKIN

Coding staff interviews: theme 4 – future concerns around UL injuries

Code	Participant	Quote	ICF code
UL injuries now more prevalent in para's and active users/ nature of UL injuries	MDT01	<i>“yeah I mean the shoulders and wrists are not designed to do what your hip joints do in terms of lifting your whole body and helping mobilise you all day in the chair... Particularly if they're lifting the chair in and out of the car every day, particularly if they're very independent and driving and things like that, they'll always be lifting and loading as well so”</i>	D445: HAND AND ARM USE
			D465: MOVING AROUND USING EQUIPMENT
			D475: DRIVING
	MDT02	<i>“Wear and tear, transfer techniques, pushing techniques, could it be prevented at an earlier stage – yes perhaps. I don't know but if there were routine reviews like say like an outreach therapist or somebody had a review of their transfer techniques and their home environment and the chair that they're sitting in if it were reviewed on a regular basis you might have a role in preventing some of that wear and tear, it's just the resources and the service aren't there.”</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
			D420: TRANSFERRING ONESELF
	MDT03	<i>““So in terms of the energy efficient pushing which is probably the big thing that we want our patients to take on board to prevent wear and tear of the shoulders which we know are not designed to do forward and back propulsion, but quite often we would find that after a while patients will revert back to this “shuffling” and sometimes you can hear them coming in to the treatment room and you know who it is because you can tell by, you know it's like hearing some body's footsteps you know so you'll have to go through that again with them”</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
D465: MOVING AROUND USING EQUIPMENT			
Factors leading to compensatory techniques	MDT01	<i>nil</i>	
	MDT02	<i>“because of tone or restrictive movement could be using adapted movement patterns and you'd be trying to teach them a more normal movement pattern because they may then have potential to gain a little more recovery or indeed a more</i>	B735: MUSCLE TONE FUNCTIONS
			B710: MOBILITY OF JOINT FUNCTIONS

		<i>normal movement pattern which might prevent wear and tear injuries or other injuries down the line"</i>	
	MDT03	<i>"it might often be issue that they're over using so people will adopt postures and compensatory techniques so a lot of our job is to try educate the patient and try to promote normal patterns of movement if there is such a thing but try to optimise their function, looking at their posture so that they're in the best seated posture for them to use their upper limb I function because we would see a lot of compensation and that's a lot of, it's very common in spinal injury where there's maybe an imbalance of muscle, strength and power so some muscles are working much harder than others so that is quite common"</i>	B710: MOBILITY OF JOINT FUNCTIONS B760: CONTROL OF VOLUNTARY MOVEMENT FUNCTIONS D445: HAND AND ARM USE
Functional impact of UL pain	MDT01	<i>"If they're not allowed to load their hand for 6 weeks, how are they going to transfer? How are they going to push their chair, do they need to go in to a powered chair for a temporary period of time. You know do they need a carer to come for 6 weeks so this chronic pain has an opportunity to settle down and doesn't get worse so I think that some of the upper limb therapists wouldn't have the level of expertise to look at it as a holistic package as opposed to thumb pain"</i>	D420: TRANSFERRING ONESELF
			E115: PRODUCTS AND TECHNOLOGY FOR PERSONAL USE IN DAILY LIVING
			D230: CARRYING OUT DAILY ROUTINE
	MDT02	<i>"for somebody who might only have limited upper limb movement, to lose a little bit is magnified for them, they lose a whole lot more as a result so they if they've only lost a little bit of range or a little bit of power it almost has a magnifying effect on their life"</i>	D240: CHANDLING STRESS AND OTHER PSYCHOLOGICAL DEMANDS
			D230: CARRYING OUT DAILY ROUTINE
			B152: EMOTIONAL FUNCTIONS: EMOTIONAL FUNCTIONS
	MDT03	<i>"I think he had maybe been upstairs in Musgrave and then hold on this man can't be discharged he can't push his chair, he can't transfer, he has no equipment at home so personally I feel if we had of been involved at that pre-assessment"</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
			D420: TRANSFERRING ONESELF
			D465: MOVING AROUND USING EQUIPMENT

		<i>perhaps there could have been a bit of better planning"</i>	
Treatment of UL injuries – the after thought	MDT01	<i>"if they needed advice on strengthening like wrist strengthening, hand strengthening or needed new splint provision, it would be good for them to be able to come back to us because I think that would save a lot more time and resources. If they manage to get referred to another service, they have to do a full assessment and a full evaluation all over again and then try and source the equipment and then send it out where as if they come to us then we just reissue exactly what they</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
	MDT02	<i>nil</i>	
	MDT03	<i>"one I can remember that certainly was an upper limb definite that needed surgery but you opened the referral and thought it was maybe going to be an hour but there was that many things that needed to be looked at afterward and it hadn't been picked up in the community for whatever reason... it was all of that then you know, he was getting on in age and you know there was lots of discussion then you know does he need a powered chair for part of the time, and then it was getting in to his vehicle and it was just, there was so much to it. And that was all down to having shoulder surgery."</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES E115: PRODUCTS AND TECHNOLOGY FOR PERSONAL USE IN DAILY LIVING
Cannot treat UL pain in isolation	MDT01	<i>"we would love to see patients face to face as outpatients again and I think it makes it more, it's an easier transition for them because if they're coming in for upper limb surgery or they're having carpal tunnel pain it doesn't just affect their hand, and I don't think you can treat that in isolation."</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
	MDT02	<i>nil</i>	
	MDT03	<i>"I mean we just don't have that service here and it's a huge issue because it's very, very difficult to get outpatient hand therapy or upper limb therapy in the community so</i>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES

		<i>there's lots of functional rehab therapists that can look at how you're managing to wash and dress yourself but there's nobody there that can sort of instruct you of an upper limb hand therapy programme"</i>	
Changes when they move home/patient ages	MDT01	<i>nil</i>	
	MDT02	<i>"In the hospital you're very much cocooned, there's a roof over your head, the doors open for you it's all on a level so it can be quiet eye opening for patients to go out and realise every pavement has a camber on it that you have to concentrate when you're moving you can't just dilly-dally looking round when you're walking you have to look round and concentrate to make sure all four wheels stay on the pavement while negotiating the crowds and carrying your shopping and crossing at the traffic lights"</i>	D240: CHANDLING STRESS AND OTHER PSYCHOLOGICAL DEMANDS
			D230: CARRYING OUT DAILY ROUTINE
MDT03	<i>"they change all the time and not saying their level of injury if they're a complete injury they're going to remain the same but their function can change and their needs can change sometimes for the better and sometimes for the worst"</i>	B152: EMOTIONAL FUNCTIONS: EMOTIONAL FUNCTIONS	
		D240: HANDLING STRESS AND OTHER PSYCHOLOGICAL DEMANDS	

Coding staff interviews: theme 5 – proposed method of improvement

Code	Participant	Quote	ICF code
Consultancy for other departments	MDT01	“I think the big thing for us as OTs is (consultant name) started off doing clinics twice a year, upper limb, then it went to four, now its 2 a month. Because there’s so much more volume of patients experiencing upper limb pain and it used to be associated with the tetraplegics who already had upper limb problems, but now it’s become very prominent in the paraplegics who are living much longer”	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
	MDT02	Nil	
	MDT03	“ideally, we probably all as a team would probably love to be able to review patients I just think a general length of stay is getting shorter overall and you know patients are being discharged and there’s a huge, there’s a lot of community rehab schemes there and patients are getting referred to community rehab schemes and it would be nice to catch up and see how things are progressing. We’re equally getting so many incomplete injuries through as well and there’s no time for you to treat them forever. And maybe you don’t need to see them every day because their changes start to become so small, but it would be so nice to see what they’re functioning at you know if it was once a week you could review them but I mean we just don’t have that service here and it’s a huge issue because it’s very, very difficult to get outpatient hand therapy or upper limb therapy in the community”	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
Potential to provide streamlined service	MDT01	“so yes we would love to see patients face to face as outpatients again and I think it makes it more, it’s an easier transition for them because if they’re coming in for upper limb surgery or they’re having carpel tunnel pain it doesn’t just affect their hand, and I don’t think you can treat that in isolation”	E580: HEALTH SERVICES, SYSTEMS AND POLICIES D240: CHANDLING STRESS AND OTHER PSYCHOLOGICAL DEMANDS B152: EMOTIONAL FUNCTIONS
	MDT02	Nil	
	MDT03	“yeah I think it would be good to review. I would like to have a review of our patients	E580: HEALTH SERVICES,

		when they're discharged because sometimes I feel the real rehab starts whenever they go home and its getting used to a new environment and they're having to do an awful lot more so they're having to be more active at home. And I think it would be good to have a review of that of each patient to see how things are going, whether that would be leaving here and going to see them in their home environment at the house to look at their seating and pressure relief again. There, I think there's a huge role there for OTs and especially for OTs that are working in spinal injuries where a lot of that might be passed on to community staff who don't know the staff as what we do."	SYSTEMS AND POLICIES D240: CHANDLING STRESS AND OTHER PSYCHOLOGICAL DEMANDS B152: EMOTIONAL FUNCTIONS
Better transition from clinic to discharge – can see baseline pre-op, assess needs and discharge smoothly	MDT01	"I think initially we would like to go to the clinics that are operating in the hospital here first so Ian Mahwinney would like us to attend those upper limb clinics so would love to be there at source seeing the people that are coming in and then if he's making that decision then to have surgery I think we could make it a much better transition for the patient because we would know what they were like pre-op, if we needed to order a chair in or something we could have all of that done in advance rather than it being a scramble at the end for whatever is free, it would be better planned for them, if they needed a care package or something then definitely we would help coordinate that and we could do, get an idea of their strength first of all as well and sometimes you're just attending transfers and it would be a good idea to see what the joint was like beforehand and how well it was supported, how strong it was instead of just seeing them when they're at their worst post op. and then to be able to bring them back and offer them that ongoing rehab would be great."	E580: HEALTH SERVICES, SYSTEMS AND POLICIES D240: CHANDLING STRESS AND OTHER PSYCHOLOGICAL DEMANDS
	MDT02	Nil	
	MDT03	"personally I feel if we had of been involved at that pre-assessment perhaps there could have been a bit of better planning and then I think he did come back to see me on a couple of occasions yeah. And it was all of that then you know, he was getting on in age and you know there was lots of discussion then you know does he need a powered chair for part of the time, and then it was getting in to his vehicle and it was just, there was so much to it. And that was	E580: HEALTH SERVICES, SYSTEMS AND POLICIES

		all down to having shoulder surgery...and equally as well it's just even like where do you even get a powered chair on loan for a period of time? So you know, otherwise you're going to be sending this man home to be lying in bed or to be sitting in a chair that he needed to be pushed about or a one arm drive that's maybe going to cause more wear and tear in one arm so yeah"	
Outpatient service	MDT01	"For clients to be able to self-refer as they do into the physio services as well would be good. So also the tetraplegics who would have had upper limb difficulties anyway, if they needed advice on strengthening like wrist strengthening, hand strengthening or needed new splint provision, it would be good for them to be able to come back to us because I think that would save a lot more time and resources. If they manage to get referred to another service, they have to do a full assessment and a full evaluation all over again and then try and source the equipment and then send it out where as if they come to us then we just reissue exactly what they...it would be much more time efficient as well".	E580: HEALTH SERVICES, SYSTEMS AND POLICIES D440: FINE HAND USE D445: HAND AND ARM USE
	MDT02	" , I personally think there would be a big role for an outreach service where for example, a physio and an OT could go out and assess somebody in their own home and look at their transfer technique or their equipment. Now there are community services out there, there are community physios and community OTs and there's domiciliary OTs and there are rehab teams out there but coming from a spinal injury background we might be better placed to look at the technique and more specialised transfers." "if there were routine reviews like say like an outreach therapist or somebody had a review of their transfer techniques and their home environment and the chair that they're sitting in if it were reviewed on a regular basis you might have a role in preventing some of that wear and tear, it's just the resources and the service aren't there."	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
	MDT03	"so we can't just accept a referral like that we have to have it in writing from Dr Maguire and then we try to keep a record of all of those requests but it is something that we have been trying to get. So were trying to record that area	E580: HEALTH SERVICES, SYSTEMS AND POLICIES

		of unmet need because we think potentially there would be a definite role for OT outpatient in the spinal service for reviews. People change you know”	
Life skills advice/education, vocational rehab	MDT01	<p>“and the area of the wheelchair skills as well, we make time to do that because we see the benefit of it but I think if we had somebody in outpatients I think we could do more group work or a little bit more wheelchair skills or, we get requests for other things like parenting skills like how do I lift a baby, how do I change a nappy, if I you know, this is maybe for the tetras who don’t have the strength, or the sensation in the upper limbs to start with, how do I lift a weight, how do I move and know that I’m not going to drop them (laughs)”</p> <p>“at the employment clinics we used to do a little bit more with disabled employment advisors about returning to work through patients are so fast at the minute that they’re all gone home really quickly they’re not really ready for work when they’re leaving us but we don’t see them maybe 10 weeks later when they would be yeah so and again giving them long term advice and to avoid repetitive strain injuries and lifting and just about their positioning and posture you know in the chair as well that they could do with. I think there’s a huge role for OT the whole way along that spectrum”</p>	D845: ACQUIRING, KEEPING AND TERMINATING A JOB
			E580: HEALTH SERVICES, SYSTEMS AND POLICIES
			E585: EDUCATION AND TRAINING SERVICES, SYSTEMS AND POLICIES
			D720
	MDT02	<p>“when their wheelchair needs reviewed there’s certainly wheelchair resource teams out there I don’t know that they have the resources to send people in to do further wheelchair skills training. We occasionally have people who have missed the backup crowd or have think they might benefit from another session we would send out fliers, outpatients can come back in but aside from that there’s not to my knowledge a great amount of wheelchair skills training out and about.”</p>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
	MDT03	<p>“you know we’re teaching it all the time and we have pressure mapping and we go through it all, we take them through it as best we can and the nurses do their bit and everybody’s advising them but pressure sores are still occurring so again even thinking of trying to reinforce all that advice at a time when they’re at home. Because I’m sure most patients when they leave hospital</p>	E580: HEALTH SERVICES, SYSTEMS AND POLICIES
E585: EDUCATION AND TRAINING SERVICES,			

		<p>they probably have a dip, perhaps even in mood, they're trying to get their life back, they're trying to get a structure on things, they're maybe not as active as they were before so I think there's a huge role for spinal staff to be able to go in and keep that advice up and keep that education going."</p>	<p>SYSTEMS AND POLICIES</p> <p>B810: PROTECTIVE FUNCTIONS OF THE SKIN</p> <p>B152: EMOTIONAL FUNCTIONS</p>
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Appendix 11A: Study Characteristics

Author Year	Name of test	Study design	Sample size, age N=number	Objective	Study population	Outcomes
Askari Kirby Parker Thompson O'Neill (2013)	The Wheelchair Propulsion test (WPT)	Cohort study	N=58 18-91years	To develop and assess some of the measurement properties of a simple and inexpensive test that can be used to evaluate the wheelchair mobility of manual wheelchair users	Amputation SCI Stroke TBI	10m propulsion – time taken, number of cycles and propulsion methods.
Cowan Nash De Groot Van der Woude (2011)	The Wheelchair Circuit	Cohort study	N=50	To assess the test-retest reliability and discriminative validity of a 14 item manual wheelchair circuit adapted from previous research	SCI	An existing 8 task manual wheelchair circuit was modified to remove the need for a treadmill and expanded to 14 tasks to attenuate floor and ceiling affects. Tests include – figure of 8, 0.12m doorstep crossing, 0.10m platform, 15m sprint, and making a level transfer, 3% and 6% ramp, 3 minute over ground wheeling, 0.4m doorstep crossing, propelling over artificial grass, opening/closing a door, 3% side slope, holding a wheelie for 10 seconds, propelling in a wheelchair.
Fliess-Doeur Van der Woude Vanlandewicjk (2013)	Test of Wheeled Mobility; Short wheelie Test	Cohort study	N=30 23-53 years	To assess the reliability of the Test of Wheeled Mobility (TOWM) and the Wheelie Test	SCI	Test-retest reliability was evaluated for the ability, time, anxiety and quality scores of both tests.
Fliess-Douer Van Der Woude Vanlandewicjk (2012)	Test of Wheeled Mobility; Short wheelie Test	Cross-sectional Study	N= 30 23-53 years	To assess the feasibility and validity of both the Test of Wheeled Mobility (TOWM) and a wheelie test	SCI	Participants ability and performance time completing the tests were recorded. Qualitative and anxiety scores were also assessed.
Gagnon Decary Charbonneau (2011)	The Manual Wheelchair Slalom Test (MWST)	Cohort study	N=15	To describe the timed manual wheelchair slalom test (MWST) and to quantify its test-retest reliability, standard error of	SCI	Participants were timed propelling around a slalom course (18m in length)

				measurement, and minimum detectable change		
Harvey Batty Fahey (1998)	6 Task Assessment tool	Cohort study	N=20	To quantify the mobility of wheelchair dependants with paraplegia	Paraplegia	Six key tasks fundamental to the mobility of wheelchair dependants with paraplegia – moving from lying to sitting, completing a horizontal transfer, vertical transfer, pushing on flat ground, pushing on ramps, negotiating kerbs.
Kirby Swuste Dupuis MacLeod Monroe (2002)	The Wheelchair Skills test	Cohort study	N=24	To evaluate the practicality, safety, reliability, validity and usefulness of a new Wheelchair Skills test (WST)	Amputations Stroke MSK disorders SCI Neuromuscular disorders	Subjects were videotaped while performing 33 skills twice (>10d apart). Their ability to perform each skill was rated on a 3-point ordinal scale. The test-retest, intra-, and interrater reliabilities were determined. Each subject's occupational therapist completed a visual analogue scale (VAS), reflecting a global rating of the subject's manual wheelchair skills. We assessed validity by evaluating whether the WST detected expected changes (construct validity) and how well the total WST scores correlated with the occupational therapists' global ratings (concurrent validity). Each occupational therapist also used a VAS to quantify the usefulness of the WST.
Kirby Dupuis MacPhee Coolen Smith Best Newton Mountain MacLeod Bonaparte 2004	The Wheelchair Skills test Version 2.4	Cohort study	N= 298 169 wheelchair users; 129 able bodied volunteers	To evaluate the measurement properties of the Wheelchair Skills test (WST)	Amputees MSK SCI CVA Able bodied volunteers	The test-retest, interrater and intrarater reliabilities were determined on a subset of 20 wheelchair users. Construct validity was assessed by evaluating whether the WST detected expected changes and concurrent validity by seeing how well the WST scores correlated with criterion measures.
Lindquist Loudon Magis Rispin Kirby Manns	The Wheelchair Skills Test Version 4.1	Cohort study	N=11	To evaluate the interrater, intra-rater, and test retest reliability of the total performance and safety scores of the Wheelchair Skills Test Version 4.1	SCI Stroke Arteriovenous Malformation	Participants were videotaped as they completed the WST 4.1 (30 skills) on 2 separate occasions 1 to 2 weeks apart. Subsequently, raters scored the WST 4.1 from the video recordings and each participant received a total score for performance and safety. Using those scores, interrater, intrarater, and test-retest reliability were determined by

(2010)						using intraclass correlation coefficients (ICCs). Percentages of agreement between raters for individual skills also were calculated.
McClure Boninger Ozawa Koontz (2011)	The Transfer Assessment Instrument	Cohort study	N=40 27-74 years	To describe the development and evaluate the reliability and validity of a newly created outcome measure, the Transfer Assessment Instrument (TAI), to assess the quality of transfers performed by full-time wheelchair users.	MS Brain Injury Amputation Guillain-barre syndrome	Participants were required to perform 4 transfers in/out of their wheelchair.
Middleton Harvey Batty Cameron Quirk Winstanley (2006)	Five additional items added to the FIM	Cohort study	N=43	To assess the validity and responsiveness of five additional mobility and locomotor (5-AML) items when used in conjunction with the Functional independence Measure (FIM) for assessing mobility of those with SCI.	SCI	The five additional items included floor to chair transfer item and three wheelchair propulsion items – 200m over flat ground, pushing up a ramp and negotiating a kerb.
Vereeken Vanderstraten Ilsbrouck (2012)	The Wheelchair Assessment Instrument for People with Multiple Sclerosis (WAIMS)	Cohort study	N=50	To assess the reliability and validity of the Wheelchair Assessment Instrument for people with Multiple Sclerosis (WAIMS), a test to measure driving skills in manual wheelchair users with Multiple Sclerosis (MS)	Multiple Sclerosis	Modified from the Wheelchair Circuit. The test consists of 6 to 8 tasks that measure wheelchair driving skills.

Appendix 11B: Outline of skills included in each test

Skill	Askari et al. 2013	Cowan et al. 2011	Fliess-Douer et al. 2013	Fliess-Douer et al. 2012	Gagnon et al. 2011	Harvey et al. 1998	Kirby et al. 2002	Kirby et al. 2004	Lindquist et al. 2010	McClure et al. 2011	Middleton et al. 2002	Vereecken et al. 2012
Propel	10m forward and backward	30m circuit in 3 minutes	10m forward one handed	10m forward one handed	N/A	50m	50m	50m	50m	N/A	50m	15m
Sprint	N/A	15m	N/A	N/A	N/A	N/A	N/A	N/A	10m	N/A	N/A	15m
Kerbs	N/A	N/A	5cm,	5cm,	N/A	2.5 cm and 15cm	10cm ascent	3.8cm and 17.8cm ascent and descent	5cm and 15cm ascent and descent	N/A	2.5cm and 15cm	10cm
Slopes	N/A	3% and 6% ascent	5% [10cm], 7.5% [15cm], 10% [20cm], 15% [30cm], 20% [40cm], 26% [50cm]	5% [10cm], 7.5% [15cm], 10% [20cm], 15% [30cm], 20% [40cm], 26% [50cm]	N/A	1:12 ascent and descent circuit	5° ascent and descent	5° ascent and descent	7.5° ascent and descent	N/A	1:14 and 1:20 ascent and descent circuit	5% and 10% ascent and descent
Wheelie	N/A	Hold a wheelie for 10secs Propel 3m in wheelie	8 tasks: Stationary 15 sec, One handed wheelie 15 sec, forward 10m, backward 10m, circle forward, uneven surface,	8 tasks: Stationary 15 sec, One handed wheelie 15 sec, forward 10m, backward 10m, circle forward, uneven surface,	N/A	N/A	Pop/hold	5 tasks: moving turns, turn in place, backward, forward, stationary	30sec stationary wheelie, turns 180° in place in wheelie	N/A	N/A	N/A

			accelerate and stop in wheelie (10m), backward over curb 5cm	accelerate and stop in wheelie (10m), backward over curb 5cm								
Transfer	N/A	From wheelchair to table	Chair transfer to a comparable wheelchair	Chair transfer to a comparable wheelchair	N/A	Horizontal transfer to plinth, vertical transfer from floor to wheelchair	Relieves weight from buttocks, Transfer to/from wheelchair	Transfer in/out wheelchair	Transfer from wheelchair to bench and back, transfer from ground to wheelchair	Standing or sitting pivot transfer to bench	Vertical transfer from floor to wheelchair,	N/A
Obstacles	N/A	Figure of 8 slalom in 120secs	4m x 4m propulsion around square	4m x 4m propulsion around square	Slalom of 18m, cones set in straight line at 3m, 2m and 1m apart	N/A	Slalom, 3-point turn and parallel parking	Slalom, 3-point turn, parallel parking and turn in place	Manoeuvres sideways, avoids moving objects	N/A	N/A	Figure of 8 shape left and right
Threshold	N/A	0.012m, and 0.04m doorstep crossing	N/A	N/A	N/A	N/A	2cm threshold	2cm threshold	2cm threshold	N/A	N/A	4cm threshold
Side slope	N/A	3% side slope	N/A	N/A	N/A	N/A	5° side slope	3° side slope		N/A	N/A	N/A

Other	N/A	Opening/closing door, artificial grass	N/A	N/A		Supine to long sitting	Wheelchair breakdown tasks, reaching for high objects, floor and knapsack, opening and closing doors, propel over soft/gravel surfaces	Wheelchair breakdown tasks, reaching for high objects, floor and knapsack, opening and closing doors, propel over soft/gravel surfaces	Rolls 2m on soft surface, gets through hinged door, 15cm pothole, ascends stairs, descends stairs, wheelchair breakdown tasks	N/A	Bed mobility to position for transfer from supine to sitting	N/A
Scoring	Speed (m/s) Push frequency (cycles/s) Effectiveness (m/cycle)	Propulsion: Distance covered in 3 minutes Remainder: 0 = unable to perform task in 120secs time frame 1 = able to perform task in 120secs Performance score = time needed to complete	Ability score 1 = task completed successfully 0.5 = successful at second attempt 0 = failure or didn't attempt	Ability score 1 = task completed successfully 0.5 = successful at second attempt 0 = failure or didn't attempt	Time taken to complete slalom	Score of 1-6 dependent on distance covered in specified time frame	Score of 0-2 0 = failure to complete task safely 1 = partial completion 2 = successful and safe completion	0 = fail 1 = pass NA = not applicable NG = not a goal	Grade of pass/fail and safe/unsafe given	Comprehensive scoring using Likert scale covering arm position, set up phase, conservation and quality	Score of 1-7 where 1 = total assistance and 7 = complete independence	Propulsion: Distance covered in 6 minutes of completing loop Remainder: Max performance time allowance given. 2 = successful 1 = minor error 0 = more than 2 errors

Legend

M = metre; N/A = not applicable; S = second

McClure et al, 2011- Transfer Assessment Instrument							X		
Middleton et al, 2002 - 5- AML	X			X	X		X		X
Vereecken et al, 2012 - WAIMS	X	X	X	X	X				

Appendix 11D: Feasibility of delivering skills tests

Author Name of test	Number of skills	Retest – how long after	How long to administer	Cost, equipment required	Own chair/ standard chair	What they measured – time, distance etc	Scoring system
Askari Wheelchair Propulsion test	1 task - propulsion	On same day after short rest	Less than 60 minutes	Area to propel chair	Own chair	Time Number of propulsive cycles	metre/s cycles/s metre/cycle
Cowan Manual Wheelchair Circuit	14 tasks	2 non-consecutive days	90 minutes	Rehabilitation centre Equipment required but not stated	Own chair 5 used a lab chair	Yes/no scoring	Sum ability score Sum performance time
Fliess-Douer Test of wheeled Mobility 2012, 2013	30 skills of TOWM and 8 tasks of Wheelie test	After 1 week	40 minutes	Gymnasium – cost or equipment not stated	Own chair	Objective testing – yes/no	4 scoring methods – ability score, performance time, anxiety score, qualitative score
Gagnon Timed Manual Wheelchair Slalom test	1 task	After 1 week	Less than one minute	Cones	Own chair	Time taken	Time metre/s
Harvey Own tool	6 tasks	Same day with short break between tests	Under 15minutes	Kerbs, cost not stated	Own chair	Yes/no skill completed	Objective measure of performance
Kirby Wheelchair Skills Test 2002, 2004	50 skills	1 day after	Under 40 minutes	Equipment required but no cost stated	Own chair	Yes/no skill completed	Measured performance
Lindquist Wheelchair Skills test	30 skills	Between 1-2 weeks after	Under 40 minutes	Skills removed on the basis of not having correct incline ramps but substituted for smaller ramps	Own chair	Yes/no completed	Measured performance

McClure Transfer Assessment instrument	1 task	4-72 hours after	2-3 minutes	No equipment required	Own chair	Breakdown of transfer yes/no completed	Successfully completed all elements of transfer
Middleton 5-AML	5 tasks	72 hours, 1 month, 3 month, 6 month	Each task took less than 3 minutes	No equipment required	Own chair	Scoring sheet assessing each task	Successfully completed all tasks
Vereecken WAIMS	8 tasks	3 tests over 3 weeks at most	20-30 minutes	Ramps	Own chair	Yes/no task completed	3 final test scores

Legend

TOWM = Test of Wheeled Mobility; 5-AML = 5 Additional Motor and Locomotion items

Appendix 12: Quality appraisal of included studies

Author	1. Clearly focused issue	2. Appropriate method	3. Acceptable recruitment	4. Minimise bias exposure	5. Minimise bias outcome	6. Confounders identified	7. Confounders accounted for	8. Follow up complete enough	9. Follow up long enough	10. Results – precise and believable	11. Results – applicable to others	12. Results – fit with available evidence	CASP score range (0-10)
Askari	Y	Y	N	Y	Y	CT	CT	Y	Y	Y	Y	N	6
Cowan	Y	Y	N	Y	Y	CT	CT	Y	N	Y	N	Y	5
Fliess-Douer	Y	Y	N	Y	Y	CT	CT	Y	N	Y	N	Y	5
Fliess-Douer	Y	Y	N	Y	Y	CT	CT	Y	N	Y	N	Y	5
Gagnon	Y	Y	N	N	N	CT	CT	Y	Y	Y	N	Y	4
Harvey	Y	Y	N	Y	Y	CT	CT	Y	N	Y	N	Y	5
Kirby	Y	Y	Y	Y	Y	CT	CT	Y	Y	Y	N	Y	7
Kirby	Y	Y	Y	Y	Y	CT	CT	Y	Y	Y	N	Y	7
Lindquist	Y	Y	N	N	N	CT	CT	Y	CT	Y	N	Y	3
McClure	Y	Y	N	Y	N	CT	CT	Y	CT	Y	N	Y	4
Middleton	Y	Y	Y	Y	N	CT	CT	Y	CT	Y	N	Y	5
Vereecken	Y	Y	Y	Y	Y	CT	CT	Y	Y	Y	N	Y	7

Legend

Y= Yes (1); N= No (0); CT = Can't tell (1)

Appendix 13: Psychometric Properties of wheelchair skills tests

Author & name of test	Sensitivity to change	Content validity	Construct validity	Test-retest reliability	Intra-rater reliability	Inter-rater reliability
Askari Wheelchair Propulsion test	Not stated	Higher speeds were seen in younger participants (P=.009), participants with rigid-frame wheelchairs (P=.015), and when propelling on tile (P<.001).	r range, 0.92 - 0.99	Not stated	ICC range = 0.80 - 0.96	ICC range = 0.72 – 0.96
Cowan Manual Wheelchair circuit	Floor and ceiling effects of FIM were addressed although not proved significant	Not stated	Not stated	ICCs exceeded .90 for the whole sample	Not stated	Not stated
Fliess-Doeur 2012 Test of Wheeled Mobility & Short Wheelie Test	Not stated	Not stated	Fair to moderate correlations	Not stated	Not stated	Not stated
Fliess-Douer 2013	Not stated	Not stated	Not stated	No significant change	ICC: .91	ICC: 0.99
Gagnon Manual Wheelchair Slalom test	Not stated	Not stated	Not stated	ICC = 0.972	Not stated	Not stated
Harvey (own assessment tool)	Not stated	Not stated	Not stated	Not stated	Not stated	K range = 0.82 ± 0.96
Kirby 2002 WST	Not stated	91% of skills endorsed by therapist	62% of subjects improved according to therapists	ICC=0.65	ICC=0.96	ICC=0.95

Kirby 2004 WST	Scoring changed to pass/fail to accommodate sensitivity	Addressed in previous study (2002)	Pearson correlation between total WST score and age ($r = -0.434$)	ICC = 0.904	ICC = 0.959	ICC = 0.968
Lindquist WST	Not stated	Not stated	Not stated	ICC = 0.901	ICC = 0.950	ICC = 0.855
McClure TAI	Not stated	Not stated	Not stated	Not stated	ICC = .642	Not stated
Middleton 5-AML	Ceiling effect in paraplegic group; high responsiveness in tetraplegic group	Not stated	Demonstrated good construct validity	ICC range = 0.20 – 0.98	Not stated	K range 0.82 – 0.96
Vereecken WAIMS	Not stated	Not stated	Can't tell	Not stated	Excellent intra-rater reliability	Poor inter-rater reliability

Legend

ICC = Intraclass coefficient; K = Kappa coefficient; R = correlation coefficient; MWST = The Manual Wheelchair Slalom Test; TAI = The Transfer Assessment Instrument; TOWM = Test of Wheeled Mobility; WAIMS = The Wheelchair Assessment Instrument for People with Multiple Sclerosis; WPT = The Wheelchair Propulsion Test; WST = The Wheelchair Skills Test; 5-AML = The 5 Additional Mobility and Locomotor test

Appendix 14A: Study Protocol

Title: Wheelchair Skills Programme for young people

The nature of this study is framed around promotion of independence in young people who are permanent high performance wheelchair users. Wheelchair users conduct all activities of daily living while in their chair therefore it is pivotal for them to grasp the skills necessary to enable them to use their chair to the best of their ability. Poor wheeling can have long term effects on secondary upper limb injuries however it is well documented that skill acquisition can improve this outlook (Oyster, Smith et al., 2012). This qualitative research project will implement a wheelchair skills test and training programme to enable users to optimise chair performance and functional ability.

The project is in line with the World Health Organisations guidelines on provision of wheelchairs (Borg & Khasnabis, 2012). These guidelines outline the process of wheelchair prescription and the follow up intervention required to provide a high and standardised level of treatment for all manual wheelchair users. Northern Ireland's Regional Wheelchair Training Occupational Therapist (OT) has independently designed a wheelchair skills training programme which can be implemented and graded to suit the clients' needs. The programme will be adapted and implemented as a standardised and measurable wheelchair skills test initially, with a training programme to follow. This project will take place in the Joey Dunlop Centre, Ballymoney.

In 2008, the Department of Health and Social Services and Public Safety, Northern Ireland launched the "Proposals for the reform of the Northern Ireland Wheelchair Service". Recommendations for service improvements were made following a 2 year review completed from partnership working between healthcare staff and wheelchair service users. Wheelchair service users identified manual wheelchair skills training for children as a priority issue to be addressed. The review highlighted that throughout the region, there was an inequitable provision of wheelchair skills training opportunities for children. Some trusts offered training via local clubs, while other trusts relied solely on charities including "Go-kids-Go" and "Whizz Kidz" to deliver

training. Skill mix of staff and sporadic engagement with the charities resulted in uncoordinated, unregulated wheelchair skills training for children across Northern Ireland. The importance of this project is to assist with identifying a skills teaching programme that can be used to standardise manual wheelchair skills training for children across Northern Ireland.

Statistics relating to wheelchair use in Northern Ireland are limited, with the most recent figures estimating approximately 30,000 of the 1.8 million population of Northern Ireland classified as wheelchair users (DHSSPS 2008). Of this, 27,000 are full time users, with children under 18 making up approximately 2,500 (9.25%) of this statistic (DHSSPS, 2008). This equates to 1.3% of Northern Ireland population which is less than the National average of 2%. The regional figures are debateable as being an accurate reflection of the true situation. Northern Ireland is behind the rest of the UK in terms of diagnosing, treating and prevention of conditions (National Audit Office, 2012). The Appleby Report (2005) for instance highlighted Northern Ireland health indices are poorer compared to the rest of the United Kingdom, with Northern Ireland having the highest incidences of birth defects, Multiple Sclerosis and road traffic accidents in Europe, all of which contribute to the incidence of wheelchair use. Hence, it is reasonable to argue that Northern Ireland's figures are underestimated, or indeed people who would benefit from a wheelchair are not accessing this service, and the true estimate should be closer to the rest of the UK than reported.

The project relates to how society supports people living with a physical disability. Changes in health behaviours, people living longer with chronic disease, a move towards more home based care, the growing strength of the social model of disability within a legislative context (DWP, 1995) that support an inclusive society, are some of the factors influencing this work. Wheelchairs are one assistive device that OT's prescribe as an intervention to promote independence, autonomy and social inclusion. Whilst significant developments have taken place clinically in terms of how the wheelchair service is strategically and operationally delivered, as a profession there is a gap in the knowledge of the optimal way to ensure wheelchair users know how to get the most from this device in the context of where they live, work and play and the roles they are required to fulfil.

Aim:

To explore the efficacy of a wheelchair skills training program on skill development and independence of young wheelchair users.

Methods**Participant recruitment**

Once ethical approval has been obtained, potential participants will be identified the caseload of Ms Lorraine Abernathy, children's occupational therapist in Ballymoney, using the inclusion and exclusion criteria listed below. A participant information leaflet, a consent form and a stamped addressed envelope, together with a letter inviting them to join the study will be posted to eligible participants. If they are interested in taking part in the study they are asked to contact the PhD researcher, Ms Adrienne McCann, by phone or email. After making contact with the researcher, potential participants will be asked to sign the consent form and return it using the stamped addressed envelope, however in the case that an issue arose where they could not return it, consent forms may also be signed the morning of testing day 1.

For the purpose of this research study we will use the inclusion and exclusion criteria below to identify our participants. There currently is a wheelchair social group in the area, namely the Causeway Wheelers which this project will closely work with. As this is a social group, the occupational therapist involved with the group (Lorraine Abernathy) will be inviting children within the age group who may not meet the inclusion and exclusion criteria below to attend. This may be due to the fact that they have complex medical needs or some other factor however we would like this project to be as inclusive as possible for all wheelchair users to benefit from the programme.

Inclusion criteria:

- Participants must be aged 5 to 15 years
- Be a self-propelling high performance wheelchair user.

Exclusion criteria:

- Powered wheelchair users
- Participants who have a cognitive issue which would prevent them from

following verbal instructions as determined by service providers

- Any predisposing condition that may worsen as a result of training
- Participants who have a deteriorative or life limiting condition

Sample size

The number of high performance wheelchair users in the Northern Trust aged less than eighteen years of age is 42. A sample size of 10 has therefore been chosen in order to gain an accurate reflection of the population and a manageable number for a group setting also.

Ethics

Ethics application is currently being prepared for application to the University Research Governance Filter Committee from there an application will be made to Office of Research Ethics, NI and submission through HSC procedures will take place simultaneously.

Wheelchair Skills Testing and Programme

The wheelchair skills programme will take place in the Joey Dunlop Centre Ballymoney. The centre is located in the centre of the catchment area for the Northern Trust participants and has good facilities and accessibility for our programme. The Regional Wheelchair Specialist for Northern Ireland has designed a wheelchair skills training programme that will form the basis of in this study. However, there will be added rigor for example: the addition of inclusion and exclusion criteria and test-retest assessment will strengthen the study. This training will replicate real life scenarios that the children will be faced with daily and their level of achievement assessed. A training programme will then follow this and a final assessment to determine how effective the training programme was for these children. This research has been identified as is a priority area for the Regional Wheelchair Service, who we will be working very closely with during the study.

Disability Sports NI are a charity involved in promoting sport for young people with a disability living in Northern Ireland. Disability NI will be running a fun sports day for wheelchair users alongside the first day of testing in each location. Participants will

have the opportunity to join in after they have completed the testing session and local coaches will be on hand to speak with parents regarding any queries regarding their child joining sports clubs or what services are available for them in their local area. The session will be optional however an enjoyable day will be had by all for any who wish to get involved.

Safety

A full risk assessment has been completed on the Wheelchair Skills Programme. As this is a physical activity there will be a risk of injury however spotters will be in place to act as a safety net for the children. Spotters are assistants who will stand behind or in a place where a risk may exist such as transfers or completing the wheelie. A first aider, the Regional Wheelchair Training OT and her assistant, will also be present during the study. She has previously completed wheelchair skills training with numerous participants and has the expertise and knowledge to ensure the children are safe at all times.

Questionnaires to be used

- A demographic questionnaire – this will include details on gender, age, primary diagnosis, make and model of wheelchair used, years using wheelchair and any previous wheelchair skills training.
- The Activity Scale for Kids. (Young, Williams et al., 2007).
- An impact questionnaire will be administered with children and their parents at the 6-month post study assessment.
- Skills Programme: The wheelchair skills programme will take place in the Joey Dunlop Centre Ballymoney over an eight month period and will consist of eight Saturdays in total. The Regional Wheelchair Training OT has agreed to carry out the wheelchair skills training.

Skills level assessment

When children and their carers/parents arrive on the first day of the programme they will be offered refreshments and introduced to the team. Then each parent and child will be asked to complete the questionnaires with the help of the researcher, this will take around 10-15 minutes. Next, the children will be asked to undertake a

wheelchair skills test. This is a test of their wheelchair skill level ranging from basic to intermediate level. The researcher and a spotter will assess the level of competency for each test. This data will be recorded in duplicate. This will take approx. 20 minutes. The spotters assigned to each child are a safety measure to ensure the child does not get into any difficulty. Data collection and analysis will occur throughout the programme recording attendance and participation at each session. Disability Sport NI will run a sports day alongside the initial day of testing in a nearby room. Participants will have the choice to join in after they have completed their test. This sports day will run throughout the day but is not part of the training programme.

Wheelchair skills training:

Approximately 1 month post initial test, the children will be invited back with their parents/carers to complete the wheelchair skills test again. This is to evaluate if there has been any improvement in their skills level from using their chair as normal. This second test will strengthen our study in assessing whether the wheelchair skills training had an effect on skill acquisition.

The data will be recorded in duplicate and again will take approx. 20 minutes. The following month, participants and their parents/carers, siblings and friends, will be invited to attend the first of the wheelchair skills training sessions. The training sessions are aimed at all levels and will give opportunities for the young people to socialise and make friends, all while learning new techniques. The skills will be taught in a fun manner, incorporating games, races and songs making the sessions enjoyable for all. We encourage both siblings, parents and friends to attend and get involved during the sessions and spare chairs will be available for anyone who wishes to join in the games. The Regional Wheelchair training Occupational Therapist will then complete wheelchair training with the participants that afternoon. The training session will focus on practicing real life scenarios using the wheelchair skills test as a guide, all while including the element of fun. and will have the scope to grade the task to the individual's specific needs. Training will range from basic skill level to advanced skills in line with the programme and has the scope to grade the task to the individual's specific needs. Comfort breaks and lunch will be provided throughout the day. Tea/coffee will also be provided.

Retesting after 6 months:

The final session of the programme will be to re-test the participants again. The same test will be used as of the initial test and again the researcher and spotter will be present. Retesting will take place post training at 6 months. This will include the same wheelchair skills test administered as before. A script will be used on both occasions to ensure consistency and standardization throughout. Data will again be collected in duplicate.

Data Collection

A member of University staff not involved in the project will issue participants with a unique identifier code prior to participation. Demographic data, the Activity Scale for Kids data and data from the Wheelchair Skills test will all be collected. All data will be stored in a locked filing cabinet in a locked room in Block 1 at Ulster University, Jordanstown. Data will be analysed by the research team using the unique identifier when the programme is completed.

Data Analysis

All data will be collected and input to Excel, for statistical analysis the data will be exported to SPSS. Data analysis of components of variation after day 2 of testing will be analysed in SPSS. Demographic data, the Wheelchair Skills Test results and the Activity Scale for Kids scores will be analysed using descriptive statistics. The Wilcoxon t-test will be used with SPSS to compare pre/post Wheelchair Skills Test and Activity Scale for Kids scores. The Impact Questionnaire will be analysed using qualitative content analysis. The results will then be compared for consistency.

Data storage and privacy

All participants' material will be stored under their unique identifier code. Consent forms will be stored in a locked filing cabinet onsite at Ulster University (within a locked office space). Technical partners and students will have access to the computer anonymous data for each participant. Data will be stored for up to 10 years after the project has completed. Research project data, whether electronic or hard-copy, will be accessible only to those people who have a legitimate purpose, including members of the project team, internal and external auditors and

representatives of regulatory bodies.

Withdrawal of participants

A participant can withdraw at any time from the project and this will not in any way adversely impact on their service experience. We will check with the participants at each session if they wish to proceed. If some data has been collected from the participants this will be included as part of the data set as per consent form, if useful. We do propose to seek consent to take audio/visual data on the sessions with consent of participants and carers. This may be used in dissemination activities i.e. conference presentations, anonymous narratives within journal papers and reports on the findings of the project. The team plan a fun filled programme with the participants and their families. We plan dissemination at many levels including soft news items. No one will be included in these if they choose not to be.

Handling distressing situations and 'what if' scenarios

Each user will be screened prior to accepting a place on the course and any medical conditions, which may impact them during the programme, will be flagged. A first aid trained member of the team will be present throughout. Training will also be provided to parents and caregivers as to spotting their child to reduce the likelihood of injury while their child is completing the training. In the case that a child discloses sensitive information as being a victim of a crime or if the researcher deems the child to be at risk of harm, the researcher is obliged to disclose this information to the relevant authorities.

The core research team at the sessions will include:

Regional Wheelchair Training OT Emma Regan, her assistant who will be our first aider, and researcher Adrienne McCann. Professor Suzanne Martin and Dr Mary Hannon Fletcher School of Health Sciences Ulster University also plan to be in attendance.

Timeline

The project is expected to start in March 2016 and finish by October 2016.

Reference List

APPLEBY, J., 2005. Independent Review of Health and Social Care Services in Northern Ireland. Belfast: Department of Health, Social Services and Public Safety.

BORG, J. and KHASNABIS, C., 2008. Guidelines on the provision of manual wheelchairs in less resourced settings. Geneva: World Health Organisation.

DEPARTMENT FOR WORK AND PENSIONS, 1995. Disability Discrimination Act. London: HMSO.

DEPARTMENT OF HEALTH, SOCIAL SERVICES AND PUBLIC SAFETY, 2008. Review of Services for People with Acquired Traumatic Brain Injury in Northern Ireland. Armagh: Southern Health and Social Care Trust.

DHSSPSNI, 2008. Proposals for the reform of the Northern Ireland Wheelchair service. Northern Ireland: DHSSPS.

LAW, M., BAPTISTE, S., CARSWELL, A., MCCOLL, M., POLATAJKO, H. and

NATIONAL AUDIT OFFICE, 2012. Healthcare across the UK: A comparison of the NHS in England, Scotland, Wales and Northern Ireland. . London: The Stationary Office.

OYSTER, M., SMITH, I., KIRBY, R., COOPER, R., GROAH, S., PEDERSEN, J. and

BONINGER, M., 2012. Wheelchair skill performance of manual wheelchair users with spinal cord injury. Topics in spinal cord injury rehabilitation, 18(2), pp. 138-139.

SAWATZKY, B., RUSHTON, P., DENISON, I. and MCDONALD, R., 2012. Wheelchair skills training programme for children: A pilot study. Australian Occupational Therapy Journal, 59(1), pp. 2-9.

YOUNG, N., WILLIAMS, J., YOSHIDA, K. and WRIGHT, J., 2000. Measurement properties of the Activities Scale for Kids. Journal of Clinical Epidemiology, 53(2), pp. 125-137.

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Wheelchair Skills Programme for Young People

1. Is your project research?

Yes No

2. Select one category from the list below:

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank
- Research database

If your work does not fit any of these categories, select the option below:

Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? Yes No
- b) Will you be taking new human tissue samples (or other human biological samples)? Yes No
- c) Will you be using existing human tissue samples (or other human biological samples)? Yes No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

England

- Scotland
 Wales
 Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- England
 Scotland
 Wales
 Northern Ireland
 This study does not involve the NHS

4. Which review bodies are you applying to?

- NHS/HSC Research and Development offices
 Research Ethics Committee
 Confidentiality Advisory Group (CAG)
 National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

- Yes No

6. Do you plan to include any participants who are children?

- Yes No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- Yes No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

- Yes No

9. Is the study or any part of it being undertaken as an educational project?

- Yes No

Please describe briefly the involvement of the student(s):
PhD project - Principal Investigator will be said student.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

Yes No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

Yes No

Integrated Research Application System
Application Form for Research administering questionnaires/interviews for quantitative analysis or mixed methodology study


Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Wheelchair Skills Programme for Young People

Please complete these details after you have booked the REC application for review.

REC Name:
South Yorkshire REC

REC Reference Number:
15/YH/0383

Submission date:
03/02/2016

PART A: Core study information
1. ADMINISTRATIVE DETAILS
A1. Full title of the research:

Wheelchair skills programme for children

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title Forename/Initials Surname
	Ms Adrienne McCann
Address	Ulster University Shore Rd Newtownabbey
Post Code	BT370QB
E-mail	mccann-a18@email.ulster.ac.uk
Telephone	00353876547473

Fax

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

PhD: A qualitative study into upper-limb musculoskeletal overuse and injury in Spinal Cord Injury: the long-term impact of manual wheelchair usage.

Name of educational establishment:

Ulster University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Mary	Hannon-Fletcher
Address	Ulster University		
	Shore Rd		
Post Code	BT370QB		
E-mail	mp.hannon@ulster.ac.uk		
Telephone	02890366914		
Fax			

Academic supervisor 2

	Title	Forename/Initials	Surname
	Prof	Suzanne	Martin
Address	Ulster University		
	Shore Rd		
Post Code	BT370QB		
E-mail	s.martin@ulster.ac.uk		
Telephone	028 90366976		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):

Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)

Academic supervisor(s)

Student 1 Ms Adrienne McCann

- Dr Mary Hannon-Fletcher
- Prof Suzanne Martin

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- Student
- Academic supervisor

Other**A3-1. Chief Investigator:**

	Title Forename/Initials Surname
	Dr Mary Hannon-Fletcher
Post	Head of School, Health Sciences
Qualifications	Level 2 Award in Team Leading, Institute of Leadership and Management (ILM) Registered Biomedical Scientist. Chartered Scientist
Employer	Ulster University
Work Address	Shore Rd Newtownabbey
Post Code	BT370QB
Work E-mail	mp.hannon@ulster.ac.uk
* Personal E-mail	
Work Telephone	02890366914
* Personal Telephone/Mobile	
Fax	0289038419

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*

A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?

This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname
	Mr Nick Curry
Address	Room 01H12, Ulster University Shore Rd Newtownabbey
Post Code	BT370QB
E-mail	n.curry@ulster.ac.uk
Telephone	028 90366629
Fax	

A5-1. Research reference numbers. Please give any relevant references for your study:

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version: 1.50

Protocol Date: 27/06/2015

Funder's reference number:

Project
website:

Additional reference number(s):

Ref.Number	Description	Reference Number
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Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

Yes No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

The nature of this study is framed around promotion of independence in young people who are permanent wheelchair users. Wheelchair users conduct all activities of daily living while in their chair therefore it is pivotal for them to grasp the skills necessary to enable them to use their chair to the best of their ability. Poor wheeling can have long term effects on secondary upper limb injuries however it is well documented that skill acquisition can improve this outlook. This research project will test their skill level and implement a training programme to enable users to optimise chair performance and functional ability.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Ethical approval will be required as the population we are working with is children. All persons involved in the project with have Access NI checks completed and have up to date manual handling training completed. All persons involved will also be aware of relevant policies and procedures for working with children outlined in the "The Children (Northern Ireland) Order 1995", "Our Children and Young People" - Northern Ireland's 10 year strategy and "Safeguarding Vulnerable Groups (Northern Ireland) Order 2007"; all of which relate to child protection in Northern Ireland. The health and safety procedures for the environments across the three different locations for the study will also be risk assessed. As this is a physical programme, a risk assessment of the programme has also been completed to ensure safety among participants. Written consent will be sought from parents however children may assent if they do not wish to be involved.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are*

ethical issues that require consideration at a full REC meeting.

Yes - proportionate review No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. Please tick all that apply:

- Case series/ case note review
- Case control
- Cohort observation
- Controlled trial without randomisation
- Cross-sectional study
- Database analysis
- Epidemiology
- Feasibility/ pilot study
- Laboratory study
- Metanalysis
- Qualitative research
- Questionnaire, interview or observation study
- Randomised controlled trial
- Other (please specify)

Test-retest design

A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.

To explore the efficacy of a wheelchair skills training programme on skill development and independence of young wheelchair users.

A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.

A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.

In 2008, the Department of Health and Social Services and Public Safety, Northern Ireland launched the "Proposals for the reform of the Northern Ireland Wheelchair Service". Recommendations for service improvements were made following a 2 year review completed from partnership working between healthcare staff and wheelchair service users. Wheelchair service users identified manual wheelchair skills training for children as a priority issue to be addressed. The review highlighted that throughout the region, there was an inequitable provision of wheelchair skills training opportunities for children. Some trusts offered training via local clubs, while other trusts relied solely on charities to deliver training. Skill mix of staff and sporadic engagement with the charities resulted in uncoordinated, unregulated wheelchair skills training for children across Northern Ireland. The importance of this project is to assist with identifying a skills teaching programme that can be used to standardise manual wheelchair skills training for children across Northern Ireland.

A13. Please summarise your design and methodology. It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person.

Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.

The study will consist of 3 days overall on which the participant will attend. Day 1 will focus on testing, Disability Sports NI will also be running some fun sports games alongside our testing where participants can join in after they have completed their tests. Day 2 consists of a further wheelchair skills test 2 months post initial test. Formal wheelchair skills training will take place once participants have completed the test. This will focus on training particular wheelchair skills used in everyday life via a set wheelchair skills training programme. Day 3 will be 6 months post training, participants will be asked to return again where they will complete the wheelchair skills test as they did on day 2. Participants will then be invited to a fun launch day after this where we will disseminate the results of our study.

Day 1: Skills level assessment

When children and their carers/parents arrive they will be offered refreshments and introduced to the team.

Then each parent and child will be asked to complete questionnaires with the help of the researcher, this will take around 10-15 minutes.

Next, the children will be asked to undertake a set of wheel chair skills ranging from basic to intermediate level. This is called the Wheelchair Skills Test. The test will be in the form of tick box where it will be stated YES/NO whether or not the skill was completed. This will take approx. 20 minutes.

The spotters assigned to each child are a safety measure to ensure the child does not get into any difficulty.

Data collection and analysis will occur throughout the programme recording attendance and participation at each session.

Day 2: Retest and Training Day

Approximately 2 months post initial test, the children will be invited back with their parents/carers to complete the wheelchair skills test again. Once the participant has completed the test, The regional wheelchair training OT will complete formal wheelchair skills training with all participants. The training session will focus on practicing real life scenarios and will have the scope to grade the task to the individual's specific needs. Training will range from basic skill level to advanced skills in line with the programme. Comfort breaks and lunch will be provided throughout the day.

Day 3: Re Testing day

This will take place post training at 6 months. This day will include the wheelchair skills test alone. A script will be used on both occasions to ensure consistency and standardization throughout. Data will again be collected in duplicate.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- Design of the research
- Management of the research
- Undertaking the research
- Analysis of results
- Dissemination of findings
- None of the above

Give details of involvement, or if none please justify the absence of involvement.

Participants have been involved in the study from the outset. Aside from the need arising from progress made from legislation such as "The Proposals for the Reform of Wheelchair Services 2008", parents have also voiced their concerns and highlighted a need in the area for further wheelchair skills training. The Regional Wheelchair Skills Training OT has highlighted the lack of evidence as the efficacy of wheelchair skills training to be a gap in practice. Service users have informed all aspects of this project informing the design, management, undertaking and analysis of the research. They will also be invited to a dissemination launch event of the findings.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

- Participants must be aged 7 to 15 years

- Be a self-propelling wheelchair user.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

- Powered wheelchair users
- Participants who have a cognitive issue which would prevent them from following verbal instructions as determined by service providers
- Any predisposing condition that may worsen as a result of training
- Participants who have a deteriorative or life limiting condition

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Attendance Day 1 wheelchair skills programme	1	0	2 hours	Participant attends in morning- optional sports day after
Demographic questionnaire, Activity Scale for Kids questionnaire	2	0	10mins	PhD researcher
Wheelchair skills test	1	0	30mins	PhD researcher
Attendance Wheelchair skills re-testing and training day	1	0	6hours	Participants attend full day
Wheelchair skills retest	1	0	30mins	PhD researcher
Wheelchair skills training	1	0	4 hours	Wheelchair skills therapist
Post training test day	1	0	2 hours	Participant attends half day
Post training test	1	0	30mins	PhD researcher
Impact Questionnaire	1	0	5mins	PhD researcher

A21. How long do you expect each participant to be in the study in total?

The participant and their carer/parent will be expected to attend on three separate days - one for the initial test, one for the second test and training day. After this, in 6 months time we would like them to return to complete the wheelchair skills test post training.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

A full risk assessment has been completed on the Wheelchair Skills Programme. As this is a physical activity there will be a risk of injury however spotters will be in place to act as a safety net for the children. Spotters are assistants who will stand behind or in a place where a risk may exist such as transfers or completing the wheelie. A first aider, the Regional Wheelchair Training OT assistant, will also be present during the study. All individuals involved in the study will have manual handling training up to date.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

Yes No

A24. What is the potential for benefit to research participants?

Participants potentially will improve their skill level in their chair, enhancing functional mobility in everyday activities. This training will replicate real life scenarios that the children will be faced with daily and their level of achievement assessed. The sessions will be enjoyable and inclusive for all and will be a fun activity for them to learn new skills in their chairs.

A26. What are the potential risks for the researchers themselves? (if any)

Movement of the equipment will be done by a van rental company however researchers may be required to move equipment. The research team will be notified of any manual handling procedures prior to this.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).

Once ethical approval has been obtained, potential participants will be identified by an administrator at the Regional Wheelchair Centre from the regional database using the inclusion and exclusion criteria. A participant information leaflet, a consent form and a stamped addressed envelope, together with a letter inviting them to join the study will be posted to eligible participants. If they are interested in taking part in the study they are asked to contact the PhD researcher, Ms Adrienne McCann, by phone or email.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

Yes No

Please give details below:

Personal information such as age, gender and information related to their wheelchair use will be visible on the register to the administrator who will be screening for possible participants.

A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?

Yes No

A27-5. Has prior consent been obtained or will it be obtained for access to identifiable personal information?

Yes No

If Yes, please give details below.

Participants and their carers are informed on the information sheet that in line with university procedure, data will be stored for up to 10 years after the project has been completed. Research project data, whether electronic or hard-

copy, will be accessible only to those people who have a legitimate purpose, including members of the project team, internal and external auditors and representatives of regulatory bodies.

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

Yes No

A29. How and by whom will potential participants first be approached?

Potential participants will be identified by an administrator at the Regional Wheelchair Center from the regional database using the inclusion and exclusion criteria. A participant information leaflet, a consent form and a stamped addressed envelope, together with a letter inviting them to join the study will be posted to eligible participants. If they are interested in taking part in the study, they are asked to contact the PhD researcher, Ms Adrienne McCann, by phone or email.

A30-1. Will you obtain informed consent from or on behalf of research participants?

Yes No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Written consent will be obtained from parents as the participants are children and under 18. Although children cannot consent to the programme they can assent to say they do not want to participate. A consent form will be posted out with information sheets with a stamped addressed envelope. However if this is not returned and the participants or their carers/parents make contact with us that they wish to participate, there is a consent form they can sign on the morning of Day 1 prior to any participation.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

Yes No

A31. How long will you allow potential participants to decide whether or not to take part?

Depending on ethical approval, we cannot contact any participants prior to this. We hope for the study to run during the month of August so participants should have approximately one month to decide whether or not they wish to participate.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)

Due to the nature of the project where participants will be asked verbally to complete a task independently, we cannot include the use of interpreters as this would not be the child completing it independently. Hence we have included this as part of our inclusion and exclusion criteria.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

- The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- The participant would continue to be included in the study.
- Not applicable – informed consent will not be sought from any participants in this research.
- Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

A participant can withdraw at any time from the project and this will not in any way adversely impact on their service experience. We will check with the participants at each session if they wish to proceed.

If some data has been collected from the participants this will be included as part of the data set as per consent form, if useful.

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)

- Access to medical records by those outside the direct healthcare team
- Electronic transfer by magnetic or optical media, email or computer networks
- Sharing of personal data with other organisations
- Export of personal data outside the EEA
- Use of personal addresses, postcodes, faxes, emails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
- Manual files including X-rays
 - NHS computers
 - Home or other personal computers
 - University computers
 - Private company computers
 - Laptop computers

Further details:

A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and

procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.

Unique identifier codes will be issued to all participants. Participants will be aware on signing of a consent form of the University's policy on data storage and we will protect it in line with this policy.
In the case that a child discloses sensitive information as being a victim of a crime or if the researcher deems the child to be at risk of harm, the researcher is obliged to disclose this information to the relevant authorities.

A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.

Participants personal data will only be seen by the administrator on screening. After this the unique identifier number will be applied. No data will be recognisable to anyone within the research team. No patient information will be stored on file; all data collected will be stored in a locked storage unit on the University grounds.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- Less than 3 months
 3 – 6 months
 6 – 12 months
 12 months – 3 years
 Over 3 years

If longer than 12 months, please justify:

Data will be stored for up to 10 years after the project has completed in line with Ulster University's policy on data collection.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

- Yes No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
Lunch will be provided for the three days.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

- Yes No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

- Yes No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

Yes No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

Yes No

Please give details, or justify if not registering the research.

Registration of research studies is encouraged wherever possible.

You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- Peer reviewed scientific journals
- Internal report
- Conference presentation
- Publication on website
- Other publication
- Submission to regulatory authorities
- Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- No plans to report or disseminate the results
- Other (please specify)

A53. Will you inform participants of the results?

Yes No

Please give details of how you will inform participants or justify if not doing so.

We will disseminate our results in visual graphs where participants can see whether there was an improvement across the whole study or not.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? Tick as appropriate:

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Review within the Chief Investigator's institution or host organisation
- Review within the research team

- Review by educational supervisor
 Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

Prior to completing this, the project has undergone internal review within Ulster University with recommendations from two senior members of staff. Both reviewers feedback has been taken on board and amendments made where necessary.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A56. How have the statistical aspects of the research been reviewed? Tick as appropriate:

- Review by independent statistician commissioned by funder or sponsor
 Other review by independent statistician
 Review by company statistician
 Review by a statistician within the Chief Investigator's institution
 Review by a statistician within the research team or multi-centre group
 Review by educational supervisor
 Other review by individual with relevant statistical expertise
 No review necessary as only frequencies and associations will be assessed – details of statistical input not required

In all cases please give details below of the individual responsible for reviewing the statistical aspects. If advice has been provided in confidence, give details of the department and institution concerned.

	Title Forename/Initials Surname
	Prof Ian Bradbury
Department	Statistical Science
Institution	Institute of Nursing and Health Research
Work Address	01F118 Ulster University Jordanstown Campus Shore Rd, Newtownabbey
Post Code	BT370QB
Telephone	028 90366459
Fax	
Mobile	
E-mail	i.bradbury@ulster.ac.uk

Please enclose a copy of any available comments or reports from a statistician.

A57. What is the primary outcome measure for the study?

The primary outcome measure used will be the Wheelchair Skills Test.

A58. What are the secondary outcome measures?(if any)

The Activity Scale for Kids is a secondary outcome measure.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size:

Total international sample size (including UK):

Total in European Economic Area:

Further details:

We plan to include a total of 30 participants across our 3 locations.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

The sample size was calculated using a power calculation and liaising with the University statistician. This was based on standard deviation values from a similar study looking at wheelchair skills training in children also, (Sawatzky, rushton et al., 2012). In order to have statistical significance within the study and allowing 10% for dropouts we concluded a sample size of 30 would be suitable for the study.

A61. Will participants be allocated to groups at random?

Yes No

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

All data will be collected and input to Excel, for statistical analysis the data will be exported to SPSS. Components of variation data will be analysed on SPSS. Demographic data, the Wheelchair Skills Test results and the Activity Scale for Kids scores will be analysed using descriptive statistics. The Wilcoxon t-test will be used with SPSS to compare pre/post Wheelchair Skills Test and Activity Scale for Kids scores. The Impact Questionnaire will be analysed using qualitative content analysis. The results will then be compared for consistency.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title Forename/Initials Surname
	Ms Emma Regan
Post	Regional Wheelchair Training Occupational Therapist
Qualifications	BSc Hons Occupational therapy
Employer	Belfast Health and Social Care Trust
Work Address	Regional Disablement Service Musgrave Park Hospital Stockman's Lane, Belfast
Post Code	BT9 7JB
Telephone	
Fax	
Mobile	
Work Email	emma.regan@belfasttust.hscni.net

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status: NHS or HSC care organisation Academic Pharmaceutical industry Medical device industry Local Authority Other social care provider (including voluntary sector or private organisation) Other

Commercial status: Non-Commercial

If Other, please specify:

Contact person

Name of organisation Ulster University

Given name Nick

Family name Curry

Address Shore Rd

Town/city Newtownabbey

Post code BT370QB

Country UNITED KINGDOM

Telephone 028 90366629

Fax

E-mail n.curry@ulster.ac.uk

Is the sponsor based outside the UK?

 Yes No*Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.*

A65. Has external funding for the research been secured?

- Funding secured from one or more funders
- External funding application to one or more funders in progress
- No application for external funding will be made

What type of research project is this?

- Standalone project
- Project that is part of a programme grant
- Project that is part of a Centre grant
- Project that is part of a fellowship/ personal award/ research training award

OtherOther – please state:
PhD research project**A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?** Yes No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title Forename/Initials Surname
	Ms Alison Murphy
Organisation	HSC R&D Manager Belfast Health & Social Care Trust
Address	Research & Development Office Room 2010, 2nd Floor King Edward Building, Royal Hospitals Site
Post Code	BT12 6BA
Work Email	Alison.Murphy@belfasttrust.hscni.net
Telephone	028 9063 6366
Fax	
Mobile	

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

A69-1. How long do you expect the study to last in the UK?

Planned start date: 26/08/2015

Planned end date: 26/11/2016

Total duration:

Years: 1 Months: 3 Days: 1

A71-2. Where will the research take place? (Tick as appropriate)

- England
- Scotland
- Wales
- Northern Ireland
- Other countries in European Economic Area

Total UK sites in study 3

Does this trial involve countries outside the EU? Yes No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:

- NHS organisations in England
- NHS organisations in Wales
- NHS organisations in Scotland
- HSC organisations in Northern Ireland
- GP practices in England
- GP practices in Wales
- GP practices in Scotland
- GP practices in Northern Ireland
- Social care organisations
- Phase 1 trial units
- Prison establishments
- Probation areas
- Independent hospitals 1
- Educational establishments 2
- Independent research units
- Other (give details)

Total UK sites in study: 3

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (NHS sponsors only)
- Other insurance or indemnity arrangements will apply (give details below)

The University's normal indemnity arrangements will apply

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (protocol authors with NHS contracts only)
- Other insurance or indemnity arrangements will apply (give details below)

The University's normal indemnity arrangements will apply

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

The University's normal indemnity arrangements will apply

Please enclose a copy of relevant documents.

PART B: Section 7 - Children

1. Please specify the potential age range of children under 16 who will be included and give reasons for carrying out the research in this age group.

The group we will carry out our intervention with is children aged 7 to 15 years. There is no standardised wheelchair training available to this population currently so we wish to run our research project on this niche population. The training is of benefit to them to help improve their wheelchair skills ability for everyday activities.

2. Indicate whether any children under 16 will be recruited as controls and give further details.

There will be no control group in this study.

3-2. Please describe the arrangements for seeking informed consent from a person with parental responsibility and/or from children able to give consent for themselves.

The children will receive information sheets describing the programme suited to children. The parents will also receive an information sheet further outlining what will happen. In order for the children to be included in the study the parent must consent on their behalf however the children are allowed assent if they do not wish to participate.

4. If you intend to provide children under 16 with information about the research and seek their consent or agreement, please outline how this process will vary according to their age and level of understanding.

We have created two participant information sheets as well as information sheets for the parents. The first information sheet will be suited to the child aged 7-11 years so it is easily understood for their reading ability. Another information sheet will be sent to children aged 12-15 years graded to their reading ability. Therefore the children can make informed decisions as they know exactly what they are being asked to do.

Copies of written information sheet(s) for parents and children, consent/assent form(s) and any other explanatory material should be enclosed with the application.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

Research site		Investigator/ Collaborator/ Contact	
Institution name	Ulster University Jordanstown	Title	Ms
Department name		First name/ Initials	Adrienne
Street address	Shore Rd	Surname	McCann
Town/city	Newtownabbey		
Post Code	BT370QB		
Institution name	Ulster University Coleraine	Title	Ms
Department name		First name/ Initials	Adrienne
Street address	Coleraine	Surname	McCann
Town/city	Londonderry		
Post Code	BT52 1SA		
Institution name	Lakeland Forum Enniskillen	Title	Ms
Department name		First name/ Initials	Adrienne
Street address	Broadmeadow,	Surname	McCann
Town/city	Enniskillen		
Post Code	BT74 7EF		
Institution name		Title	
Department name		First name/ Initials	
Street address		Surname	
Town/city			
Post Code			
Institution name		Title	
Department name		First name/ Initials	
Street address		Surname	
Town/city			
Post Code			

PART D: Declarations**D1. Declaration by Chief Investigator**

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
 - ◊ Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
 - ◊ May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
 - ◊ May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
 - ◊ Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
 - ◊ May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

Chief Investigator

- Sponsor
- Study co-ordinator
- Student
- Other – please give details
- None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Mary P.A. Hannon-Fletcher on 28/07/2015 13:05.

Job Title/Post: Head of School
Organisation: Ulster University
Email: mp.hannon@ulster.ac.uk

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

Please note: The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by Mr Nick Curry on 29/07/2015 17:18.

Job Title/Post: Research Governance
Organisation: Ulster University
Email: n.curry@ulster.ac.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Suzanne Martin on 27/07/2015 20:40.

Job Title/Post: Professor Occupational Therapy
Organisation: Ulster University
Email: s.martin@ulster.ac.uk

Academic supervisor 2

This section was signed electronically by Mary P.A. Hannon-Fletcher on 28/07/2015 13:03.

Job Title/Post: Head of School
Organisation: Ulster University
Email: mp.hannon@ulster.ac.uk



Health Research Authority

NRES Committee Yorkshire & The Humber - South Yorkshire

Unit 001
Jarrow Business Centre
Rolling Mill Road
Jarrow
Tyne and Wear
NE32 3DT

Telephone: 0191 428 3561

12 August 2015
(revised 4 March 2016)

Dr Mary Hannon-Fletcher
Head of School, Health Sciences
Ulster University
Shore Rd
Newtownabbey
BT370QB

Dear Dr Hannon-Fletcher

Study title: Wheelchair skills programme for children
REC reference: 15/YH/0383
IRAS project ID: 169094

The Proportionate Review Sub-committee of the NRES Committee Yorkshire & The Humber - South Yorkshire reviewed the above application on 12 August 2015.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Assistant Miss Kerry Dunbar, nrescommittee.yorkandhumber-southyorks@nhs.net Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission (“R&D approval”) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites (“participant identification centre”), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion”).

Summary of discussion at the meeting

Recruitment arrangements and access to health information, and fair participant selection

Members requested that the opt-in process be better described in the information sheet (and amended in the Children's information sheet) by replacing the existing heading "What happens next" with "If you wish to participate" followed by information on how to contact the researchers (telephone, text, email) or with a dedicated "opt-in" contact form.

Ms Adrienne McCann replied that the opt-in process had been further detailed on the Parents information sheet and both children's information sheet. A "Parents' consent form" is also included as part of the parents information sheet as a dedicated "opt-in" form. This was separate to the previous consent form.

The Sub Committee was satisfied with the response given to the issue raised.

Informed consent process and the adequacy and completeness of participant information

Members requested that the informed Consent and Assent to be taken by the Researcher on Day 1 and reconfirmed on subsequent days in all instances.

Ms McCann replied that all of the information sheets now state that informed consent would be taken on each morning of the project.

Members required that the Consent Form had the standard HRA paragraph on access by Regulatory Authorities.

Ms McCann replied that the standard HRA paragraph on access by regulatory authorities had been included on all consent forms.

Members stated that the "Use of Photography Statement" was inadequate and should be re-constructed as a separate participant information sheet and specific Consent Form, which needed to describe:

- The details of the imagery – the various media and formats
- When imagery would be taken
- Storage of the imagery (reference to the relevant University data policies)
- Future destruction
- Precise details of the future uses
- If images and video were to be placed on the internet then specify where and highlight that it may not be possible to guarantee these cannot be downloaded/copied

Ms McCann replied that a information sheet relating to use of audio-visual material and a separate consent form had now been completed and each of the points as outlined in the recommendations had been included.

The Sub Committee was satisfied with the responses given to the issues raised.

Independent review

Members requested copies of the assessments by the Academic Supervisor and other Supervisors required as specified at A54 on the IRAS form.

Ms McCann replied that two independent peer reviews were carried out by 2 senior members of staff within Life and Health Sciences in Ulster University and were called RG2 forms and had

2 documents missed from favourable opinion letter

been included. The project went through Nursing and Health Sciences Filter Committee of which Professor George Kernohan was chair and is the RG3 form.

The Sub Committee was satisfied with the response given to the issue raised.

Other general comments

Members asked for justification on A50 of the IRAS form regarding why this study was not being registered on a publicly accessible database. Failure to register research was unethical especially when you make the case that research in this area was lacking. This study could be registered on; an open University website, an appropriate charity website or any other website where it was identifiable by a standard internet search engine.

Ms McCann replied that the project was registered on the INVOLVE database and was funded by the National Institute for Health Research, to support active public involvement in NHS, public health and social care research. Although the project was registered it was never officially submitted for review by their staff, however this had now been rectified. A screenshot of the application for review was enclosed with the response.

The Sub Committee was satisfied with the response given to the issue raised.

Approved documents

The documents reviewed and approved were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Cover letter]	1.0	29 July 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Letter from sponsor]	1.0	27 July 2015
IRAS Checklist XML [Checklist_30072015]		30 July 2015
Non-validated questionnaire [Demographic questionnaire]	1.0	30 July 2015
Non-validated questionnaire [Impact questionnaire]	1.10	30 July 2015
Other [Cover Letter to PRSC]		10 August 2015
Other [RG2 Adrienne McCann]		25 May 2015
Other [RG2 Adrienne]		
Other [RG3 Martin MHF]		
Other [Screenshot INVOLVE]		
Participant consent form [photography consent form]	1.0	30 July 2015
Participant consent form [Audio Visual Media Consent]	Version 1.0	10 August 2015
Participant consent form [Wheelchair Skills Programme Consent Form]	Version 1.10	08 August 2015
Participant information sheet (PIS) [PIS - Children 12-15 years]	Version 1.10	08 August 2015
Participant information sheet (PIS) [PIS - Children 7-11 years]	Version 1.10	08 August 2015
Participant information sheet (PIS) [PIS - Audiovisual medical]	Version 1.0	09 August 2015
Participant information sheet (PIS) [PIS - Parents]	Version 1.3	08 August 2015
REC Application Form [REC_Form_29072015]		29 July 2015
Research protocol or project proposal [Study Protocol]	1.50	30 July 2015

2 documents missed from favourable opinion letter

Summary CV for Chief Investigator (CI) [Summary CV CI]	1.0	27 July 2015
Summary CV for student [Student CV]	1.0	28 July 2015
Summary CV for supervisor (student research) [Supervisors CV]	1.0	27 July 2015
Summary CV for supervisor (student research) [Supervisors CV]	1.0	30 July 2015
Validated questionnaire [Activity Scale for Kids Questionnaire]	1.0	02 June 2015
Validated questionnaire [Scoring sheet for ASK]	1.0	02 June 2015
Wheelchair skills test risk assessment		22 July 2015
Wheelchair skills test		22 July 2015

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee’s best wishes for the success of this project.

15/YH/0383

Please quote this number on all correspondence

Yours sincerely

pp



Dr Ian Woollands
Chair

Email: nrescommittee.yorkandhumber-southyorks@nhs.net

Enclosures: List of names and professions of members who took part in the review
“After ethical review – guidance for researchers”

Copy to: Mr Nick Curry, Ulster University
Ms Alison Murphy, HSC R&D Manager Belfast Health & Social Care Trust

NRES Committee Yorkshire & The Humber - South Yorkshire

**Attendance at PRS Sub-Committee of the REC meeting on 12 August 2015
via correspondence**

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>	
Dr Ahmed H Abdelhafiz	Consultant Physician, Elderly Medicine	Yes		
Dr Rhona Bratt	Retired Multimedia Project Manager	Yes		
Dr Ian Woollands (Chair)	Retired Clinical Director, Occupational Health	Yes		

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>	
Miss Kerry Dunbar	REC Assistant	



Health Research Authority

Yorkshire & The Humber - South Yorkshire Research Ethics Committee

Unit 001
Jarrow Business Centre
Rolling Mill Road
Jarrow
Tyne and Wear
NE32 3DT

Tel: 0191 4283563

24 February 2016

Ms Adrienne McCann
Student
Ulster University
Shore Rd
Newtownabbey
BT370QB

Dear Ms McCann

Study title:	Wheelchair skills programme for children
REC reference:	15/YH/0383
Amendment number:	1, 17.12.15
Amendment date:	17 December 2015
IRAS project ID:	169094

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a **favourable ethical opinion** of the amendment on the basis described in the notice of amendment form and supporting documentation.

Members stated that a copy of the Invitation Letter on headed notepaper would need to be provided.

Members stated that copies of the new Participant Information Sheet on headed paper (as "clean version" to show layout) would be required.

You confirmed that the Invitation letter had been copied on to headed paper along with the Participant Information Sheets.

Members stated that confirmation that the new Participant Information Sheets and Invitation Letter had been reviewed by an appropriate PPI group and their comments (if any) considered.

You confirmed that the new Participant Information Sheets and invitation letter were reviewed by members of your steering group. Their comments included some grammar and format changes but agreed that they were happy for the documents to be submitted to the REC.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper		04 February 2016
Covering letter on headed paper [Covering email]		24 February 2016
Letters of invitation to participant	V1.0	23 February 2016
Notice of Substantial Amendment (non-CTIMP)	1, 17.12.15	17 December 2015
Other [Flyer]	V1.0	17 December 2015
Participant information sheet (PIS) [5 - 9 years]	V1.20	17 December 2015
Participant information sheet (PIS) [10 - 15 years]	V1.20	17 December 2015
Participant information sheet (PIS) [Parents]	V1.30	17 December 2015
Research protocol or project proposal	1.60	17 December 2015

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/YH/0383:	Please quote this number on all correspondence
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Yours sincerely



pp

Dr Ian Woollands
Chair

E-mail: nrescommittee.yorkandhumber-southyorks@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Dr Mary Hannon-Fletcher, Ulster University

Yorkshire & The Humber - South Yorkshire Research Ethics Committee

Attendance at Sub-Committee of the REC meeting via correspondence

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mr Ian Cawthorne	Pharmacist	Yes	
Dr Ian Woollands (Chair)	Retired Clinical Director, Occupational Health	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mrs Helen Wilson	REC Manager

Information Sheet

Wheelchair Skills Training for children

Hello,

My name is Adrienne McCann, I'm an Occupational Therapist currently taking my PhD at Ulster University. I would like to invite you to take part in a research study we are undertaking as part of my PhD. I'm really keen to support young people who use wheelchairs to maximise their use indoors and outdoors. I'm working with Emma Regan, the regional wheelchair therapist based at Musgrave Park Hospital. She has been involved in prescribing wheelchairs and together we are exploring if the provision of a wheelchair training skills programme helps young people use their chairs.

It is important that you understand the purpose of the research and what it will entail before you make your decision. Please take time to read the following information carefully.

We are approaching you in the first instance as the named representative for the young person we have allocated a self-propelling wheelchair to. We are seeking your consent for them to take part in the study. When you consent for us to approach them we will also seek further consent from them to participate. If you have consented for them to join the study but they do not want to then we will not pursue their participation.

Title of study: Wheelchair skills programme for young people.

What is the aim of this study?

The aim of this study is to implement a wheelchair skills training programme with young wheelchair users who use a high performance chair. The programme aims to improve wheelchair skill acquisition and promote independence in the above population group.

The nature of this study is framed around promotion of independence in young people who are permanent high performance wheelchair users. Wheelchair users conduct all activities of daily living while in their chair therefore it is pivotal for them to grasp the skills necessary to enable them to use their chair to the best of their ability. Poor wheeling can have long term effects on secondary upper limb injuries however it is well documented that skill acquisition can improve this outlook. This project will

implement a wheelchair skills test and training programme to enable users to use their chair to the best of their ability, promoting skill acquisition and independence.

What is involved?

We would like for you and your child to take part in this study. The study will take place over an 8 month period which will run alongside the Causeway Wheelers group which is currently in place. We would like to complete the wheelchair skills assessment with your child on the first Saturday of the programme. Thereafter training will take place on the first Saturday of each month so as your child has an opportunity to practice these new skills and a social outlet to meet other children. Children will then be tested again at the end of the programme to observe any improvement in their skill acquisition. A provisional outline of dates has been included (subject to change).

Date	Activity
5 th March 2016	Initial test
9 th April 2016	Training
7 th May 2016	Training
4 th June 2016	Training
2 nd July 2016	Training
13 th August 2016	Training
10 th September 2016	Training
8 th October 2016	Retest

The programme will take place in the Joey Dunlop Centre located in Ballymena. The programme is aimed at young people aged 5-15 years who are both part time and full time wheelchair users however we would like to use this programme as an opportunity to encourage those young people who may not meet our inclusion criteria to get involved too. Every young person who consents to be included in the programme are eligible to take part, however we will only use the data of those children who meet our criteria in the study. The training will be ran as fun sessions while still focusing on key techniques. This will be conducted by Emma Regan (Regional Wheelchair training OT for Northern Ireland) and occupational therapists from the wheelchair service in Ballymoney. The programme aims to be as inclusive as possible and we would encourage any siblings and parents to come along.

What is the wheelchair skills test?

The wheelchair skills test consists of different skills and techniques your child is most likely already doing in their chair. The test is only to establish a baseline of their current skill level and to see how they manage using their chair independently. The test will look at skills ranging from basic to advanced level for example negotiating between cones, wheeling up and down ramps and carrying an object while propelling their chair, to name just a few.

Outline of the programme:

Please note we will seek consent from both you and your child at each stage of the programme and you may withdraw at any time.

Testing: The first day you attend will be to test your child and gather a baseline of the skill level they already have. There will be some conversation type assessments with you and your child which will cover some general questions such as age, gender, time in chair etc. to gather some demographic information for the study. The testing should take no longer than 1 hour.

Training: As mentioned above, the programme will run on the first Saturday of every month. On the following Saturday we will begin the training programme which will be two hour sessions. These training days will be fun filled giving the young person an opportunity to socialise with friends and meet new people all while learning some new techniques in their chair. There will be regular comfort breaks and tea/coffee provided. 2 months after the initial testing, we want to bring you and your child back for another test and wheelchair skills training. The test will be repeated to see if there has been any improvement in their skills level over the 2 months. After this there will be some formal wheelchair skills training which will include a variety of skills from basic to advanced level. There will be regular comfort breaks and lunch provided.

Final Test: On completion of the above training programme, the skills test will be repeated with each of the participants as before. This will be to establish if there has been any improvement in their skill level after completing the training. Participants will be required to attend a re-testing session 6 months after the initial training. This will consist of repeating the initial wheelchair skills test.

Why have you been approached?

You have been approached as your child is a manual wheelchair user who may benefit from attending a wheelchair skills training programme.

Do I have to take part?

No, it is up to you whether or not you wish for you and your child to participate. If you do, you are still free to withdraw at any time. A participant can withdraw at any time from the project and this will not in any way adversely impact on their service experience. We will check with the participants at each session if they wish to proceed. If some data has been collected from the participants this will be included as part of the data set as per consent form, if useful.

What are the possible disadvantages and risks of taking part?

A full risk assessment is completed on the wheelchair skills programme outlining possible risk of injury or harm. As this is a physical activity there will be a risk of injury however spotters will be in place to act as a safety net for the wheelchair users. Spotters are assistants who will stand behind or in a place where a risk may exist such as transfers or completing the wheelie. The Regional Wheelchair Training Occupational Therapist has a wealth of experience in wheelchairs and wheelchair skills training also.

What happens to the information?

We will give you a unique identifier code that will be used instead of your name during the completion of the testing and training. At no point will your name be identifiable. Consent forms will be stored in a locked filing cabinet onsite at Ulster University (within a locked office space). Technical partners and students will have access to the computer anonymous data for each participant. All data will be stored

securely and subsequently destroyed in accordance with Ulster University's data protection policy after ten-years. Please be aware that in the case that a child discloses sensitive information as being a victim of a crime or if the researcher deems the child to be at risk of harm, the researcher is obliged to disclose this information to the relevant authorities.

How can you make a complaint?

Your child's well-being is of great importance to us and we hope that through careful planning, participating in the training programme and the subsequent analysis and publication of the data gathered throughout will not cause you distress. Complaints can be discussed in the first instance with me and I will try to resolve your complaint to your satisfaction. If I fail to resolve your concern or complaint, you can direct your complaint to Ulster University. Your complaint will be addressed in accordance with Ulster University's Complaint Process.

What happens next?

If you are willing to participate, please return the consent form to my address as listed below. A stamped addressed envelope has been provided for your ease. We will then be in contact to arrange suitable times and dates for the assessments and training.

Thank you for reading this information sheet and considering participating in this study. Please contact me on the details below should you have any queries.

Yours sincerely

Adrienne McCann

(PhD Student) Email: mccann-a18@email.ulster.ac.uk

Block 1 Level F
Ulster University Jordanstown
Shore Road
Newtownabbey
BT37 0QB

Appendix 15B: Participant Information Sheet for Children 5-9 years

Participant Information Sheet

Hello!

I'm looking for some kids to help me out with a really cool project on wheelchair skills training. Think you can help? Let's see...

Are you:

- ✚ Aged 5-15 years?
- ✚ Use a self-propelling wheelchair?
- ✚ Can understand instructions without the help of Mum/Dad/carer?

Unfortunately, if using your chair lots or for long periods of time makes you feel worse or worsens your overall condition then it is safer for you that we do not include you in our project.



If you think you might be suitable, ask your parent/carer to double check these points and read on!

We have a new way of testing how good you are in using your chair. As part of our project we want to trial this new test with you and then show you some cool tricks too. Our project will have 3 days in total, all of which we hope you can attend. Here's what will happen:

You will arrive at the centre and we will meet you. We want you and your parent to fill out some questionnaires which we will help you with. After these we will show you an obstacle course we have set up and ask you to have a go at completing it in your chair. There will be ramps and curbs and different skills that you can do sitting in your chair.

Once we have completed the test with you it's time for the fun part to start! We have organised some really fun training sessions where you can work on your skills from the test. There will be loads of games and time to take a rest if you need. The session will be for two hours one Saturday a month. In 2 months' time we want you to come back and repeat the obstacle course you did before. Once you have this done there will be a fun training day where you will learn lots of cool tricks and skills. If you thought you couldn't do a skill from the test we have a teacher on hand to show you how to do the skills! There will be lunch and breaks throughout the day in case you get tired. After this we won't see you for 6 months and your parents/siblings/friends can all join in too!

For our very last session we are going to do the same obstacle course we did on the first day we saw you. Today we want you back to complete the obstacle course again. This is to see if you have improved over the last 6 months and see if you found our training helpful. After you re-do the obstacle course we want you and your carer/parent to complete one last questionnaire about how you enjoyed the whole project and that will be you finished!

If you think you might enjoy this project let your carer/parent know, they have a consent form to sign and once that is returned we can send you more details about when and where the project will happen. We hope to see you soon for some fun wheelchair skills training!



Appendix 15C: Participant Information Sheet 10-15 years

Participant Information Sheet

Hello!

I'm looking for some young people to help me out with a wheelchair skills training project I'm hoping to get up and running. The project is a research project from Ulster University and we're hoping to find some manual wheelchair users who could partake in a small wheelchair skills testing and training programme. Think you can help? Let's see, below is a list of the criteria we need you to meet first...

Are you:

- Aged 10-15 years?
- Use a self-propelling wheelchair?
- Can understand instructions without the help of Mum/Dad/carer?



Unfortunately, if using your chair lots or for long periods of time makes you feel worse or worsens your overall condition then it is safer for you that we do not include you in our project. If you think you meet the criteria for the study then read on...

The project will be split over 3 days. Here's what we want you to do:

On the first day you will attend a short appointment with your carer/parent. We will meet and greet you and explain what will happen. First of all we want you and your parent to fill out some questionnaires on some basic information about you. After this we want you to complete an obstacle course type test (we call this the wheelchair skills test) in your chair. It's not a difficult test - there will be ramps and curbs and some static skills. Once this is finished there will be some sports games running in a room next door that you can join in.

Our programme will be on one Saturday every month. Once you've completed the test, we want you to have as much fun as possible learning new skills and tricks in your chair. The next 6 weeks will be all about trying new skills and anything you might have had trouble with during the test. There will be a teacher there who will demonstrate all the skills from the test and the best technique for doing them and. You can ask her any questions you might have about these. There will be lunch provided and various breaks throughout the day.

In 6 months time after the training programme we will ask you back to complete the wheelchair skills test again just like before. This is to see if there is any difference from when we did the skills training with you. We also have a questionnaire to see what you enjoyed about the day and anything you would change. This will be the last day and the project will then be finished!

If you think you might be interested in joining our project tell your carer/parent.

Unfortunately as you are under 18 we need your parents to consent for you. They have a consent form that you can return to us and we can give you more details about where and when the project is going to start. We hope to see you there!

Appendix 15D: Consent form for participation in wheelchair skills study

Consent Form

Title of Project: Wheelchair skills programme for children
Chief Investigator: Dr Mary Hannon-Fletcher
Principal Investigator: Adrienne McCann
Supervisors: Prof Suzanne Martin; Dr Mary Hannon-Fletcher
Research team: Emma Regan (Regional Wheelchair Specialist)

Please initial

- I confirm that I have been given and have read and understood the information sheet for the above study and have asked and received answers to any questions raised.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights being affected in any way
- I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law) and I give permission for the researchers to hold relevant personal data
- I agree for my child to take part in the above study

Name of Child

Signature

Date

Name of parent who consents

Signature

Date

Name of researcher

Signature

Date

Appendix 15E: Consent form for use of audio-visual material

USE OF AUDIO-VISUAL MATERIAL

Dear Parent/carer

As part of our research project, sometimes visual media such as video recording and photographs of the session can be used to record training events, projects, group work etc. As it would be extremely difficult to obtain permission for every single photo taken we are requesting an overall consent from you where by you and your child consent for audio-visual material to be taken during the research programme.

Often we would use photos in dissemination activities i.e. conference presentations, anonymous narratives within journal papers and reports on the findings of the project. The team plan a fun filled few days with you and your family and we plan dissemination at many levels including soft news items. No one will be included in these if they choose not to be.

We will not use any of these photographs for external publication or pass them on to anyone else without asking for your permission.

By circling "do" below you consent to visual media to be taken throughout the research programme and used as outlined above. If you are not happy with this arrangement please circle "do not" below.

I _____ do/do not consent to the use of visual media of me or my child during this study for dissemination purposes.

Appendix 16: NI Regional Manual Wheelchair Skills Assessment Checklist

Wheelchair Training for Occupational Therapists (NI)

Guidelines for teaching wheelchair skills using the NI Regional Wheelchair skills checklist

1. The wheelchair checklist can be used as an aid for teaching wheelchair skills. The skills are graded from basic to advanced. Within each skill level the skills are ranked in order of difficulty. Wheelchair users should progress through the skills in this order.
2. All wheelchair users who can self propel and have no upper limb or cognitive impairment, have the potential be independent with all basic and intermediate skills. For wheelchair users who are not independent, carers should be instructed on how to assist the user to complete these skills. In these situations tick no in the user column but also tick yes to record the carer is independent. It is not appropriate to progress to advanced skills with these users.
3. If users have any degenerative bone conditions (osteoarthritis etc) skills requiring castor flicking are not appropriate.
4. When teaching back wheel balance training, ensure the user's wheelchair is supported by the therapist to prevent the user tipping backwards out of the wheelchair. A strap can be attached to the back of the wheelchair to avoid the trainer suffering back strain.
5. The set-up of the wheelchair (ie, position of the back wheel) should be arranged to accommodate the user's ability to achieve and control a back wheel balance:
 - Forward position of back wheel – W/chair more unstable, easy to tip.
 - Backwards position of back wheel – W/chair more stable, more difficult to tip.Initially the wheelchair should be set up quite stable to enable the wheelchair user to build confidence with their wheelchair skills.
6. In meeting the criteria for ultra lightweight wheelchair provision users must be demonstrate a higher level of skills competency. In exceptional circumstances were users fail to achieve higher level of skills competency, they can still be considered for High performance /Ultra lightweight provision on an individual basis (eg. tetrapleia). In such cases a risk assessment should be completed to record the safety measures taken to prevent the user falling out off the wheelchair.

NI REGIONAL MANUAL WHEELCHAIR SKILLS ASSESSMENT CHECKLIST

Wheelchair User:		Occupational Therapist:	
Carer:		Skills Trainer/s:	

BASIC SKILLS	Wheelchair user Independent		Carer Independent		Skill N/A	Date achieved
	Yes	NO	Yes	N/A		
1. Wheelchair Features Be able to : - <ul style="list-style-type: none"> • Operate the brakes • Remove the armrests • Swing away and replace foot plates • Remove and replace the wheels • Fold and safely lift the wheelchair • Open/close wheelchair belt • Understand how to move anti tip levers • Locate the tie down points on the W/chair 						
2. Short distance pushing Push wheelchair 10 meters in a straight line (forwards/backwards)						
3. Long distance pushing Use an energy efficient push over a long distance <ul style="list-style-type: none"> • Forwards • Backwards 						
4. Shift body weight <ul style="list-style-type: none"> • Can use pressure relieving techniques • Understands how the wheelchair responds to moving body weight within the wheelchair. 						
5. Turning <ul style="list-style-type: none"> • Turns wheelchair 90° to the left and right • Turns wheelchair 180° to the left and right • Turns wheelchair 360° within its own turning circle. 						
6. Introducing obstacles Negotiate a simple obstacle course using forward/backwards pushing and turning techniques.						

INTERMEDIATE SKILLS	Wheelchair user Independent		Carer Independent		Skill N/A	Date achieved
	Yes	No	Yes	N/A		
1. Doors <ul style="list-style-type: none"> • Open door • Go through door • Close door 						
2. Carry objects when propelling: <ul style="list-style-type: none"> • Carrying object in the lap and propelling • Understand how a loads attached to the back of the chair alters the stability of the wheelchair. • Holding object in one hand and pushing rim with wrist • Pushing alternate rims and changing object between hands • Holding object in one hand while using the other to push alternate rims 						
3. Gradients Push wheelchair up/down a ramp of 1:12 gradient: <ul style="list-style-type: none"> • Straight • Weaving 						
4. Flicking the castors: <ul style="list-style-type: none"> • When Static • Over tape • Over a rope • Onto foam mat • Onto 2" kerb While travelling over grass/uneven ground						
5. Facilitating an attendant going up and down a kerb i.e. being able to give instruction to:- <ul style="list-style-type: none"> • Approach the kerb • Flick the front castors • Push the rims while leaning forwards (Going up) • Reverse to edge of kerb • Lean forward • Feed rims through hands controlling wheelchair on dismount (Going Down) 						

ADVANCED SKILLS <i>NB: Advanced skills should only be completed with users who are independent in basic and intermediate skills</i>	Wheelchair user Independent		Risk Assessment Required		Skill N/A	Date achieved
	Yes	No	Yes	No		
1. Locate balance point. <ul style="list-style-type: none"> Establish point at which the w/chair is balanced with assistance. Bring castors to the ground in an emergency. Move between a deep and shallow balance with assistance. 						
2. Independent back wheel balance <ul style="list-style-type: none"> Maintain and control a back-wheel balance in a stationary position for 10 seconds. Move between a deep and shallow balance independently. 						
3. Self-protection <ul style="list-style-type: none"> Upright the wheelchair when falling backwards. 						
4. Travelling forward on a back wheel balance: <ul style="list-style-type: none"> back-wheel balance and move forward/backwards from a stationary position (5 meters). 						
5. Turning on a back wheel balance <ul style="list-style-type: none"> Back wheel balance in wheelchair and turn 360° in a full circle. 						
6. Back wheel balance and negotiate an obstacle course <ul style="list-style-type: none"> Negotiate a simple obstacle course using forward/backwards pushing and turning techniques on back wheels. 						
7. Go up a 4" kerb on back wheels						
8. Go down a 4"kerb: <ul style="list-style-type: none"> On back wheels Land on all 4 wheels 						
9. Back wheel balance and move forward over uneven ground: <ul style="list-style-type: none"> Sand Gravel Grass 						
10. Negotiate wheelchair in crowded situations (e.g. school/hospital/shops)						
11. Cross a road safely.						
12. Go down a slope on back wheels, <ul style="list-style-type: none"> Straight Weaving Stop ½ way and maintain a balance. 						
13. Breakdown the wheelchair. <ul style="list-style-type: none"> Remove wheels Remove armrests/footrests Fold wheelchair (backrest) 						
14.						
15. Get in/out of a car with an ultra-lightweight wheelchair.						

High performance /Ultra Light-weight Wheelchair Provision Risk Assessment

Wheelchair user:	
Referring Occupational Therapist:	

Justification for Ultra lightweight wheelchair provision:

Risk/s Identified:

Actions taken to minimise risk:
(should be agreed with Wheelchair Therapist before wheelchair is ordered)

Wheelchair User declaration: I _____ understand the above risks and have agreed the action to minimise these risks with my Occupational Therapist.

Signed:

Wheelchair User

Occupational Therapist

Date action agreed: _____

Review required YES/NO (delete)

Action for review: _____

