

Outpatients



The All Party  
Parliamentary  
Group on Spinal  
Cord Injury

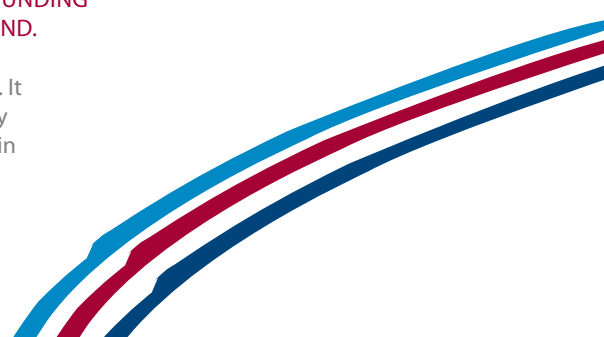


# A PARALYSED SYSTEM?

An Inquiry into the provision of local health services for people being discharged from Spinal Cord Injury Centres

**THIS REPORT WAS RESEARCHED BY THE SPINAL INJURIES ASSOCIATION WITH FUNDING PROVIDED BY THE SLATER AND GORDON HEALTH PROJECT AND RESEARCH FUND.**

This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House or its Committees. All-Party Parliamentary Groups are informal groups of members of both Houses with a common interest in particular issues. The views expressed in this Report are those of the Group.





# INDEX.

<b>3</b>	Foreword
<b>4</b>	Executive Summary
<b>5</b>	Key Recommendations
<b>7</b>	What is Spinal Cord Injury?
<b>8</b>	Spinal Cord Injury Centres
<b>12</b>	Part 1 - Delayed admission to a Spinal Cord Injury Centre
<b>16</b>	Recommendations for acute services
<b>17</b>	Part 2 - Delayed discharges
<b>26</b>	Recommendations for NHS Continuing Healthcare
<b>28</b>	Recommendations for Care Provision
<b>30</b>	Recommendations for equipment other than seating
<b>35</b>	Recommendations for wheelchair provision
<b>36</b>	Emerging initiatives to assist in reducing delays in discharge
<b>37</b>	Summary
<b>38</b>	Bibliography
<b>39</b>	Glossary
<b>40</b>	Appendix 1 – Contributors
<b>41</b>	Appendix 2 – Simplified flowchart of assessment for NHS CHC

# FOREWORD.

In the 1940s Sir Ludwig Guttmann, one of the pioneers of spinal cord injury (SCI) medicine, recognised that the treatment and rehabilitation of SCI people was best provided at a specialist SCI Centre. He believed that an SCI person should be supported by a specialist multi-disciplinary team for their initial rehabilitation, with a programme of life-long follow-up. For a long time this approach saw the UK at the forefront of SCI care.

However, in 2015 not everybody who sustains a spinal cord injury is able to access this high quality, specialist rehabilitation in a timely manner - if indeed at all – due to the increased pressure of blocked beds caused by delayed discharge.

Delayed discharges frequently occur due to prolonged negotiations over the provision of locally provided services such as NHS Continuing Healthcare, care packages and the provision of wheelchairs or specialist equipment such as ventilators.

These delays threaten to undermine hard won confidence of SCI people and undo many of the specialist skills they have learnt during their rehabilitation. Ultimately, they may impede the SCI person's ability to reintegrate successfully back into society.

Delayed discharges also have a considerable impact on those patients awaiting a bed in an SCI Centre. Prolonged waits for admission to a specialist centre have been shown to lead to increased risk of avoidable complications such as pressure ulcers, contractures and urinary tract infections. This in turn will result in longer lengths of stay in the SCI Centre and, most devastatingly of all, will often lead to poorer rehabilitation outcomes.

Whilst these issues can affect all SCI people, the situation is most acute in those with a high level of SCI and particularly those reliant on mechanical ventilation for their breathing.

Delays in admitting vented SCI people to the SCI Centres will, in turn, block critical care beds elsewhere in the health service, and impact other, non-SCI patients.

The All Party Parliamentary Group on SCI was instrumental in establishing Care Pathways for SCI people in 2013. For the first time, SCI people had a defined pathway of care which would map their journey from the point of diagnosis through to their discharge from a specialised SCI Centre. However, the pathways are increasingly hindered by a system which has created delays in returning SCI people to the community and freeing up vital capacity in the centres.

In the wake of increasing numbers of SCI people who are unable to access essential, specialised treatment in an SCI Centre, or receive suitable services to enable them to maximise their independence on discharge, the All Party Parliamentary Group on Spinal Cord Injury - supported by the Spinal Injuries Association - has conducted this Inquiry into the issues affecting the service.

I would like to thank all of the SCI people and their families, charitable organisations, health professionals and others who submitted their evidence and experiences to this Inquiry.



*Ian Lucas MP, Chair of APPG on Spinal Cord Injury 2008-2015*

# EXECUTIVE SUMMARY.

The UK's Spinal Cord Injury Centres form a highly specialised NHS rehabilitation service, which supports spinal cord injured (SCI), people from their initial injury and throughout their lives.

The capacity of the service to meet the needs of SCI people is increasingly threatened by bed blocking and delayed discharges. Such delays often result from protracted negotiations over local health services, such as wheelchairs and NHS Continuing Healthcare.

In the face of growing evidence that SCI people are finding it increasingly difficult to access the SCI Centre service, the All Party Parliamentary Group on SCI conducted an Inquiry into the effect that the provision of local health services is having on SCI Centres and the people they support.

The Inquiry found:

- A system paralysed by delays caused by the fragmentation of services, a lack of cohesion and poor communication between different organisations.
- A system clogged with patients awaiting discharge from SCI Centres but unable to leave due to delays in the provision of community services such as NHS Continuing Healthcare and equipment such as essential ventilators and wheelchairs.
- A system which is failing those with the highest level of need, particularly those reliant on mechanical ventilation for their breathing.
- SCI patients awaiting transfer from a general hospital for months on end before beds become available in SCI Centres, often acquiring additional complications such as pressure ulcers and infections.

- Considerable waste of resources and money in a system which denies SCI people timely access to an SCI Centre.
- Assessments and recommendations by specialist SCI Centre professionals being frequently ignored by Clinical Commissioning Groups with little experience of SCI.

## KEY RECOMMENDATIONS.

As NHS budgets for specialist services come increasingly under pressure, it is imperative that the Government acts now to ensure that the service is able to meet the needs of the 40,000 SCI people in the UK.

To achieve this, the All Party Parliamentary Group on SCI is calling on the Government to:

- Conduct an urgent service review to ensure that access to, and the capacity of, SCI specialist treatment and rehabilitation centres meet the demand of all SCI people.
- Mandate a prompt start to the assessment process for NHS Continuing Healthcare of SCI people that gives due regard to the judgement of NHS SCI health professionals.
- Ensure consistent and lawful decisions on NHS Continuing Healthcare eligibility that give due regard to key case law, particularly The Coughlan Judgement, given its unique and direct relevance to all SCI people.
- Monitor the delivery of NHS Continuing Healthcare by Clinical Commissioning Groups and impose sanctions on those that fail to deliver timely, consistent and lawful outcomes for SCI people.
- Eradicate the postcode lottery of wheelchair provision by bringing together community wheelchair services and SCI Centres to develop national guidelines on assessment, prescription and provision of wheelchairs for SCI people.
- Mandate a clear and consistent process for funding, ordering and delivery of appropriate equipment required for discharge into the community, including ventilators.





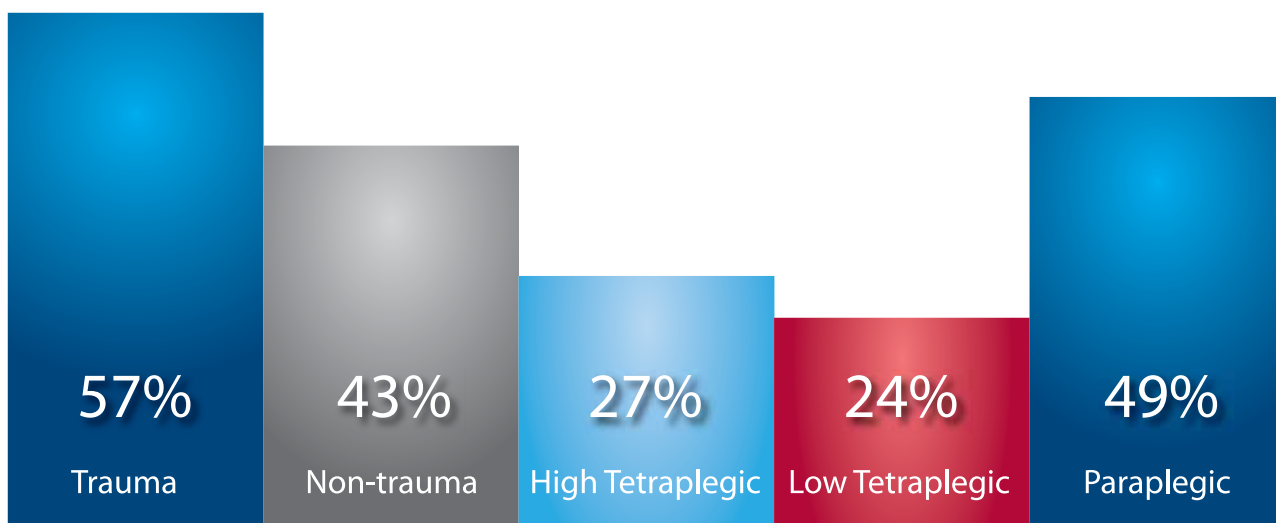
# WHAT IS SPINAL CORD INJURY?

Spinal cord injury (SCI) is a rare and complex condition affecting approximately 40,000 people in the UK. Damage to the spinal cord results in full or partial paralysis in either the lower limbs (paraplegia) or all four limbs (tetraplegia).

SCI causes all the systems of the body to function differently to those of a non-paralysed person, and lead to other issues such as loss of feeling, double incontinence and loss of sexual function. Tetraplegics with particularly high levels of injury may also lose the ability to breathe for themselves, relying on mechanical ventilation.

SCI can either be caused by trauma, for instance a fracture, or non-trauma such as a tumour or infection. In 2013/14<sup>1</sup>, the ratio of trauma to non-trauma and the level of injury were as illustrated in Figure 1.

**FIGURE 1.** Cause and level of injury for 2013/14.



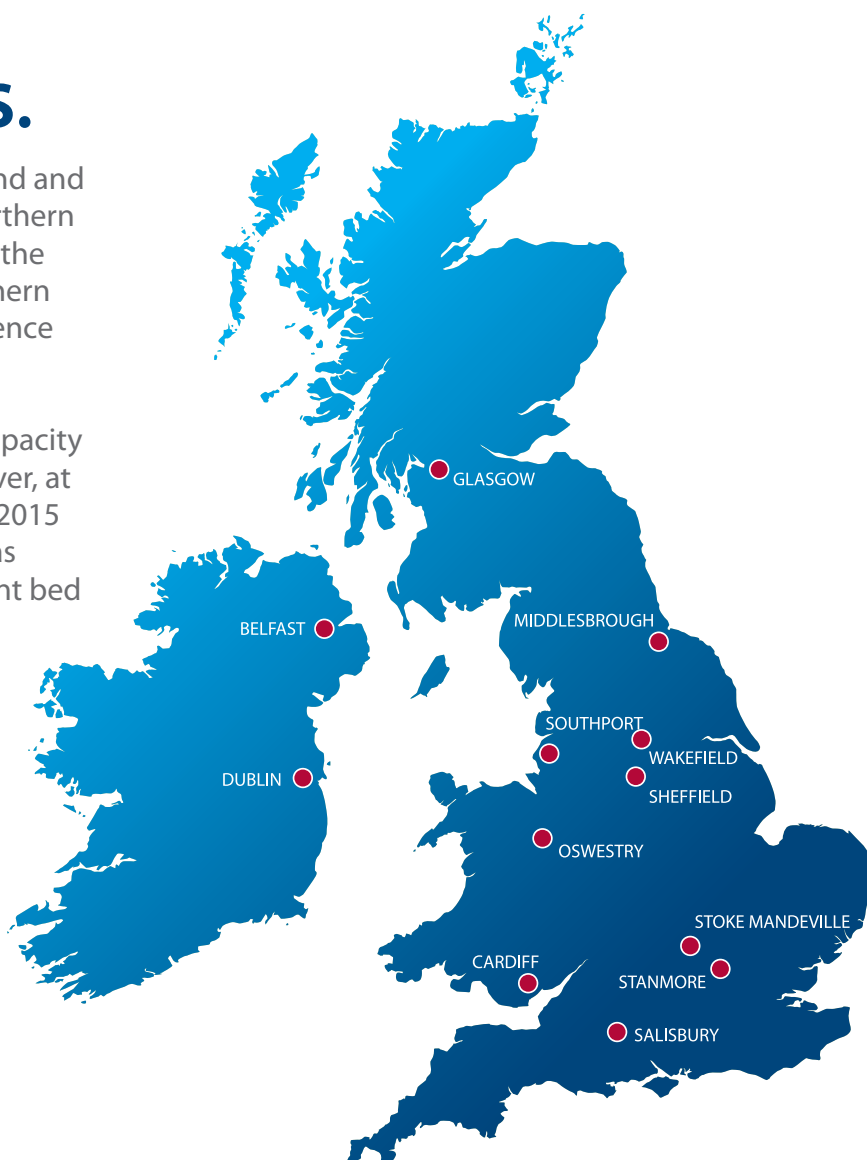
<sup>1</sup> National SCI Database



# SPINAL CORD INJURY CENTRES.

There are eight SCI Centres in England and one each in Wales, Scotland and Northern Ireland. As different systems govern the centres in Wales, Scotland and Northern Ireland, this Inquiry focuses on evidence relating to the situation in England.

The reported combined total bed capacity of all eight SCI Centres is 399. However, at an audit conducted on 27 February 2015 the number of beds closed was 24, as illustrated in Table 1, leaving a current bed capacity of 375.



**TABLE 1.** Current bed capacity across all eight SCI Centres in England.

	Oswestry	Wakefield	Middlesbrough	Stoke Mandeville	Southport	Sheffield	Stanmore	Salisbury	Total
Total capacity	44	32	24	115	46	62	34	42	399
Beds closed	0	0	0	12 <sup>1</sup>	0	8 <sup>2</sup>	0	4 <sup>3</sup>	24
<b>Current capacity</b>	<b>44</b>	<b>32</b>	<b>24</b>	<b>103</b>	<b>46</b>	<b>54</b>	<b>34</b>	<b>38</b>	<b>375</b>

<sup>1</sup> Beds closed due to staffing levels. Verbal confirmation of funding to re-open on 18/02/2015 but at the time of audit no formal offer received from Commissioners. Currently medical outliers occupy six of the spinal beds.

<sup>2</sup> Beds closed due to essential refurbishment to provide additional isolation facilities. New capacity will be 58 SCI beds (loss of four beds).

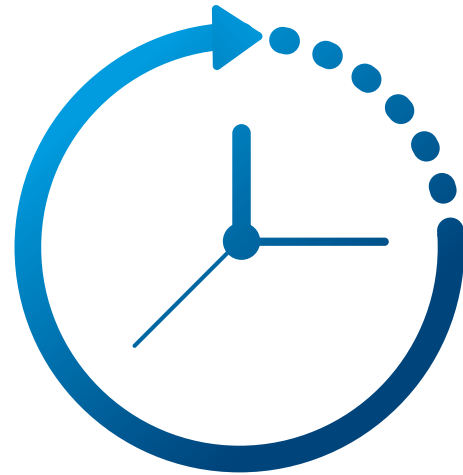
<sup>3</sup> Beds closed due to lack of nursing staff.

## The patient journey.

SCI Services are classified as specialised services and have been commissioned and managed by the NHS Commissioning Board, now NHS England, since 1st April 2013. In order to ensure that all SCI patients receive the specialist treatment and rehabilitation available in these specialist centres, National SCI Care Pathways were developed. They set out key milestones and the clinical, social and commissioning interventions, which are expected to occur within a given timescale (1).

Once someone has been diagnosed with an SCI, an electronic referral to an SCI Centre should be made via the National SCI Database, established in 2013. To facilitate the referral process each Major Trauma Centre is linked to an SCI Centre. The link SCI Centre may decide to make further referral to a second SCI Centre if thought appropriate, for instance where the initial link SCI centre may be a long way from where the patient resides, or where specialist services are required which are not available at all SCI Centres, such as paediatric services or ventilator-dependent care.

The recommended timescale set out in the National SCI Care Pathways is for telephone contact to be made with the linked SCI Centre within four hours of an SCI being diagnosed, in order to determine the optimum management of the patient; the decision on whether or not it is appropriate for the patient to be referred on to an SCI Centre should be made within 24 hours of the diagnosis of an SCI. Once a referral has been made, it is the responsibility of the link SCI Centre to provide ongoing advice and support via its Outreach Services, until the patient can be admitted to the SCI Centre. The Outreach Service is expected to make contact with the referring hospital within five days of the referral. Data for the year 2013/14 show that this standard was met in 72% of referrals made<sup>2</sup>.



- The SCI Centre should be contacted within 4 hours of diagnosis.
- Referral should be made within 24 hours of diagnosis
- Outreach visit should be made within 5 days of referral

<sup>2</sup>National SCI Database

## Current situation - access and capacity.

To determine the current situation relating to access and capacity, a snapshot audit was undertaken on 27 February 2015. Data was harvested from two sources:

- first from the National SCI Database to inform the present situation regarding the number and details of patients referred to an SCI Centre
- second from the eight SCI Centres to establish the bed capacity of each centre on this date.

On 27 February 2015, the total number of patients who had been referred to an SCI Centre was 118. The time from injury to contact with the link SCI Centre and the time from injury to referral are outlined in Table 2.

**TABLE 2.** Time from injury to contact with SCI Centre and from injury to referral.

	Minimum	Maximum	Median
Date of injury/ contact with SCI Centre	0	174 days	6 days
Date of injury/ date of referral	0	176 days	8 days

Contact with an SCI Centre was made on the day of injury for nine out of the 118 patients listed. Delay in contacting an SCI Centre may be due to difficulty in diagnosing the SCI because of the condition of the patient. However, once contact had been made, the patient tended to be referred very quickly.

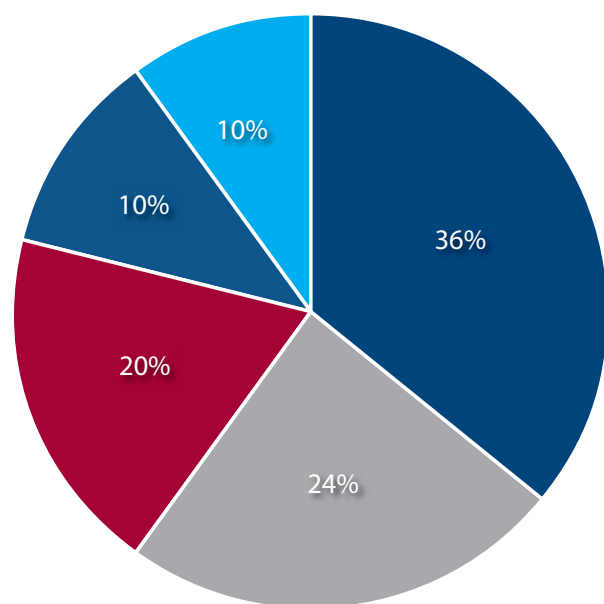
**78% of patients referred on the same day SCI Centre was contacted**

For 92 out of the 118 patients (78%), the referral was made on the same day that the SCI Centre was contacted. Referral was made within one week of injury for 56 patients (47%) which is consistent with data for 2013/14 (49%).

It is important to realise that although a referral has been made, this does not mean that the patient has been accepted for admission to an SCI Centre.

Following the referral and consultation with the link SCI Centre, an Outreach visit will help to determine whether or not the patient is suitable for admission to the link SCI Centre. The referral status of the 118 patients is illustrated in Figure 2.

**FIGURE 2.** Referral status of 118 patients on the National SCI Database on 27 February 2015



- 36% Additional information requested before decision on admission suitability (N=42)
- 24% Accepted for admission when bed is available (N=28)
- 20% Accepted for admission but clinically unfit for transfer (N=24)
- 10% Not accepted for acute admission but suitable for outreach or out-patient services (N=12)
- 10% Other (N=12)

The distribution of the 94 patients who had been accepted for admission, or were potentially suitable for admission subject to further information, is illustrated in Table 3 according to referral status and link SCI Centre.

**TABLE 3.** Referral status and link SCI Centre for the patients potentially suitable for admission.

Referral status / SCI Centre	Oswestry	Wakefield	Middlesbrough	Stoke Mandeville	Southport	Sheffield	Stanmore	Salisbury	N
<b>Accepted for admission when bed is available</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>5</b>	<b>13</b>	<b>7</b>	<b>2</b>	<b>28</b>
Accepted for admission; clinically unfit for transfer	4	3	0	4	1	6	2	4	24
Additional information requested	0	1	0	9	1	6	17	8	42

According to this snapshot audit, three SCI Centres had no patients waiting for admission (Oswestry, Middlesbrough and Stoke Mandeville) whereas the Sheffield centre had 13 delayed admissions. For the 28 patients with delayed admission across all the centres, the time from referral to snapshot ranged from 3 – 100 days with a median delay of 8 days (mean 30). Data from the National SCI Database for the year 2013/2014 reveals that the time from referral to admission ranged from 0 – 279 days with a median delay of 14 days (mean 24).

The number of delayed admissions taken as a proportion of the capacity might be considered indicative of the pressure on any one centre, for instance the 13 patients accepted and ready for admission to the Sheffield centre constitute a quarter of its current capacity (54).

In 2013/14 the time from referral to admission to SCI Centre: 0 - 279 days

# PART 1 - DELAYED ADMISSION TO A SPINAL CORD INJURY CENTRE.

## The effect on the patient....

**“ In eight months there must have been 30 people die in my four bedded bay ”**

*(SCI patient in intensive Care Unit, submitted by Respiratory Team, Sheffield)*

The effect on waiting for a bed in an SCI Centre on the individual and their family can be profound, particularly if the waiting occurs in an Intensive Care Unit. Patients are often in a high state of uncertainty about their prognosis, feeling overwhelmed by unanswered questions. For all patients awaiting a place in an SCI Centre, there is the fear of losing a ‘window of opportunity’, that the wait will adversely affect their potential functional outcome. This fear is not entirely unfounded, as evidence suggests that delay in admittance to an SCI Centre can lead to an increased risk of acquiring avoidable complications, such as pressure ulcers, contractures and infections. These secondary complications are not only an additional health hazard to the patient, they have also been shown to result in longer lengths of stay and present a real risk to the functional outcome for the patient. Data from the National SCI Database shows that for the period 2013/14, 8% of patients with delayed admission to an SCI Centre had a history of pressure ulcers; a situation that is completely avoidable with appropriate care.

Delay in admission to an SCI Centre frequently leads to psychological issues such as increased levels of anxiety, which often eases once the individual can engage in the rehabilitation process in the specialist centre. It brings with it more clarity for patients about their rehabilitation potential and prognosis. Remaining in a non-specialist facility makes it more likely that the patient remains in a higher state of anxiety and uncertainty for longer, which is detrimental to their well-being. Being cared for and treated by SCI specialists is likely to make the patient feel safe and reduce anxiety (2).

This is particularly evident for the ventilator-dependent patients. Not all ventilator-dependent patients will be suitable for weaning off the ventilator. The special interest group, Respiratory Information for Spinal Cord Injury (RISCI), has produced guidelines to assist professionals in non-SCI Centre settings in the weaning process ([www.risci.org.uk](http://www.risci.org.uk)). However, the evidence submitted to this Inquiry suggests that assessment for weaning off the ventilator is frequently deferred until a suitable bed is found outside of the Intensive Care Unit environment. This delay potentially deprives the patient not only of independent breathing but also of swallowing and speech. It may also reduce the potential for future interventions such as diaphragmatic pacing (electrical stimulation of the diaphragm to enable independent respiration) as the diaphragm has become de-conditioned through prolonged mechanical ventilation.

Depriving somebody of speech unnecessarily is devastating to the individual but also to the family.

**8% of patients with delayed admission to an SCI Centre had a history of pressure ulcers**

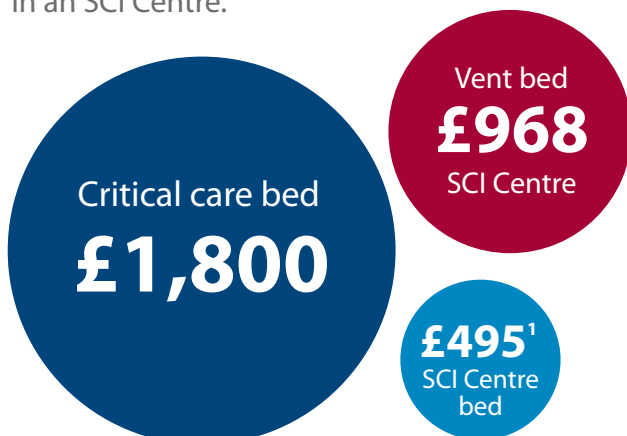
## The effect on the family....

This Inquiry heard evidence from the wife of a young father of three, AB, with a high cervical SCI and ventilator dependent, who had to wait 14 months before finally getting a bed in an SCI Centre. Whilst in non-specialist care, AB had been told that his situation would not change and that he would remain ventilator dependent for the rest of his life, without independent speech or ability to eat. It was the complete inertia, the inability to explore AB's potential and lack of stimulation and engagement with AB that had the most profound effect on Mrs AB:

*"I can cope with lack of movement in his arms and legs ... it does not bother me. It is the lack of speech and the lack of being able to eat with the family that bothers me the most. They are the things that make a human. They are the things that make you a family and, you know, with 3 kids he wants to be able to take them to McDonald's and have food. He wants to be able to speak to them and ask them how their day has been and nobody wanted to seem to want to try to resolve that and yet, upon entrance into [the SCI Centre], it is completely different. Their whole attitude is completely different. They focus on him, he is the patient, he is the one that they tell the information to."*

## The cost of delayed admission.

There is considerable difference in the cost of beds in a Critical Care Unit compared to beds in an SCI Centre.



<sup>1</sup> Cost of SCI Centre bed £495 - £554

"Today (September 16 2014) we have a patient on a ventilator on general adult intensive care who has been waiting for a ventilated bed on the spinal injury unit since July 2014.

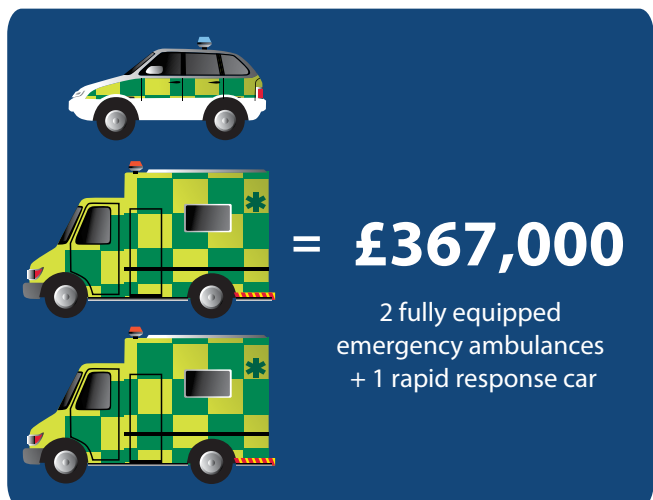
Cost to date:

60 days @ £1,800 = £108,000 compared to  
60 days in SCI Centre @ £968 = £58,080.  
Waste to the NHS = £49,920"

Critical Care Consultant, Sheffield



As not all the SCI Centres are able to support patients who are ventilator dependent, the waiting time for a bed can be very long. In a review carried out at the Sheffield SCI Centre between May 2012 and September 2014, fifteen ventilator dependent patients were admitted to the centre. The average waiting time for admission to the centre was 100 days, the maximum was 286 days. The total waiting time for all 15 patients was 1,505 days. It was estimated that it cost the NHS £367,220 more to care for these patients in a Critical Care Unit than a specialist ventilator bed in the SCI Centre.





An audit carried out by the SCI Centre at Stanmore over a three-month period in 2010 looked at ventilated patients in, or waiting to be admitted to, the SCI Centres at Stanmore, Stoke Mandeville and Salisbury. At the beginning of the audit seven patients were waiting for admission; at the end of the audit period this had risen to 10. For newly-injured patients admitted during the audit period, the time from referral to admission ranged from 0 days to over six months with a mean average of 58 days.

A critical care consultant from Sheffield submitted data on eight ventilated SCI patients admitted to the Critical Care Unit over the previous 24 months. Of the eight patients, six were transferred directly to the link SCI Centre after a length of stay in the Critical Care Unit ranging from 16 – 164 days. Due to pressure on beds in the Critical Care Unit, two patients were transferred to a District General Hospital (DGH) awaiting onwards transfer to the SCI Centre. One patient stayed in the Critical Care Unit for 72 days and a further 244 days in the DGH before being admitted to the SCI Centre. The other was transferred to the DGH after 43 days and had waited 28 days for a bed in the SCI Centre at the time of submission.

### Current capacity status for ventilator dependent patients.

The question of capacity for ventilator dependent patients was raised in the written as well as the oral evidence to this Inquiry. The snapshot audit on 27 February 2015

helped to inform the Inquiry about the current capacity for patients requiring full mechanical ventilation. This data was compared to the waiting list data harvested from the National SCI database on the same day.

The number of beds occupied by patients needing mechanical ventilation across all eight SCI Centres on February 27 2015 is illustrated in Table 4.

**“ Depending on associated injuries, it is estimated that most ventilator dependent patients can be stabilised and ready for discharge from the Critical Care Unit within 14 days of injury ”**

*Critical Care Consultant*

The capacity across all eight centres for fully-ventilated patients was 28. No beds commissioned as ventilator dependent beds were reported closed, although one ventilator-dependent bed at Stoke Mandeville was reported to be used by a non-SCI vented patient.

**TABLE 4.** Ventilatory capacity across all eight SCI Centres in England on 27 February 2015

	Oswestry	Wakefield	Middlesbrough	Stoke Mandeville	Southport	Sheffield	Stanmore	Salisbury	Total
Number of Beds	0	0	2	6	9	6	2	3	28



Of the 118 patients on the referral list, 15 were recorded as requiring mechanical ventilation. One ventilated patient was deemed to be unsuitable for admission but was accepted for Outreach Services. Table 5 illustrates the referral status of the remaining 14 patients with their respective waiting times measured as the time from referral to the date of data collection (27 February 2015).

**TABLE 5.** Referral status and waiting time for patients requiring mechanical ventilation (N=14)

	Number of Patients	Waiting Time
Accepted for admission when bed is available	2	15- 94 days
Accepted for admission but clinically unfit for transfer	8	8 - 73 days
Additional information requested	4	1 - 37 days

Data for the period 2013/14 indicates that 34 patients were fully ventilated on admission to the SCI Centre. The time from referral to admission for fully ventilated and non-ventilated patients is illustrated in Table 6.

**TABLE 6.** Time from referral to admission for fully ventilated and non-ventilated patients in 2013/14

	Referral - admission	Median delay	Mean delay
Ventilated patients (N = 34)	0 - 164	20 days	33 days
Non-ventilated patients (N = 761)	0 - 279	13 days	24 days

Part 1 of this report has outlined the intense pressure on the SCI Centre beds and the sometimes excessive waiting times for admission to an SCI centre in England. The situation is most acute for patients dependent on mechanical ventilation due to the limited number of dedicated beds for ventilator-dependent patients in SCI Centres. This also effects critical care bed capacity for other, non SCI patients outside of the SCI Centres.

## RECOMMENDATIONS FOR ACUTE SERVICES.

- NHS England to support a formal, full service review of SCI services.
- NHS England to conduct an urgent review of nationwide capacity for ventilator dependent patients with SCI.
- SCI Centres to actively promote and support cuff-down ventilation in Intensive and Critical Care Units to facilitate communication and feeding, according to RISCI guideline.



## PART 2 - DELAYED DISCHARGES.

**“ Nearly every discharge is a struggle for community cohesion and agreement: referrals passed round community teams within area leading to delays in vital assessments “**

*(Submitted by SCI Centre, Salisbury)*

The delay in admission to an SCI Centre is closely linked to difficulties associated with discharging other patients back into the community in a timely fashion.

### Scale and cost of delayed discharges.

The National Spinal Injuries Centre at Stoke Mandeville Hospital records numbers of delayed discharges weekly. The target is for a maximum of 6% of rehabilitation patients being delayed at any one time. In 2014 the maximum reached was 11% for a period of 4-5 months.

An audit of 43 patients at Stoke Mandeville with delayed discharges in 2012 revealed that the total number of lost bed days was 2,910.

**2,910 bed days =  
6 months rehabilitation stay in  
an SCI Centre for 16 patients**

Sheffield SCI Centre submitted evidence based on discharges over the previous six months for non-ventilator dependent patients with SCI and over 18 months for individuals with SCI requiring ventilatory support.

The maximum delay in discharge for a non-ventilated patient was 85 days representing an additional cost burden of £47,090.



For ventilator-dependent patients the delays in discharge ranged from 14 – 232 days. The cost burden of these delayed discharges is illustrated below.

Shortest delay – 14 days (@ £968 = £13,552)  
Average delay – 106 days (@ £968 = £102,995)  
Longest delay – 232 days (@ £968 = £224,576)

## Current situation – delayed discharge.

The snapshot audit on 27 February 2015 established the number of patients waiting to be discharged across all eight SCI Centres. The numbers in Table 7 are given as a fraction of the current capacity and in percentages. In total, 28 patients were recorded as being delayed in their discharge.

**TABLE 7.** Number of patients recorded as delayed discharge for each SCI Centre (N=28).

	Oswestry	Wakefield	Middlesbrough	Stoke Mandeville	Southport	Sheffield	Stanmore	Salisbury	Total
Delayed Discharges / SCI Centre capacity	1/44	4/32	0/24	7/103	5/46	4/54	1/34	6/38	28/375
% of capacity	2.2%	12.5%	0%	6.8%	10.9%	7.4%	2.9%	15.8%	7.5%

For the period 2013/14, a total of 125 patients were recorded as delayed discharge (> 14 days) – a third of the total bed capacity for England.

## Reasons for delayed discharges.

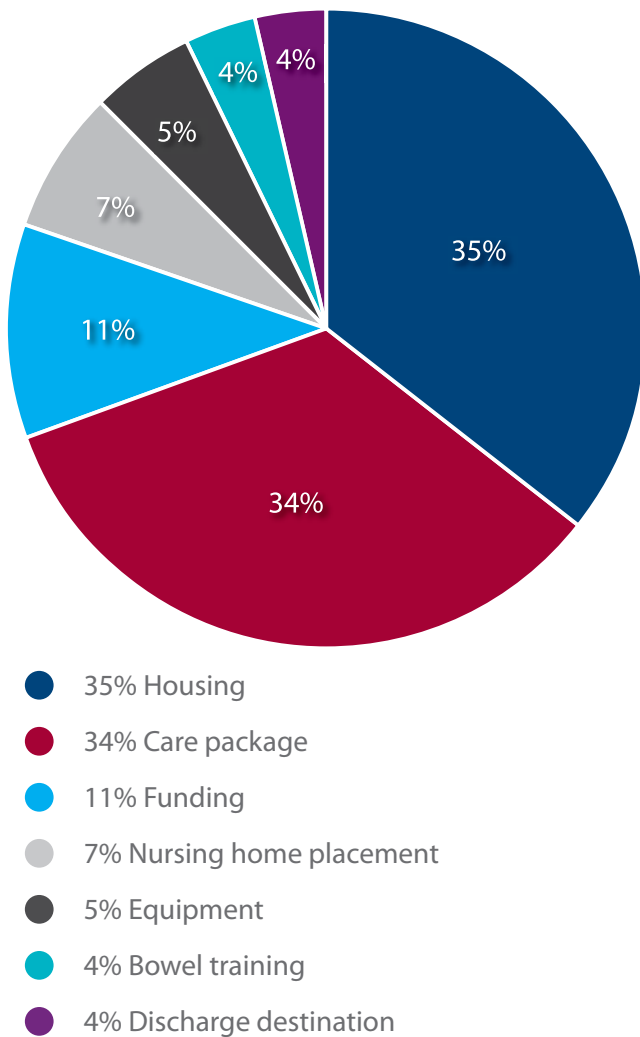
The reasons for delayed discharge can be many and may be inter-related. Housing is frequently cited as a main cause of delay in discharging an individual from an SCI Centre. As this comes under the responsibility of the Local Authority and not the Clinical Commissioning Group (CCG), it falls outside of the remit of this Inquiry. It is, however, relevant to consider housing when looking at other issues that have been raised relating to the overall assessment of an individual's needs and the provision of services to meet these needs on discharge from an SCI Centre.

### On 27 February 2015

- 28 individuals had been accepted and were fit for admission to an SCI Centre
- 28 patients were delayed in their discharge from a SCI Centre

The reasons for the delay in discharging the 28 individuals identified in the snapshot audit are illustrated in the chart below. One individual was delayed due to problems with both care package and equipment.

**FIGURE 3.** Reasons for delayed discharge from SCI Centre (N=28)



From the evidence submitted to this Inquiry, the three main themes concerning the causes for delayed discharge were very clearly identified as:

- Assessment for NHS Continuing Healthcare funding
- Care package and care provision
- Equipment provision, especially wheelchairs

## NHS Continuing Healthcare.

When care and support is required to enable an individual to live independently in the community, this care can be funded either through social services or through NHS Continuing Healthcare (CHC). Social care is funded by the Local Authority and subject to means testing, which is not graduated. In other words, even when a person has substantial levels of care need, they may not be entitled to any support from social services if they fail the means testing. NHS CHC is funded by the Clinical Commissioning Groups (CCG) and, as with other NHS services, is not means tested and free at the point of delivery.

The process of deciding whether the individual is the responsibility of the NHS or social services involves dividing their care interventions into “health” care needs or “social” care needs. There is no clear legal definition of the difference between social care needs and healthcare needs – generally speaking social care needs can be described as relating to activities of daily living, maintaining independence and social interaction and participation, whereas healthcare needs are seen as relating to the treatment, control or prevention of an illness, injury or disability. In the oral evidence session it was pointed out that this divide between ‘social’ and ‘health’ is essentially an artificial divide when it comes to determining somebody’s needs.

**Example of the artificial divide between ‘social’ and ‘health’ needs:**  
 ‘Eating and drinking’ = social need;  
 ‘Nutrition’ = health need

It is important to establish that the dividing line of the responsibilities of social services and the NHS is not a matter of policy. It is a matter of law. In 1999 the Court of Appeal clarified this dividing line in the Coughlan Judgement by ruling that there is a lawful limit to the “health” care that can be provided by a Local Authority. If the “health” elements of an individual’s care are assessed to be beyond what a local authority can lawfully provide, what is known as a ‘primary health need’, that individual is entitled to free NHS CHC. This remains the underpinning legal principle of eligibility for NHS CHC.

The Coughlan Judgement is particularly significant for SCI individuals because Pamela Coughlan is a C5/6 complete tetraplegic with no significant additional health needs. Furthermore SCI is almost unique amongst long-term conditions in that, with ‘complete’ injuries (i.e. complete loss of movement and feeling below the level of the injury) it is possible to make direct comparisons between the level of disability and care need of individuals based on the neurological level of their injury.

The Court found that Pamela Coughlan has “health” care needs that require services ‘of a wholly different order’ to those that a local authority can lawfully provide. In other words, she is not a “borderline” case when it comes to eligibility for NHS CHC funding, but rather she falls well within the responsibility of the NHS. It would therefore be expected that other tetraplegics who present with similar “health” care needs would also be eligible for NHS CHC.

Eligibility for NHS CHC is determined through a strict assessment process, which is described in the National Framework for NHS Continuing Healthcare (3). The evidence submitted to this Inquiry highlighted several problems with this process:

### **1. Timeliness of assessment.**

The National Framework states that eligibility for NHS CHC is not based on diagnosis and that the assessment should be undertaken

when the individual’s needs on discharge can be clearly defined (paragraph 68). In effect, this means that the assessment may not start until a definitive discharge date is set, which may only be a month before the actual discharge. A simplified flowchart of the whole assessment process can be found in Appendix 2.

According to the National Framework, the whole process from referral to eligibility decision should not exceed 28 days (paragraph 95). The reality is very different.

Seven SCI Centres in England submitted data relating to the discharge planning of 63 patients from 55 different CCGs:

- 33% of the NHS CHC assessments met the 28 day standard for completion
- 31 out of the 63 patients were recorded as delayed discharge
- Maximum delay was 371 days
- Total number of bed days wasted for the 31 patients = 2,553 days

All the SCI Centres who submitted evidence to this Inquiry assert that in the case of an individual with a complete SCI, the non-improving nature of the condition and the experience of the multidisciplinary team in the SCI Centre enables the team to predict the likely care needs very early on in the rehabilitation process. This may be as early as within the first week of admission to the centre. The frustration of the SCI Centres is that this is rarely accepted by the CCGs, who continue to insist on deferring the assessment until the patient is essentially ready for discharge months later. This blatant disregard for the universal consensus of opinion of highly specialised and experienced teams of health professionals, is held to be wholly unacceptable.

The evidence submitted by the SCI Centres highlights how simply referring somebody for this assessment can be delayed due to great difficulty in identifying the responsible individual within the CCG. In total there are 211 CCGs in England. It is an issue for all the SCI Centres that they deal with numerous CCGs at any one time. This is particularly so for the larger centres. This situation is compounded by some CCGs having 'subcontracted' the responsibility for CHC assessments to Clinical Support Units, who are third party organisations contracted to the CCGs. As was pointed out in the oral evidence, this adds a layer of opacity to a process that should be very transparent.

## **2. Inconsistency in the application and interpretation of the assessment tools.**

The two assessment tools mandated by the Department of Health, the Checklist and the Decision Support Tool, are intended to assist the assessors in establishing whether the level of health care needs of the individual places them beyond the level of care a Local Authority can lawfully provide.

When the referral has been accepted, it is the responsibility of the CCG to appoint a co-ordinator whose role it is to oversee the actual assessment process. The assessment itself may take place either in a hospital setting or in the community, but the evidence suggests that it is most commonly carried out in the SCI Centre. Where the CCG insists on having their own assessors carry out the assessment, it has a responsibility to ensure that they are made available to attend without undue delay.

The CHC assessment process involves looking at the individual's care needs across 12 broad areas of care known as domains. It is a two-stage process:

The first stage is an initial screening tool known as a checklist. This is intended to establish whether the individual should be put forward for a full assessment. The threshold for triggering a full assessment has been

set intentionally low (paragraph 72) in the National Framework, but there is evidence that CCGs are insisting on substantial additional documentation at this stage, effectively making it a de facto full assessment. It should also be noted that the Checklist stage is not mandatory and CCGs could move straight to a full assessment.

The second stage is a full assessment using the Decision Support Tool. This is a detailed look at each of the domains where the individual is scored and the level of need is identified as No Need, Low, Moderate, High, Severe or Priority. Unfortunately, there is evidence of huge variance in how these domains are scored. Despite clear guidance that assessors should not use the scores mechanistically but use their professional judgement to ensure decisions that are consistent with past ombudsman and court decisions, particularly the Coughlan Judgement, this variance has the devastating and potentially unlawful consequence for the individual of not being found eligible for CHC. This is due to variations in the level of experience and understanding of SCI by CCG assessors and of NHS CHC by SCI Centre professionals, or entrenched attitudes that have a mindset of ineligibility of need for all but the most morbidly ill individuals.

The National Framework states quite clearly that the assessment for NHS CHC eligibility should be carried out by a multi-disciplinary team of at least two professionals who have an up-to-date knowledge of the individual's needs, potential and aspirations. In the case of somebody undergoing rehabilitation in an SCI Centre, this would clearly point to the team of professionals working with the individual in the SCI Centre. However, CCGs are not obliged to 'appoint' this team as the multidisciplinary team and can use their own professional assessors to conduct the assessment, although it is unlikely that they could meet the multidisciplinary team definition above.



Where it is the case that the SCI Centre team is used and their recommendation is accepted by the CCG, delays in the process are significantly reduced. The evidence suggests that more commonly the SCI Centre teams carry out the assessment and submit their recommendations to the CCG, who then, despite clear guidance in the National Framework that they shouldn't question the recommendation (paragraph 91), insist on conducting their own assessment, often with the same result. The Inquiry also heard how in some cases CCGs will not engage at all with the professionals in the SCI Centre and insist on their own representatives conducting the assessment, even though they may have very little experience of SCI and not be familiar with the individual.

It is the view of NHS England's Clinical Reference Group for SCI that the CCGs should either accept the assessment recommendation from the SCI Centre, or ensure that staff are available to attend the assessment together with the SCI professionals.

As stated, the National Framework gives clear direction that assessors must not use the assessment tools mechanistically but must use their professional judgement when deciding on CHC eligibility. The experience of the discharge teams in the SCI Centres and the Spinal Injuries Association (SIA) is that the extent to which assessors use professional judgement shows limited and patchy understanding of SCI and the complexity of the associated healthcare needs.

This is particularly apparent when it comes to so-called 'well-managed needs'. SCI can be described as a non-improving and complex condition. It involves all body systems and has complications which are unpredictable and potentially life threatening in nature if not managed appropriately. However, the occurrence of these complications can be minimised with good care. The Inquiry heard how all too often the absence of complications is interpreted by CHC assessors as the absence of need.

## Absence of complications does NOT mean absence of need

A classic example is Autonomic Dysreflexia (AD) which is a condition almost unique to individuals with an SCI lesion at or above mid-thoracic (T6) level. AD is defined as "an unpredictable, potentially life-threatening condition whereby there is sudden, rapid and un-controlled increase in blood pressure..... and is triggered by an acute pain or some other noxious or non-noxious stimulus experienced below the level of the spinal cord injury"<sup>3</sup>.

All too often assessors insist that unless there is historical evidence of an episode of AD, they refuse to accept that the individual is susceptible.

**" 52yr old, male, C5 tetraplegic, at risk of Autonomic Dysreflexia and with PRN medication in case of AD episode; also had severe weight loss and nasogastric tube for overnight feeding, although also eating small amounts with encouragement during the day. Both aspects scored as 'low' and did not get CHC funding. "**

*(Submitted by SCI Centre, Middlesbrough)*

<sup>3</sup> 'A Statement on Autonomic Dysreflexia' by BASCIS, MASCIP and SIA ([www.spinal.co.uk/page/statement-on-AD](http://www.spinal.co.uk/page/statement-on-AD))

To illustrate the significance of 'well managed needs' in respect of SCI, the Inquiry heard how life expectancy for people with SCI has improved dramatically since WW2. When the first SCI Centre opened at Stoke Mandeville Hospital under Sir Ludwig Guttmann, universally recognised as one of the pioneers of SCI medicine and rehabilitation, surviving even the first year with an SCI was rare. The causes of death related primarily to urinary tract complications and renal failure (4;5). The dramatic improvement in life expectancy is not only due to advances in the treatment of the SCI itself, but also very much due to better understanding and management of the consequences of the multi-system trauma that is SCI. In other words, while a cure for SCI has not been developed, people are surviving substantially longer following SCI because of the improvement in managing their care needs and preventing complications.

The inconsistencies highlighted in this section of who conducts the assessment and how the assessment tools are applied and interpreted clearly compromise the individual's access to a fair and equitable assessment. Instead of being placed at the centre of the assessment and decision-making process, vulnerable individuals with SCI find themselves subject to an almost random mechanism for one of the most significant determinations of their eligibility for care funding. It also creates delays in the assessment process and in many cases, wastes scarce resources by duplication of effort.

### 3. Funding decision.

In order to assist them in their decision making, the CCGs often request significant amounts of additional supporting evidence. This can add greatly to the time taken to complete the decision-making process. Whilst SCI Centre staff are happy to submit all relevant professional documentation, endlessly ongoing requests for further evidence and information are perceived as unfounded and unhelpful. At best, they are seen as delaying tactics and at

worst, deliberate attempts by the CCG to pressurise the SCI Centre staff to change their recommendation on NHS CHC eligibility.

In this context, it should be pointed out that the National Framework states that:

**“ Only in exceptional circumstances and for clearly articulated reasons should the recommendation of the multidisciplinary team **not** be accepted by the CCG ”**

*Paragraph 91, National Framework for NHS Continuing Healthcare*



Where the individual is found to be ineligible for NHS CHC funding, the decision can be appealed. However, the appeals process is lengthy, commonly taking three to six months to complete. Hence there is a de facto disincentive for SCI Centre staff to appeal as it will simply add to delays in transfers of care.

It was reported in the oral evidence session that there seems to be an emerging trend for CCGs to 'fund without prejudice' to allow the individual to be discharged home or into an interim placement such as a Nursing Home. A full assessment will then be carried out 12 weeks later at which point, it is argued by CCGs, it will be easier to get a full picture of the individual's care needs. This directly contradicts the non-improving nature of SCI which enables the SCI Centre team to predict ongoing care needs early on in the rehabilitation process. In addition, concern was expressed that this approach could potentially put the individual in a very disadvantaged and vulnerable position, as the eventual assessment is very unlikely to have any input from the professionals from the SCI Centre at that stage.

It has been suggested that having skilled and specially trained Patient Advocates could support the patient and their families throughout this process and help provide continuity.

It is clear from the evidence that the local variation in how the assessment tools are applied and the lack of understanding and experience of SCI by most assessors is resulting in serious inconsistency in eligibility decisions across CCGs. In other words, SCI people with similar levels of disability and need are receiving different eligibility decisions depending on where they live.

It would also appear that the 'eligibility bar' for NHS CHC is being set higher than that laid down by the Court of Appeal in the Coughlan Judgement of 1999. However, the National Framework and assessment tools are only Government 'guidance' and as such, they cannot override the law as interpreted by the Court. Unfortunately, 'proving' that this is the case is extremely difficult, not least because no data was available from NHS England regarding:

- the proportion of referrals being accepted for full assessment
- the proportion of those assessed found eligible for funding
- the proportion of those found ineligible who appeal the decision
- the proportion of decisions of ineligibility overturned at appeal
- any 'condition specific' information

However, the unique nature of SCI that enables close comparison of individuals with similar neurological levels of injury and the strength of the Coughlan Judgement provides clear insight into flawed assessments and eligibility decisions.



Where the individual is found to be in-eligible for full NHS CHC funding, the decision may be taken to provide care jointly between the NHS and social services. This frequently leads to disputes over who funds each element of the care package, leading to delays as seen from this example:

*“51yr old, T7 paraplegia. Admitted with severe pressure sores requiring surgery and then complete bed rest for 3 to 4 months. Needed to be discharged to a nursing care home for bed rest. Decision Support Tool took place within 9 days of referral but disagreement over funding. The subsequent dispute between CCG and social services went on for 3 weeks with the patient remaining in an acute hospital bed”*

*(Submitted by SCI Centre, Middlesbrough)*

The evidence paints a picture of a constant opening and closing of a case as it is passed between health and social service teams depending on where it is in the process for funding and planning. At the heart of each of these cases is an individual coming to terms with a life-changing injury.

**“ One referral for a Community OT has been passed to eight different health/social care teams in Wiltshire since 1st of July 2014 and still an access visit has not been completed ”**

*(Submitted by Salisbury SCI Centre, September 2014)*

#### **4. Care Package Commissioning.**

The Inquiry heard that there is a separation between the CCG teams responsible for making NHS CHC eligibility decisions and

those teams responsible for commissioning care packages. It is common for the case to be closed by the NHS CHC team once eligibility has been decided but not necessarily passed on to the team with responsibility for commissioning the care package in preparation for discharge. In some cases, the different systems used by the different CCG teams led to the commissioning team requesting yet another assessment before deciding on the appropriate care package. Time and again it would seem that the SCI Centre professionals are left with the frustrating and time-consuming task of identifying the appropriate team to keep the process going.

#### **5. Accountability.**

The frustration of not knowing how to hold the CCG to account when they breach the National Framework was clear in much of the evidence. Although NHS CHC appears on the CCG Quality Surveillance agenda, the absence of data on the performance of the CCGs makes it impossible to monitor their performance. This Inquiry heard how NHS England can only advise and encourage the CCGs to adhere to the National Framework.

It would appear that at present, nobody has the mandate to sanction CCGs if they do not deliver on their lawful obligations in respect of NHS Continuing Healthcare.

It is the responsibility of the NHS England Area Teams to assure the delivery of NHS CHC by CCGs, but as it has not been effectively addressed through the Quality Surveillance process this has not happened. NHS England has now developed an Operating Model and Assurance Framework to improve the implementation of NHS CHC across the country. Key to the success of these improvement tools is placing NHS CHC firmly on the CCG Quality Surveillance Framework. It is the intention that at least twice a year the Area Teams will have data available in order to assess the performance of the CCGs with regard to assessments for CHC funding.

The question of charging the CCGs, if a delayed discharge is due to them, was raised in the oral evidence session. The NHS England Service Specification for Spinal Cord Injuries states that non-clinical delayed discharges are not classified as specialised service and are therefore chargeable to the CCG. It appears that not all SCI Centres are aware of this and where they are, it is not clear how to charge for this. It was suggested that NHS England would be able to impose this through the 'Payment by Results Framework', which governs the contracting and the pricing of contracts across the NHS and the national tariff system for payment.

## RECOMMENDATIONS FOR NHS CONTINUING HEALTHCARE.

- NHS England must develop an improved system for identifying the individuals responsible for NHS CHC assessments and care commissioning within individual CCGs.
- CCGs must accept early referrals for NHS CHC assessments where the consensus view of the SCI Centre professionals is that the individual's long-term clinical outcome is clear.
- NHS England must develop agreed timeframes for each step of the assessment and care planning process.
- CCGs must either accept the assessment and recommendations from the SCI Centre Multidisciplinary Team or ensure that their staff are available to attend the assessment together with SCI professionals.
- CCGs must not overburden SCI Centre Multidisciplinary Teams with demands for excessive additional information on top of the national assessment tools.
- CCGs must not dismiss 'well-managed needs' because of the absence of historical complications related to the need.
- CCGs must make NHS CHC eligibility decisions that are consistent and lawful, particularly in line with the Coughlan Judgement, recognising its unique and direct relevance to all SCI people.
- NHS England must develop the CCG Assurance Framework to monitor the quality and consistency of CCGs delivery of NHS CHC across the country.
- NHS England must bring clarity to the process of holding CCGs to account when they fail to deliver timely, quality and lawful NHS CHC implementation.
- NHS England must develop a system of Patient Advocacy as part of the discharge process for SCI people.



## Care Provision.

The Inquiry identified a number of problems with the care provided by both the NHS and social services.

By far the most worrying aspect of the evidence relating to the provision of care was the fact that two SCI Centres (Salisbury and Oswestry) reported experience of CCGs and Local Authority areas that simply did not provide 24-hour care for tetraplegics, irrespective of need and risk to the individual. The legality of this was questioned in the evidence given on behalf of the Clinical Reference Group for SCI, but it is not clear how this can be challenged.

A common thread in the evidence for the provision of care was the lack of understanding on the part of the Commissioners of the complexity, intensity and unpredictability of the specific care needs of an individual with SCI. This inevitably leads to higher care costs than for many other patient groups. The following examples from the SCI Centre at Oswestry are a demonstration of the frequent disputes over the cost of the care package recommended:

*“Patient A was awarded social services funding for a nursing home placement. The cost of this was £1,200 per week. He was delayed for 81 days due to the cost for the nursing home placement being questioned as nursing homes would normally cost in the region of £600. The high cost was due to the level of care that patient A required:*

*81 days in Nursing Home = £13,800  
81 days in SCI Centre = £40,095  
– an additional cost of £26,295”*

*“Patient B was awarded NHS Continuing Healthcare Funding for a care package at home at a cost of £1,300 per week. Currently delayed 54 days waiting for a decision as to which care agency will be used.*

*54 days at home = £10,028  
54 days in SCI Centre = £26,730  
– an additional cost of £16,702.”*

The availability of suitably trained care providers would appear to be a considerable issue when putting a care package together. There is neither a programme for systematic and compulsory training of carers nor a standard for testing the competencies required in the care of an individual with SCI, whether that care takes place in the home or in a Care Home setting. Using generic local domiciliary care agencies rather than agencies that specialise in the care of individuals with SCI may appear to be a cheaper option but also more likely to lead to unnecessary secondary complications and re-admissions that prove more costly to the NHS in the long run.

A recurring theme in the evidence presented to the Inquiry, was the lack of provision of appropriate bowel management. Not only is there a problem with insufficient District Nurses cover in the community to offer daily bowel care, there are also reports of District Nurse being reluctant to provide the required interventions, possibly based on unfamiliarity with the procedure. Whatever the reason, the absence of appropriate bowel care will result in complications such as constipation, faecal incontinence and re-admission to hospital and is one of the most common triggers for an episode of Autonomic Dysreflexia. In extreme cases, faecal impaction can lead to bowel perforation (‘stercoral perforation’). For the individual, the lack of a reliable and appropriate bowel regime is not only dangerous, it is also undignified and humiliating and likely to lead to social isolation.

Relieving pressure, whether sitting in a wheelchair or lying in bed, is key to maintaining skin integrity and preventing pressure ulcers. This is usually achieved through a combination of pressure-relieving equipment and changes in position, which can be achieved manually or by the use of turning systems such as a TOTO ('turn-or-tilt'). Salisbury SCI Centre reports that no county in their catchment area apart from West Berkshire provides turning at night:

*"Hampshire CCG turned down a request for a TOTO turning system for a C4 patient on the ground that 'the primary need for the TOTO is for saving care'. The CCG then declined to provide the night time care to turn the patient and suggested he go into a nursing home. Two months later they then agreed to fund the TOTO."*

To put this into perspective, the cost of a TOTO system is £1,845. The two month delay in agreeing funding for the TOTO cost in the region of £30,000.

## RECOMMENDATIONS FOR CARE PROVISION.

- The Department of Health, NHS England and the Department for Communities and Local Government must acknowledge the complexity and unique care needs associated with SCI that are required to effectively avoid unnecessary and expensive complications.
- Statutory funders of care must acknowledge and accept the cost premium involved in specialist packages of care for high-level tetraplegics and those with co-morbidities.
- NHS England must address the inconsistencies in the provision of bowel care for SCI people across the country.



## Equipment.

**“ Equipment ..... provides the gateway to independence, dignity and self-esteem. It is central to effective rehabilitation! ”**

*(Audit Commission Report 'Fully Equipped', 2000)(6)*

In the context of living with a disability, 'equipment' encompasses anything that is required to enable the person to maintain health and live independently, ranging from a padded toilet seat to a ventilator. The variety of equipment on the market is huge and the suppliers many.



The evidence tells of problems with terminology when ordering equipment, for instance what is considered 'standard' in the SCI Centre may be 'special' in the community and hence requires a different ordering process. The ordering process for 'specials' may not be very familiar to the community staff involved or has to go to a higher level for approval before ordering can take place. Confusion over whose responsibility it is to order specific equipment seems commonplace. The SCI Centre staff will know the equipment details and supplier but have no authority to order. Community staff may have the authority to order but are not always willing to accept the recommendation from the SCI Centre staff:

*“District Nurses sometimes state that they cannot order pressure relieving equipment such as mattresses because they have not assessed the patient. This is despite the patient having undergone months of assessment by specialist staff. When the District Nurses are invited to the Centre to assess the patient, they are not able to come (geography, time, funding)”*

**“ The CCG would not order other equipment until a definite discharge date could be given, and we could not give an actual discharge date until the equipment requested was in situ ”**

*SCI Centre*

When considering the complexity and cost of the care package required for an individual who is ventilator dependent it seems extraordinary that extensive delays are caused by disputes over who pays for the necessary consumables, such as suction catheters and tubing. Here are some examples from Salisbury SCI Centre:

*“Wiltshire CCG declined to give authorisation to purchase any ventilator equipment for their patient who has been on [Salisbury SCI Centre] since December 2012”.*

*“Windsor, Ascot and Maidenhead CCG declined to give authorisation for the [Salisbury SCI Centre] to purchase ventilator equipment for a patient and declined to order it themselves until quotes were provided, even though a list of equipment needed and the cost had already been submitted”.*

There are also examples of equipment provided prior to CHC funding being replaced by new (but identical) equipment funded by CHC.

In recent years, cough-assist machines have been established as an essential tool in the respiratory care of patients with a compromised ability to cough. Clinical indications for use are for treatment as well as for prevention of respiratory complications. It is reported that applications for funding for this equipment to be used prophylactically in the community are frequently turned down. The cost of a cough-assist machine is in the region of £4,500, a fraction of the cost of a hospital admission due to pneumonia.

## RECOMMENDATIONS FOR EQUIPMENT OTHER THAN SEATING.

- SCI Centres and local services to agree classification for ‘basic/standard’ and ‘specialist’ equipment for the most commonly used equipment.
- SCI Centres and local services to develop a clear process for ordering equipment for discharge with a mutually agreed, dedicated person responsible from either the SCI Centre or the community.
- NHS England to mandate all CCGs to follow the process for the ordering of specialist equipment as agreed in the National Framework for NHS CHC.

## Wheelchairs.

For any person dependent on a wheelchair for their mobility, the wheelchair is much more than simply a mobility aid:

*“For many people, an appropriate<sup>4</sup>, well-designed and well-fitted wheelchair can be the first step towards inclusion and participation in society.”*

*“Providing wheelchairs that are fit for the purpose not only enhances mobility but begins a process of opening up a world of education, work and social life.”*

*‘Guidelines on the provision of manual wheelchairs in lesser resourced settings’, WHO, 2008.(7)*

This may well be the aspiration of the wheelchair services and the SCI Centres but the evidence submitted to this Inquiry paints a very different picture. It describes a system struggling to meet people’s needs and expectations; a system with huge variations in service delivery across the country compounded by a lack of recognised standards, variation in professional skills within both wheelchair services and SCI Centres, variation in interpretation of clinical need, excessive waiting lists and poor communication between SCI Centres and wheelchair services.

Nowhere is the variation more evident than to an individual undergoing rehabilitation in an SCI Centre. There are 151 wheelchair services in England. The larger of the SCI Centres may deal with up to 60 different wheelchair services at any one time, all with their own set of protocols, guidelines and procedures. Not only does this make it extremely time consuming for the SCI Centres to become familiar with which procedure to follow and with which service, it also leads to very different wheelchairs being provided to people with essentially the same clinical need, solely because they live in different areas of the country.

The wheelchair services are funded by CCGs and, as with other services, the decisions regarding what can be provided and to what level rests with the Commissioners. The Inquiry heard how the absence of recognised national standards for provision of wheelchairs and the lack of engagement by Commissioners with the wheelchair services makes equity in provision across the country very difficult. The National Wheelchair Managers Forum (NWMF) published ‘Healthcare Standards for NHS-Commissioned Wheelchair Services’ in 2010 (8). Although some CCGs are independently using parts of these standards in the absence of any clear guidelines, attempts to get them endorsed by the Department of Health have so far failed. Without this recognition it is very difficult to see how they can be enforced.

Although a posture and seating assessment is recognised as part of the commissioned rehabilitation programme at an SCI Centre, funding for the wheelchair is not included. This gives rise to an anomaly: the SCI Centre therapists have in-depth knowledge of the patient, their ability and needs but no authority to prescribe the wheelchair. Whilst recognising that wheelchair service therapists have knowledge and experience of a wide range of disabilities, they are unlikely to have the same in-depth understanding of SCI as this group constitutes less than 2% of the wheelchair-using population (9). However, they alone have the authority to prescribe. Whilst the SCI Centre therapist may recommend a certain wheelchair, the evidence submitted to the Inquiry suggests that some wheelchair services will take this into consideration, whilst others will ignore it.

**SCI people constitute less than 2% of the wheelchair-using population**

<sup>4</sup>WHO definition of ‘Appropriate’: a wheelchair that meets the user’s needs and environmental conditions; provides proper fit and postural support; is safe and durable

The Inquiry heard that an increasing number of wheelchair services are insisting on carrying out their own assessment in addition to the assessment already carried out at the SCI Centre. One of the reasons given for this trend is experience of SCI Centres recommending a higher specification wheelchair than thought needed by the wheelchair service. There is a perception amongst some wheelchair services that the SCI Centres raise the expectations of the patient. The SCI Centre therapists have a duty to work within the scope of NHS wheelchair provision whilst at the same time educating the patient about advantages and disadvantages of a wider range of wheelchairs.

In the past, some wheelchair services have elected to carry out a joint assessment with the SCI Centre therapist. This was regarded as a very constructive way of reaching an agreement on provision but the travel has obvious implications for staff time and loss of clinical time for other clients. However, the same can be said for a patient travelling to the wheelchair service for an assessment, escorted by SCI Centre staff and the additional cost of hospital transport. Furthermore, this approach may not result in the best assessment outcome and may even pose some risk to the patient:

*“A gentleman in his 80s was required to travel 70 miles to his wheelchair service with hospital transport and his therapist escorting him on two separate occasions. The assessment was undertaken when the gentleman was not at his best and resulted in a decision to carry out a further assessment once the patient had been discharged home.”*

*“A high level tetraplegic with challenging postural requirements and limited sitting tolerance was expected to make the journey to his local wheelchair service with the knowledge that his abilities, behaviour, comfort and skin tolerance would be compromised by the journey.”*

## **The use of interim provision for discharge.**

The person with SCI is likely to continue to grow in confidence and consolidate skills learnt during the rehabilitation process for some time after discharge. Furthermore, most people are discharged to housing that is either temporary or awaiting adaptations. Consequently, many people are not able to determine exactly what they need from their wheelchair until they have been able to spend some time in their home environment. For these reasons, a system of discharging people with an interim wheelchair has been adopted by most SCI Centres and wheelchair services. This can work well provided the wheelchair enables the person to continue using the skills learnt during rehabilitation, particularly advanced skills such as going up and down kerbs and loading the chair independently into a car. Where this does not occur, the evidence submitted to the Inquiry indicates that increasingly people are being discharged with unsuitable, basic wheelchairs, jeopardising the entire rehabilitation outcome. In some instances, not even an interim wheelchair can be provided. There is evidence of people being discharged home on stretchers with no wheelchair at all, awaiting an assessment from the wheelchair service within 24 hours. A letter from one wheelchair service states that:

*“It is now our policy to only review these out of area clients once they have completed rehabilitation and returned to their home address. At that point we will assess their needs and home environment ourselves.”*

It is not clear how these paralysed individuals are expected to manage until the wheelchair service has visited and provided them with a wheelchair. This policy may have been instigated due to poor experience of prescription from an SCI Centre and may no longer be the case. It still demonstrates a complete disregard for, or unwillingness to understand, the impact that the total lack of mobility will have on this person's quality of life.

Similarly, a high-level tetraplegic (68 yr old male, C5) was informed by his wheelchair service that he did not meet their criteria for an urgent review and that the waiting list was very long. As the individual was unable to propel his own wheelchair, the wheelchair service was not prepared to provide a manual wheelchair for 'static' sitting and suggested that an armchair could be provided instead. The seating offered was rejected by the SCI Centre therapist as being unsuitable for postural management and pressure relief as well as depriving the individual of assisted mobility. The SCI Centre therapist received the following justification from the wheelchair service manager:

*"The wheelchair is not essential for discharge. Without a wheelchair, the patient/client will still be able to go home although we are aware it won't be in the most ideal condition and they will be bed bound. However, as was discussed, he doesn't have to be bed bound if he can be provided with an armchair to alternate from lying in bed to sitting in order to minimise the risk of pressure sore.*

*"The wheelchair will not affect his package of care. As was explained to me, he will be receiving a full package of care with or without a wheelchair. The wheelchair will not allow independent mobility as the patient/client will not be able to self-propel.*

*"I am sorry that this is my answer, but we have strict criteria to put anyone on the priority list and unfortunately, there are other people ahead of him on the waiting list who are in a similar situation."*

Whilst the individual could not propel a wheelchair themselves they were not even provided with a wheelchair someone else could push, effectively confining them to their house and, in all probability, a single room.

A system of providing an interim manual wheelchair with a mutually agreed timeframe for review assessment may in principle seem to be a good way of managing provision

on discharge. However, the type of interim provision described to the Inquiry fails the individual completely by not enabling them to maintain and consolidate their level of function and independence after leaving an SCI Centre.

An additional risk to using interim provision on discharge is that unless a review date is agreed with the wheelchair service as part of the discharge planning, the individual may end up being placed on the waiting list. This can be particularly long for assessment for powered mobility. The Inquiry heard evidence from different parts of the country of waiting times varying from 1 – 5 years.

Waits for powerchair assessments varied from one to five years.

In no other area of the NHS is this considered an acceptable waiting time for intervention.

### **Assessment and prescription.**

Both manual and powered wheelchairs have become considerably more complex in the last 30 years with a much wider range of chairs on the market. It is no longer the case that the individual has to fit the chair; it is now possible to make the chair fit the individual. This increased choice and technical complexity demands greater competencies from the professionals involved in the assessment and prescription. There is a lack of a standardised assessment protocol in both SCI Centres and wheelchair services, and without this it is difficult to establish and monitor the competencies of the professionals involved in the assessment. This situation is compounded by a general lack of funding to support staff, with most therapists relying on learning through working with more experienced colleagues rather than specific training.



For manual wheelchair users, competent wheelchair skills are key to wider independence and confident community participation and social integration. All SCI Centres have the facilities and expertise to teach basic as well as advanced wheelchair skills, often assisted by wheelchair skills trainers from Back Up who are themselves wheelchair users. This includes skills such as independently loading the wheelchair in and out of a car, backwheel balance, kerbs, rough ground, slopes and, in some cases, steps. The wheelchair services recognise that they have neither the time nor, in most cases, the skills or facilities to teach wheelchair skills to this level.

A critical aspect of the manual wheelchair assessment in the SCI Centre is educating the individual about maintaining upper limb health and reducing the risk of developing secondary complications such as shoulder pain. This is now a well recognised problem for manual wheelchair users. A study carried out by 10 SCI Centres in the UK in 2008 established the prevalence of shoulder pain to be 66% in full-time manual wheelchair users with SCI less than 10 years post injury (10). The factors associated with increased risk of developing upper limb pain are posture, propulsion technique, weight (user and seating), and wheelchair configuration (11-14). It is based on this growing body of evidence that SCI Centres advocate the provision of the lighter and more configurable wheelchairs for manual wheelchair users in combination with education about posture and robust wheelchair skills training. It is this range of wheelchairs which are frequently perceived by wheelchair services as being 'over-prescription'.

Inevitably, these types of wheelchairs are more expensive than the traditional style of wheelchair. They have however been proven to be more durable and cost effective (15;16). With no real increase in funding for the wheelchair services in decades, the increase in demand for this style of wheelchair has led to other aspects of service provision being cut. Consideration also needs to be given to the ability of services to maintain and repair

an ever increasing variety of wheelchairs. Typically, an individual with compromised walking ability will lose outdoor mobility long before they require a wheelchair for indoor mobility. However, an increasing number of wheelchair services no longer provide any manual wheelchair for people who have the ability to walk just a short distance.

As was heard in the oral evidence session, the wheelchair services do however still provide people with single or double lower limb amputations with a manual wheelchair as back-up in case the individual is unable to use their prosthetic limbs. Although the mobility needs are the same for a person with SCI, no such back-up chair is provided. In case of a puncture, the person is confined to bed or static chair until the tyre can be mended by the wheelchair service. It was suggested that as all the wheelchairs have detachable rear wheels, the provision of just a spare wheel would keep the person mobile and in fact enable the person to take the punctured wheel for repair at a time convenient to them and at less cost to the service. There are examples of this approach being used by some wheelchair services.

Although many problems have been identified in negotiating a suitable wheelchair for discharge, there was very strong consensus between the Chair of the Multidisciplinary Association for SCI Professionals (MASCIP) and the Chair of the National Wheelchair Managers Forum (NWMF) that the current system was not working to anybody's satisfaction and that a different approach to the whole process was required. It was agreed that time was being wasted in protracted negotiations and unnecessary repetition of assessments. There was agreement to collaborate in reviewing current practices and develop a new approach to wheelchair provision, particularly for discharge.



## RECOMMENDATIONS FOR WHEELCHAIR PROVISION.

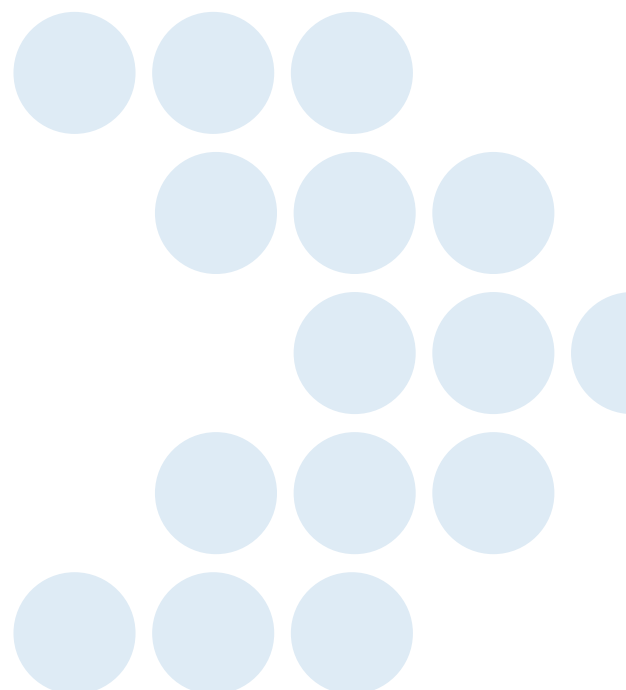
- MASCIP and NWMF to develop a list of wheelchairs (manual and powered) which can be considered for provision on discharge from the SCI Centre. The wheelchair provided on discharge must enable the person with SCI to maintain the level of independence they achieved during rehabilitation.
- Delegate the initial assessment, prescription and provision of the wheelchair (manual/powered) and cushion to SCI Centre therapists based on current evidence and using a mutually agreed range of equipment and documentation, accessing contract prices as negotiated by the wheelchair services.
- The wheelchair service to retain responsibility for the service and maintenance of the wheelchair following discharge and any subsequent assessment when the wheelchair needs replacing.
- MASCIP, in collaboration with NWMF, to take the initiative to develop and publish a national guideline for the assessment, prescription and provision of manual wheelchairs for people with SCI.
- MASCIP and NWMF to formulate the training requirements for all staff involved in the assessment for and prescription of manual wheelchairs, powered mobility, cushions and backrests.
- SCI Centre and wheelchair services to consider the use of Telemedicine where joint assessments are deemed to be necessary.

## EMERGING INITIATIVES TO ASSIST IN REDUCING DELAYS IN DISCHARGE.

The use of local hotel facilities has been tried by some centres for patients who are ready for discharge and are completely independent but have no interim or permanent placement to go to. Not only does this release a bed in the SCI Centre, it also offers the individual an opportunity to test their skills and gain confidence whilst still being able to access advice and support from the SCI Centre. Disputes over who pays for this has stifled the initiative even though the cost saving is obvious.

The development of 'Step-Down' facilities are being strongly encouraged by NHS England and the Clinical Reference Group for SCI. Patients discharged to Step-Down facilities will continue to receive rehabilitation input from the SCI Centre Outreach Team. Southport SCI Centre already has 12 beds for this purpose and Stanmore has got agreement to open a similar facility with 14 beds. Stoke Mandeville is in the early stages of looking into developing a Step-Down facility.

North West of England, which commissions the Step-Down service in Southport, has been able to demonstrate that patients in Major Trauma Centres are getting into Southport SCI Centre more quickly and that the invested £1.2 million on an annual basis for those 12 extra beds has saved them £2.8 million. Patient feed-back has been very positive. The scheme is supported on a national basis by the Quality Improvement and Productivity Scheme (QUIP). It has been put forward to all Area Teams who commission specialised services across England. They have been strongly encouraged to consider opening similar facilities in their areas but as mentioned previously in this report, NHS England has no mandate to compel area teams to develop these facilities. Currently there are some similar facilities offered by the private sector.



## SUMMARY.

“ Once patients with SCI have reached their rehabilitation goals they need to put into practice what they have achieved. A protracted delay in returning to the community, or an inappropriate placement (or equipment) where maximum independence is not achieved, are effectively a waste of the combined hard work of the patient and the SCI Centre, and a waste of NHS investment ”

*(The NHS England Service Specification for Spinal Cord Injuries)*

It is clear from the evidence submitted to this Inquiry that the patient journey from injury through the SCI Centre to home passes through several different clinical teams and funding streams, delayed by fragmentation and lack of cohesion in the services provided. As long as this fragmentation exists, precious resources will continue to be wasted due to duplication of assessments, difficult communication and time-consuming negotiations between teams.

This Inquiry has focused on the access and capacity issues for people with newly-acquired spinal cord injury. It is recommended that an in-depth service review is conducted in order to establish the true access and capacity requirement of all the SCI Centres to be able to meet the changing needs of all SCI people throughout their lifetime.

The evidence submitted to this Inquiry suggests that the number of delayed admissions to the SCI Centres could be greatly reduced and possibly eliminated if discharges can be managed in a timely fashion. It is therefore not the acute sector of the NHS that is failing the SCI person. It is the services in the community. Based on this evidence, the responsibility for the delay in discharging a person from an SCI Centre rests in the main

with the Clinical Commissioning Groups. However, the apparent lack of monitoring thus far of the Clinical Commissioning Groups by NHS England must also be a cause for concern.

Due to the fragmentation of services and the many funding streams involved, the constant challenge facing clinicians is not just how to provide the best outcomes for the SCI person, but how to persuade one budget holder to carry the cost for an intervention or a piece of equipment in order to save money in another sector of the NHS.

# BIBLIOGRAPHY.

- (1) NHS England. National Spinal Cord Injury Care Pathways. 2013.
- (2) Bridges W. Transitions: making sense of life's changes. 2nd ed. Cambridge, MA: Da Capo Press; 2004.
- (3) NHS England. National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care. 2012.
- (4) Frankel HL, Coll JR, Charlifue SW, Whiteneck GG, Gardner BP, Jamous MA, et al. Long-term survival in spinal cord injury: a fifty year investigation. *Spinal Cord* 1998 Apr;36(4):266-74.
- (5) Whiteneck GG, Charlifue SW, Frankel HL, Fraser MH, Gardner BP, Gerhart KA, et al. Mortality, morbidity, and psychosocial outcomes of persons spinal cord injured more than 20 years ago. *Paraplegia* 1992 Sep;30(9):617-30.
- (6) Audit Commission. Fully equipped - the provision of equipment to older or disabled people by the NHS and social services in England and Wales. London: Audit Commission; 2000.
- (7) World Health Organisation. Guidelines to provision of manual wheelchairs in lesser resourced settings. 2008.
- (8) National Wheelchair Managers Forum. Healthcare standards for NHS-commissioned Wheelchair Services. 2010.
- (9) Lachmann S ML&MG. The Provision of Wheelchairs and Special Seating: Guide for Purchasers. London: Royal College of Physicians; 1995.
- (10) Rose L. The impact of wheelchair type on reducing the risk of shoulder overuse injuries following spinal cord injury. UCL (University College London); 2012. <http://discovery.ucl.ac.uk/1358180/>
- (11) Boninger ML, Cooper RA, Baldwin MA, Shimada SD, Koontz A. Wheelchair pushrim kinetics: body weight and median nerve function. *Arch Phys Med Rehabil* 1999 Aug;80(8):910-5.
- (12) Boninger ML, Baldwin M, Cooper RA, Koontz A, Chan L. Manual wheelchair pushrim biomechanics and axle position. *Arch Phys Med Rehabil* 2000 May;81(5):608-13.
- (13) Boninger ML, Souza AL, Cooper RA, Fitzgerald SG, Koontz AM, Fay BT. Propulsion patterns and pushrim biomechanics in manual wheelchair propulsion. *Arch Phys Med Rehabil* 2002 May;83(5):718-23.
- (14) Hastings JD, Fanucchi ER, Burns SP. Wheelchair configuration and postural alignment in persons with spinal cord injury. *Arch Phys Med Rehabil* 2003 Apr;84(4):528-34.
- (15) Cooper RA, Robertson RN, Lawrence B, Heil T, Albright SJ, VanSickle DP, et al. Life-cycle analysis of depot versus rehabilitation manual wheelchairs. *J Rehabil Res Dev* 1996 Feb;33(1):45-55.
- (16) Cooper RA, Gonzalez J, Lawrence B, Renschler A, Boninger ML, VanSickle DP. Performance of selected lightweight wheelchairs on ANSI/RESNA tests. American National Standards Institute-Rehabilitation Engineering and Assistive Technology Society of North America. *Arch Phys Med Rehabil* 1997 Oct;78(10):1138-44.

# GLOSSARY.

<b>AD</b>	Autonomic Dysreflexia
<b>APPG</b>	All Party Parliamentary Group
<b>BASCIS</b>	British Association of Spinal Cord Injury Specialists
<b>CCG</b>	Clinical Commissioning Group
<b>CHC</b>	Continuing Healthcare
<b>CRG</b>	Clinical Reference Group
<b>MASCIP</b>	Multidisciplinary Association of Spinal Cord Injury Professionals
<b>MDT</b>	Multidisciplinary Team
<b>NWMF</b>	National Wheelchair Managers Forum
<b>Paraplegia</b>	Spinal cord injury to the thoracic or lumbar spine. Trunk and lower limbs will be affected.
<b>SCI</b>	Spinal Cord Injury
<b>SIA</b>	Spinal Injuries Association
<b>Tetraplegia</b>	Spinal cord injury to the cervical spine (neck). Upper limb as well as trunk and lower limbs will be affected.
<b>TOTO</b>	'Tilt or Turn' patient turning device

# APPENDIX 1.

This report is a summary of the evidence submitted to the Inquiry instigated by the All Party Parliamentary Group on SCI. In order to get as complete a picture of the current situation as possible, a wide range of stakeholders were invited to submit written evidence to the Spinal Injuries Association. This included NHS England, SCI clinicians and their representative bodies, patients and their relatives, and key related organisations. Evidence was also heard at two oral hearings held at the Palace of Westminster in January and February, 2015.

We would especially like to thank the SCI people and their relatives who took the time to submit their personal experiences to this Inquiry.

## Written evidence from organisations

*Spinal Cord Injury Centres:*

*Princess Royal Spinal Injury Centre, Sheffield*

*Golden Jubilee Regional Spinal Cord Injuries Centre, Middlesbrough*

*Midlands Centre for Spinal Injuries, Oswestry*

*National Spinal Injuries Centre, Stoke Mandeville*

*London Spinal Cord Injury Centre, Stanmore*

*Duke of Cornwall Spinal Therapy Centre, Salisbury*

BASCIS – Dr Alan McLean, President of BASCIS and Consultant in SCI, Glasgow

MASCIP – Dot Tussler, Chair (collated from several SCI Centres)

National Wheelchair Managers' Forum – Krystyn Jarvis, Chair

Major Trauma Centre – Kelly Saunders, Clinical Lead PT, Barts Health (The Royal London Hospital)

Clinical Reference Group (CRG) for SCI – David Stockdale, Commissioner for CRG for SCI

Dr Thearina de Beer, Critical Care and Anaesthetic Consultant, Nottingham University Hospitals NHS Trust and member of the CRG for SCI

ASPIRE – Krupesh Hirani, Policy and Research Officer

Back Up – Stef Cormack, Head of Services

Cauda Equina Syndrome Association (CESA) in association with JMW Solicitors – Kelly Hindle, Clinical Negligence Communications Manager

Irwin Mitchell LLP Solicitors – Anne Luttmann-Johnson, Client Support Manager

Livability – Stephen Muldoon, Assistant Director, International and Complex Care Development

MEARS NursePlus – Tracey Johnson, Clinical Case Manager

Plymouth Neurophysio LTD – Becky Isserlis, Director and Clinical Lead Neuro PT (Out-pt rehab)

RFU Injured Players Foundation – Dr Mike England, Director

## Oral evidence

Mrs Verney – daughter of SCI person

Mrs B – wife of SCI person

Prof Charles Greenough, Consultant in SCI and Chair of the CRG for SCI

David Stockdale, Regional Programme of Care Manager (North) for Trauma and Commissioner for CRG for SCI

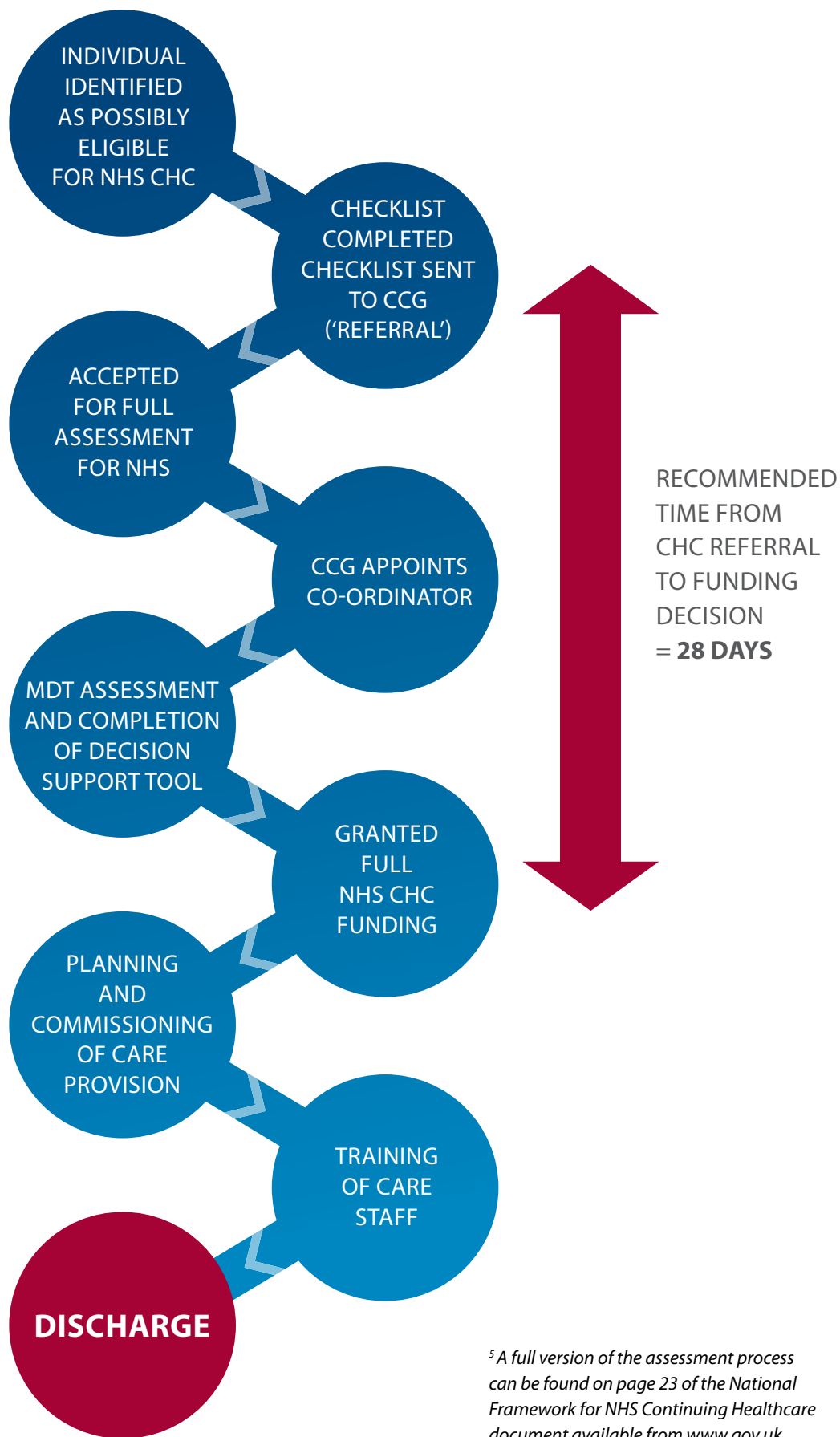
Mr Brian O'Shea – NHS Continuing Healthcare Adviser, Spinal Injuries Association

Krystyn Jarvis, Chair of the National Wheelchair Managers' Forum

Dot Tussler, Chair of the Multidisciplinary Association of SCI Professionals



## APPENDIX 2. Simplified flowchart of assessment for NHS CHC<sup>5</sup>





## Members of the inquiry panel:

Mr Ian Lucas, MP, Chair of APPG on Spinal Cord Injury 2008-2015

Baroness Rosalie Wilkins

Baroness Susan Masham

Dr Fred Middleton, Consultant in Spinal Cord Injury

Dan Burden, Head of Public Affairs, Spinal Injuries Association

Report written by: Lone Skriver Rose, MPhil, MCSP, SRP, Researcher to APPG on SCI



### The All Party Parliamentary Group on Spinal Cord Injury:

The All Party Parliamentary Group on Spinal Cord Injury is a group formed of members from the House of Commons and House of Lords, that works with spinal cord injured people, their charities and health care professionals. The group was formed to address the specific issues being faced by spinal cord injured people, particularly relating to medical treatment, care, support and developments in treatments as well as social care and wider issues that affect the lives of the UK's 40,000 spinal cord injured people.



### Slater and Gordon Health Projects and Research Fund:

For nearly 80 years, Slater and Gordon has worked for social and economic justice in the community. They are committed to preventing illness and injury from occurring and where this is not possible, to advocating for the best possible care and treatment for those affected. The Health Projects and Research Fund is a philanthropic grants initiative focused on the improvement of care and treatment for people with asbestos related illnesses, occupation caused cancers or significant disability caused by serious brain or spinal injury. Slater and Gordon will provide £500,000 in the United Kingdom and \$1 Million AUD for projects by 2020, building on existing philanthropic efforts to support health professionals, rehabilitation and research organisations to improve the lives of others.



### Spinal Injuries Association:

The Spinal Injuries Association (SIA) is the leading national user-led charity for spinal cord injured people. Being user led, we are well placed to understand the everyday needs of living with spinal cord injury and aim to meet those needs by providing key services, to share information and experiences, and to campaign for change ensuring each person can lead a full and active life. SIA exists to support spinal cord injured people from the moment their spinal cord injury happens, and for the rest of their lives.