

# Preserving and Developing the National Spinal Cord Injury Service

## Phase 2 – Seeking the Evidence

# RESEARCH REPORT

May 2009

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The Spinal Injuries Association also wishes to thank the charities ASPIRE, BACKUP and SPINAL RESEARCH for their assistance with hosting links to the User Group Survey.

The pro-active participation and positive contribution by all stakeholders in this project has enabled the Project Team to achieve all the study objectives and beyond. SIA looks forward to continued and strengthened collaboration to move forward from the platform of the All Party Parliamentary Group on Spinal Cord Injury to deliver a work plan that will 'Preserve and Develop a National Spinal Cord Injury Service' that is 'Fit for Purpose' for the 21st Century.

The Spinal Injuries Association also wishes to thank Shoosmiths Solicitors for their generous financial sponsorship of this project.

# 1. Executive Summary

Spinal cord injury (SCI) is a rare and complex impairment which will result in some degree of loss or reduction in voluntary muscle activity, sensory deprivation and disruption of autonomic function related to the level and severity of the cord damage.

Incidence, aetiology and the demographics of the spinal cord injury population vary world-wide but evidence supports the need for people with spinal cord injury to be managed in a continuum of care, through the initial period of treatment and rehabilitation to on-going lifelong support, delivered by a specialist spinal cord injury service designed to meet the needs of the specific patient population served.

The Spinal Injuries Association (SIA) is a national charity, working on behalf of spinal cord injured people to help, support, advise and campaign on all aspects of spinal cord injury. Evidenced by views of the SIA members, SIA's vision for better care and services for spinal cord injured people is set out in the Manifesto 'Campaigning for Change'<sup>1</sup>. Members highlighted the need to preserve and develop a national SCI service, with particular reference to key aspects of the service – capacity and location of the specialist Spinal Cord Injury Centres; models of care and service provision; funding and information management. The primary purpose of this project therefore was to:-

- Examine the evidence base required to support the SIA Strategy and Model of Care<sup>2</sup>, through investigation of existing clinical service delivery and commissioning practice
- Establish a national collaborative network to design and implement consistent, evidence-based working practices for Specialist SCI Services, in line with recommendations from the Darzi 'NHS Next Stage Review'<sup>3</sup>, the Carter 'Review of Commissioning Arrangements for Specialised Services'<sup>4</sup>, and other statutory requirements<sup>5</sup>.
- To provide evidence to support and guide the work plan of the newly formed All Party Parliamentary Group on Spinal Cord Injury.

Using an action research approach, to optimise stakeholder engagement and collaborative protocol development, Phase 1 of the study examined the existing patient population served, staffing, facilities and services provided by the individual SCI centres. Results of the surveys and interviews demonstrated the range in patient experiences and service provision nationally and highlighted key issues of concern around access, discharge planning, information management and financial constraints for service users and providers<sup>6</sup>. These findings focussed development, by all stakeholder groups, of the Phase 2 protocol, to provide objective evidence to quantify the patient, provider and funding position of specialist Spinal Cord Injury Services in England and Wales.

In order to achieve a comprehensive and balanced review of the service, it was essential to obtain information from all of the key stakeholder groups ie specialist spinal cord injury service users, providers and commissioners and also other NHS services (acute, tertiary and primary care) which provide any form of health care to patients with spinal cord injury.

Service users, providers and commissioners were surveyed to establish the national population of SCI persons using specialist SCI services and other NHS services in the financial year 2007/2008, identify their clinical needs, describe existing pathways of care and patient experiences, re-visit facility and service provision and clarify patterns of commissioning.

## Key Findings

### User Survey

- 10% Never under the care of specialist SCI Centre
- 59% Experienced significant SCI related problems
- 43% Reported additional medical conditions
- 44% Using other health care services

### Specialist SCI Centres

- 74% New patients discharged to own homes
- 21% New injuries not referred within 1 month of injury
- 41% New injuries not admitted within 1 month of injury
- Delay between injury and admission to SCI Centre increased risk of complications
- 29% Elective re-admissions were for management of SCI related problems
- 29% Out-Patients required further active treatment

### Service Commissioners

- Individual Specialised Commissioning Groups procure services at multiple SCI Centres
- No national standardised currency for commissioning

### Other NHS Services

- SCI Patients use diverse range of other NHS services
- Identification of SCI Patients problematic and information not available as routine

This extensive review has demonstrated the importance of specialist management for people with spinal cord injury to address their complex and discrete healthcare requirements, confirmed a patient population failing to gain access to the service and highlighted the disadvantages of not gaining timely and appropriate access to specialist spinal cord injury care.

Each of the patient populations examined in this study experienced health problems unrelated to their spinal cord injury. The National Service Framework for Long Term Conditions<sup>5</sup> requires that provision of healthcare to patients with long-term neurological conditions, in any healthcare setting, should not compromise management of the patient's neurological condition or personal care. It is important, therefore, for the specialist spinal cord injury centres to provide an accessible service interface for their patients, to ensure that any health care need is managed within the context of their spinal cord injury.

Retrieval of information across the service was complex and problematic. A variety of clinical data management systems were in place across the SCI Centres; measures of service profile were not standardised; limited contract monitoring data was available and identification of SCI patients within other NHS services proved difficult. This report highlights particular areas of information deficit, in order that prospective data collection is improved, to ensure the required capacity planning, service procurement and funding, and programme development are adequately addressed.

Principles of management for spinal cord injury have moved on from issues of survival and now aim to minimise impairment, prevent further disability and optimise activity and participation. Goals for rehabilitation are to achieve successful reintegration for the individual within their chosen community and maintain lifelong health and well-being<sup>7</sup>. Scientific advances continue, which in time may impact on initial and late stage management of spinal cord injury, to reduce impairment and enhance functional recovery of the central nervous system. All future service planning must incorporate facilities and practices which enable implementation and evaluation of evidence-based innovation in spinal cord injury management.

In the immediate future, key areas for service development that will enhance the patient experience, improve and quantify clinical outcomes and increase service efficiency are:-

- **National guidelines and standards for identification and clinical management of SCI patients**
- **Clinical networks and care pathways for acute admission and lifelong support of SCI patients in specialist SCI centres and other NHS services**
- **Standardised information management - minimum SCI patient data set, clinical and service outcome measures and compatible data collection in all SCI Centres**
- **Standardised commissioning framework and currencies**

In order to maintain continuity and momentum, 'Phase 3' of this SIA Campaign initiative should commence at the earliest opportunity, to take forward these recommendations, build upon development work by some SCI Centres and Specialist Commissioners in each of these areas and to consolidate and deliver the work plan for the All Party Parliamentary Group on Spinal Cord Injury to 'Preserve and Develop a National Spinal Cord Injury Service' which is 'Fit for Purpose' for all those who will require it in the 21st century.

## 2. Background

### Spinal Cord Injury

Spinal cord injury (SCI) is rare and results in complex multi-system impairment.

#### *Specialised Services National Definition – Number 6. Part 1.*

*Specialised spinal injuries encompasses any traumatic insult to the spinal column at cervical (neck), thoracic (chest), thoraco-lumbar, lumbar, lumbo-sacral (lower back) or multiple levels which causes or threatens complete or partial interruption of spinal cord function<sup>8</sup>.*

The consequence of spinal cord injury is loss or reduction in voluntary muscle activity, sensory deprivation and disruption of autonomic function related to the level and severity of the cord damage.

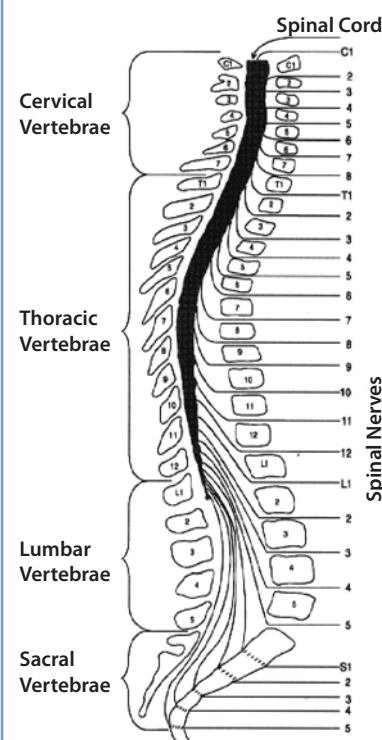
Incidence, aetiology and the demographics of the spinal cord injury population vary world-wide. Evidence to support delivery of specialist spinal cord injury services should therefore be relevant to the specific patient population served. Subjective reports from the UK specialist SCI Centres indicate a change in the demographics of patients sustaining cord injury, with an increase in the number of elderly patients and non traumatic injuries being referred to the specialist service.

Accurate figures for the incidence of SCI in the UK have been difficult to obtain due to a number of factors<sup>6</sup> – accurate diagnosis and classification of injury, incomplete submissions of the required dataset to the national database, lack of standardised care pathways and management of SCI patients in other specialist or non-specialist services, as there is no existing mandate to refer SCI patients to the specialist SCI Centre in England and Wales at present<sup>6</sup>. The UK national SCI database aims to capture all new patients admitted to SCI Centres but does not include patients referred to the service who are not admitted to a SCI Centre or patients managed through SCI Centre outreach or out-patient services.

Principles for the management of this diverse patient group have moved on from issues of survival and now aim to minimise impairment, prevent further disability and optimise activity and participation<sup>9,10</sup>. Goals for rehabilitation are to achieve successful reintegration for the individual within their chosen community and maintain lifelong health and well-being<sup>7</sup>. Specialist spinal cord injury care incorporates the core components of acute care, restorative rehabilitation, reintegration into the community and long term follow-up into a seamless clinical service<sup>11</sup>.

Scientific advances continue, which in time may impact on initial and late stage management of spinal cord injury, to reduce impairment and enhance functional recovery of the central nervous system. Future plans for specialised spinal cord injury care must incorporate facilities and practices which enable implementation of evidence-based innovation in spinal cord injury management<sup>10</sup>.

**Figure 1:**  
**Spinal Column & Cord**



## Specialist Spinal Cord Injury Centres

Eleven specialist spinal cord injury centres are now operational within the United Kingdom, with one further centre in the Republic of Ireland, to support patients sustaining spinal cord injury through the initial period of treatment and rehabilitation and on-going lifelong support. Each of the 9 SCI Centres in England and Wales are individual centres within a larger host hospital but the number of beds and facilities available on site are not standardised<sup>6</sup>.

Common principles of care underpin the services provided by these SCI Centres but no universal model of care has been adopted across the service. This reflects the lack of high quality evidence to support a preferred model of care, as identified by two Cochrane reviews<sup>9,10</sup> examining basic aspects of spinal cord injury management.



Standards have been devised<sup>11,12,13</sup> to provide a framework for the development and monitoring of specialist spinal cord injury services<sup>11</sup> which embrace the quality requirements of the National Service Framework for Long-Term Conditions<sup>5</sup> and NHS reform<sup>3</sup>. However awareness and implementation of such standards is not consistent across the specialist SCI centres within the UK.

The importance of appropriate acute management and rehabilitation programmes, delivered by an expert interdisciplinary team in dedicated specialist centres, has been demonstrated in various studies<sup>9,10</sup> although further objective studies are required<sup>9,10</sup>. Subjective reports from the UK SCI Centres indicated an increase in the number of patients being referred and admitted to the service with complications secondary to spinal cord injury, which may have been prevented by early specialist management<sup>6</sup>. Management of such problems delays progress within rehabilitation, prolongs lengths of stay for rehabilitation patients and results in unsatisfactory patient experiences and inefficient use of specialist resources.

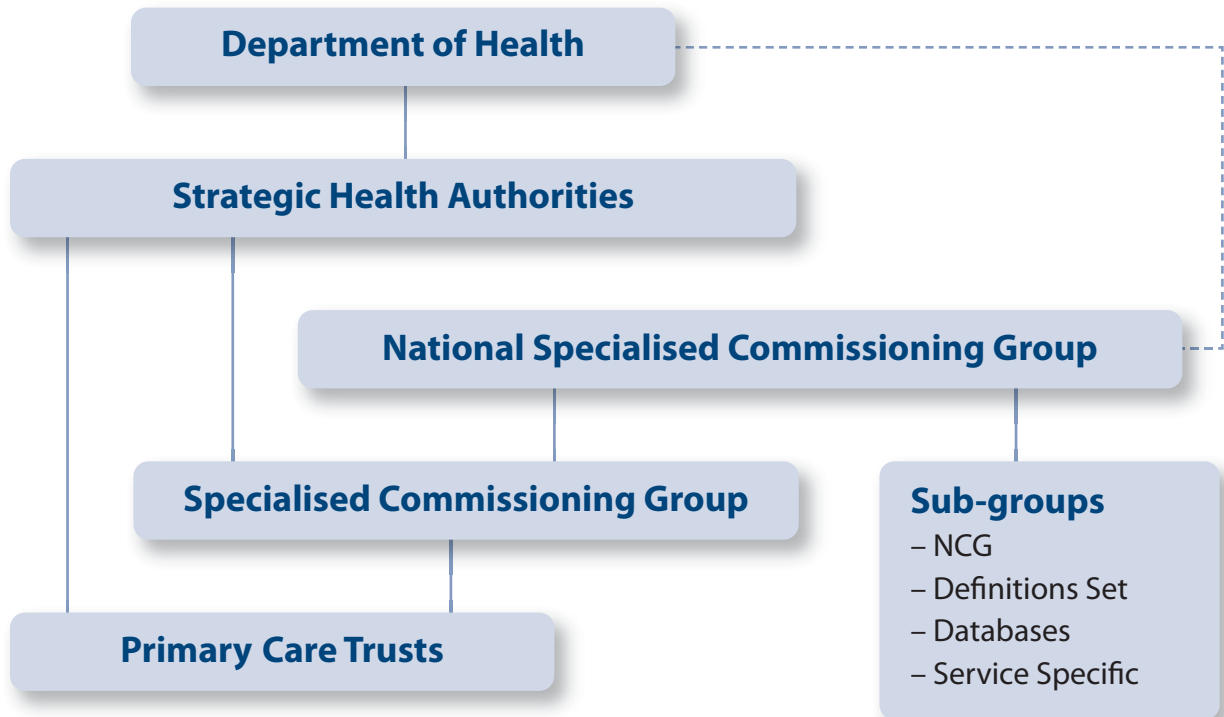
## Commissioning of Specialist Spinal Cord Injury Services

Health care services for the management of spinal cord injury fall into the category of specialised services. Specialised services are those provided in relatively few centres for more than a million people ie not provided by every hospital. There are currently 35 specialised services identified in the Specialised Services National Definitions Set (under review at present) which are high cost, low volume interventions and treatments.

In 2006, Lord David Carter chaired an independent review of commissioning arrangements for all specialised services in England<sup>4</sup>, with the aim of improving the commissioning process to address consistency and to ensure a good fit with the wider NHS reform programme to create a patient-led service. The review identified strong support for simplification and streamlining of the decision-making and commissioning processes and made a total of 32 recommendations for a revised national infrastructure and process.



## Revised Commissioning Infrastructure



National Commissioning is now the responsibility of the 10 Strategic Health Authorities (SHAs) who monitor the performance of the primary care trusts, including their commissioning of specialised services. In order to commission specialised services for the larger populations required, Primary Care Trusts (PCTs) within each Strategic Health Authority organise themselves into joint committees of Specialised Commissioning Groups (SCGs). The 10 SCGs have been set up with boundaries co-terminous with the SHA boundaries and have pooled budgets and financial risk sharing arrangements. Each SCG has a dedicated commissioning team, with SCG decisions being binding on all PCT members.

The National Specialised Services Commissioning Group was created on 1 April 2007, to take overall responsibility for the oversight of specialised commissioning and is responsible to the 10 Strategic Health Authorities.

## Spinal Injuries Association

The Spinal Injuries Association is a national charity, working on behalf of spinal cord injured people to help, support, advise and campaign on all aspects of spinal cord injury. Evidenced by views of the SIA members, SIA's vision for better care and services for spinal cord injured people is set out in the Manifesto 'Campaigning for Change'<sup>1</sup>. Members highlighted the need to preserve and develop the national SCI service, with particular reference to 5 specific aspects of the service:-

**Capacity** – To provide sufficient in-patient and out-patient facilities to ensure access to specialist management for diagnosis, initial management, rehabilitation, reintegration and life long support to the UK SCI population.

**Location** – To provide appropriate services to a designated population, to enable access to and partnership working with acute sector and community based agencies to ensure supported reintegration for people with spinal cord injury within their chosen community

**Statistics** – To establish a national database to record incidence and prevalence of SCI in the UK and demonstrate outcomes for specialist management

**Funding** – To establish a single body to fund, monitor and evaluate the SCI service and ensure standardised commissioning practice and financial transparency between commissioning and service provision.

**National Model** – To establish a national model of care and service provision

The primary purpose of this project therefore was to examine the evidence base required to support the SIA Strategy and Model of Care<sup>1,2</sup>, investigate existing clinical service delivery and commissioning practice in Specialist SCI Centres across the UK, establish a national collaborative network to design and implement consistent, evidence-based working practices for Specialist Spinal Cord Injury Services, in support of the SIA Model of Care, and to meet recommendations from the Carter Report<sup>4</sup> and other statutory requirements<sup>3,5,7</sup>.

### 3. Process

An action research approach was adopted to optimise engagement of SCI Centre staff and the populations they serve throughout the project and ensure the focus of the research could develop and be directed as appropriate. The project and the main data set were centred on the 9 SCI Centres in England and Wales, due to a variance in commissioning and governance arrangements but exploration of the SCI Centres in the Scotland and Northern Ireland and their models of care were also included in the study.

#### PHASE 1 – INITIAL REVIEW

A postal survey was sent to all UK Specialist Spinal Cord Injury Centres to examine designated geographic population and actual patient population served, staffing, facilities and services provided by the individual centres. Responses were received from all 11 Centres which were then validated and expanded through 1:1 interviews with the Senior Clinicians, Service Managers and SIA Peer Support Workers in each of the SCI Centres.

Results of the surveys and interviews demonstrated the range in patient experiences and services provision nationally and highlighted key issues of concern around access, discharge planning, information management and financial constraints for service users and providers. A detailed report was published in May 2008<sup>6</sup> in which key findings were:-

#### Capacity and Location

- 95% of available bed capacity in England and Wales was open in 2007. 5% bed capacity was unfunded

- All SCI Centre beds fell under host Trust bed management policy and may be used by non-SCI patients if unoccupied
- Range of bed management policies existed within SCI Centres – no standardised process existed to ring-fence beds for specific patients groups
- Lack of designated catchment areas for SCI Centres. 7 out of 8 centres admit patients from outside designated patient population with large geographical spread
- Patients were referred to more than one SCI Centre to optimise potential for admission
- Lack of co-ordinated referral and admission management across geographically linked SCI Centres
- Delayed referrals and admissions to SCI service were reported
- SCI Centres reported an increasing number of complications noted on admission
- A variation in provision and availability of services on site (within SCI Centre or host Trust). Lowest scores for outreach, access to psychiatric services, neurosurgery, vocational training and sports facilities
- Variation in staff to patient ratio across all disciplines
- 2 SCI Centres were located in Foundation Trusts. The Host Trusts of 2 further SCI Centres were seeking Foundation Trust status
- Plans approved for 1 facility to be re-built. Planning in progress and awaiting decision for 2 further existing SCI Centres to be re-built

## Statistics

- All SCI Centres were using different data management systems – 2 SCI Centres planning to use IMS MAXIMS data management system (1 already in operation) and 1 Centre developing new stand alone database
- Incomplete data set for national database – data set should contain all new patients admitted to SCI Centre.
- National SCI Centre database does not include patients served by out-patient services or non-acute admissions
- No comprehensive data available on patients referred but not admitted to SCI Centres
- Variation in case mix across centres (ratio of traumatic to non-traumatic SCI)
- Lack of standardisation in outcome measures across all centres, including classification of injury

## Funding

- Host trust financial cost improvement programmes impacted on all SCI Centres, resulting in reduction in services, staff establishment, bed capacity and prevention of service developments.
- A minimum of 5% overall reduction required of all SCI Centres by their host Trusts in financial year 2007/08
- Posts lost and absence cover not provided in response to Host Trust cost improvement plans
- Cost improvement programmes failed to take into account financial position of SCI service for previous year
- Lack of involvement and dialogue of SCI Centre clinical and management team in commissioning of local SCI services
- 3 SCI Centres had become involved with the South of England Consortium Board and 5 SCI Centres participate in relevant Board sub-groups to review the commissioning of services

## Model of Care

- Lack of evidence base to support preferred model of care <sup>9,10</sup>
- Variation in clinical management approach – surgical /conservative management of acute injury, target length of stay, desired discharge location
- Informal acute and follow-up Outreach services provided by 8 SCI Centres with no additional funding identified to support the service
  - 1 SCI Centre has outreach model across designated catchment area
  - 1 SCI Centre provides training for link nurse role within acute hospitals
- Range in availability of psychiatric services on site
- Lack of provision of counselling service by some SCI Centres
- Variation in access to and provision wheelchair services
- Variation in provision of benefits advisory services
- Variance in organisational structure within host trust and grouping with other services.
- Therapy services belong to different directorates/clinical division

These findings focussed development, by all stakeholder groups, of the Phase 2 protocol to provide objective evidence to quantify the patient, provider and funding position of specialist Spinal Cord Injury Services in England and Wales.

## PHASE 2 – SEEKING THE EVIDENCE

In order to achieve a comprehensive and balanced review of the service, it was essential to obtain information from all of the key stakeholder groups ie specialist spinal cord injury service users, providers and commissioners and also other NHS services (acute, tertiary and primary care) which provide any form of health care to patients with spinal cord injury.

Service users, providers and commissioners were surveyed to establish the national population of SCI persons using specialist SCI services and other NHS services, identify their clinical needs, describe existing pathways of care and patient experiences, re-visit facility and service provision and clarify patterns of commissioning.

## SERVICE USERS

### Spinal Cord Injured Persons

A population of SCI persons, including and beyond the Spinal Injuries Association membership, was targeted through an on-line Survey, posted on the SIA website but signposted from other key user group websites to examine:-

- SCI population demographics
- Level and severity of spinal cord injury
- Location and nature of care and support (SCI Centre or other NHS services)
- Consequences of SCI and co-existing medical conditions.

## SIA Peer Support Team

The Spinal Injuries Association (SIA) Peer Support Team provides personal support and information to patients, their families and friends at the specialist SCI Centres and for patients awaiting admission to a specialist centre who are being treated in the community or district general

hospitals. The Peer Support Team submit monthly reports to their Team Manager, summarising and highlighting questions and concerns raised by patients, families and health care professionals which provide a useful reflection of the frontline issues facing patients going through or trying to access the service.

The Peer Support Team reports from 10 Spinal Cord Injury Centres (Belfast, Cardiff, Middlesbrough, Oswestry, Salisbury, Sheffield, Southport, Stanmore, Stoke Mandeville and Wakefield) for the period April 2007 – March 2008 were reviewed to identify key themes and issues of concern and difficulty for patients, families, carers and staff in SCI Centres.

## SPECIALIST SPINAL CORD INJURY CENTRES

Four survey pro forma's were sent to each SCI Centre in England and Wales to examine:-

### ■ All new in-patients and emergency re-admission patients discharged

1 April 2007 – 31 March 2008

Demographics; Level and severity of injury; Associated injuries and pre-existing medical conditions; Reason for and length of admission; Complications on and during admission; Discharge destination and delays; Referral and funding sources

### ■ All Planned Re-Admission Patients Discharged From SCI Centre

1 April 2007 – 31 March 2008

Demographics; Level and severity of injury; Reason for admission; Length of admission; Discharge destination and delays; Referral sources

### ■ Out-Patient Attendees From

1 September – 31 December 2008

Demographics; Referral Sources; Reason for Referral; Treatment Required; Referral to other services

### ■ SCIC Staff and Facilities

Existing and recent change in SCI Centre services/staff posts in 07/08

Proposed service and staff changes for 2008/09

## SERVICE COMMISSIONERS

A survey pro forma was sent to each Strategic Health Authority Commissioning Team to identify:-

- Established contract activity with individual SCI Centres
- Funding for non-traumatic SCI
- Knowledge of SCI patients in other NHS services

## OTHER NHS SERVICES

A survey pro forma was sent to Chief Executives of all acute NHS Trusts to identify:

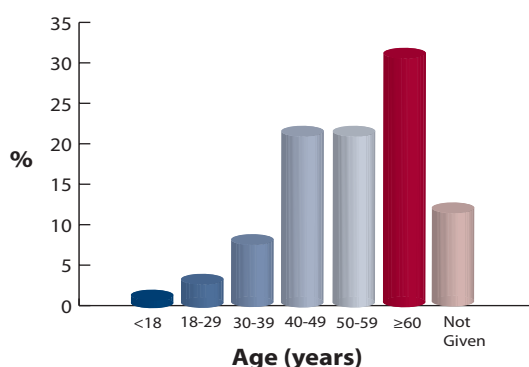
- Number of SCI patients managed within acute NHS Trust April 1 2007 – 31 March 2008
- Trust clinical services involved in management of SCI patients and nature of treatment given
- Incidence of referral to specialist SCI Centres

## 4. Findings

### SERVICE USERS On-Line User Survey

829 people with spinal cord injury completed the user survey. Details of the population are shown in Figures 1 - 3.

**Figure 1: Respondent Age**

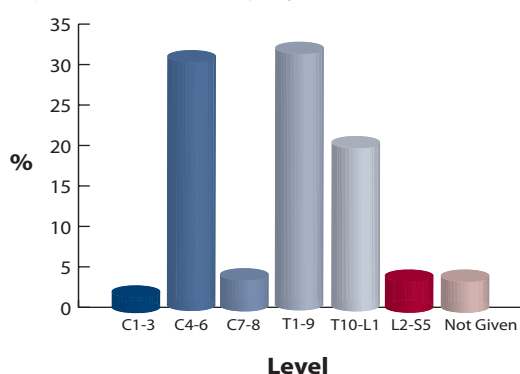


A majority of the respondents (67%) were male (gender not stated by 2% respondents) and 32% were greater than 60 years of age.

75% of respondents reported their injury was a result of trauma. 21% reported non-traumatic causes of injury, which included infection, other stable conditions and disc prolapse. Cause of injury was not stated by 4% of respondents.

The largest groups of injuries were T1 – 9 (33%) and C4 – 6 (32%). 53% of respondents reported their injury resulted in complete loss of voluntary muscle power and sensation. 44% reported some degree of neurological function below the level of their injury and 3% provided no information regarding severity of injury.

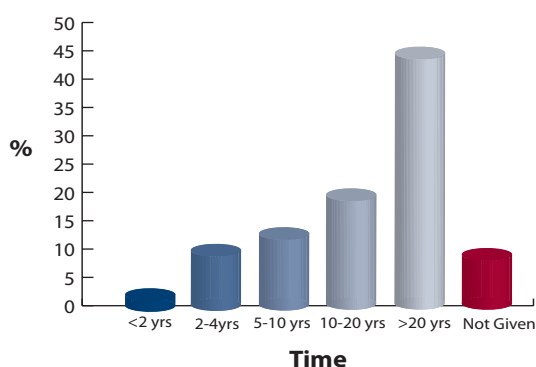
**Figure 2: Level of Injury**



10% reported that they had never been under the care of a specialist SCI Centre.

66% of respondents reported that they had received a continuity of care post discharge from their SCI Centre. 25% reported a change in follow-up care provision, the majority of which related to care being transferred to another specialist SCI Centre (85%) following relocation of residence. 9% of respondents did not answer this question.

**Figure 3: Time Post Injury**



59% of the respondents reported that they had experienced significant health problems or complications related to their spinal cord injury since their initial discharge from hospital. The most frequently occurring problems were bladder related (36%) and pressure sores (15%).

43% of the respondents reported that they had other medical conditions in addition to their spinal cord injury. 8% did not answer this question. 44% of the respondents reported using other NHS services, of which 8% stated that they required treatment for health problems unrelated to their spinal cord injury.

### Key Facts

- 10% Never under care of SCI Centre
- 59% Experienced significant SCI related problems
- 43% Reported additional medical conditions
- 44% Using other health care services

## Peer Support Team Reports

The Peer Support Team reports for the period April 2007 – March 2008 were reviewed. 1668 contacts were analysed and individuals involved in each of the Peer Support contacts were divided into 3 categories:-

- i. **Patient** (out-patient and in-patient – new or re-admission)
- ii. **Relatives, friends or carers**
- iii. **Staff** (SCI Centre staff or non-SCI Centre health professionals)

Figure 4: Contact Personnel

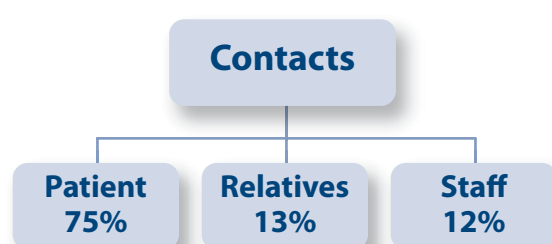
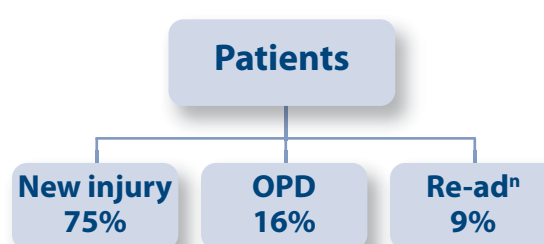


Figure 5: Patient Contacts



Content analysis was performed on all the reports to identify key themes and issues of concern and difficulty for patients, families, carers and staff in SCI Centres. Where multiple issues were reported in one contact, all issues were recorded and attributed to the relevant category. The number and nature of the contacts varied from centre to centre, dependent on the number of Peer Support staff and the frequency of attendance at the Centre. Key themes identified across all the centres were:-

**Advice** – Peer Support Team members provided practical advice and signposting on a number of topics, including wheelchairs, driving, travel, housing and independent living, benefits, equipment, care packages. The topics most frequently discussed were housing (21%), benefits (14%) and care packages (13%).

**Support and Advocacy** – Peer Support Team members often facilitated discussions or were approached for support by patients experiencing difficulties related to adjustment to

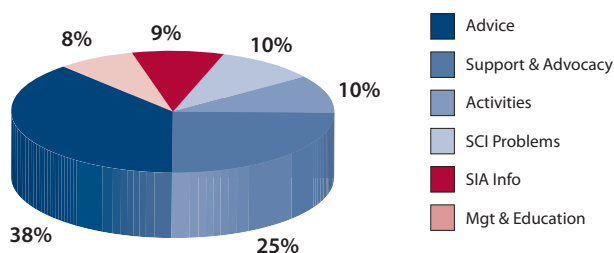


injury, relationships or carers. Most frequent needs were related to adjustment to injury (62%) and management of carers (22%).

**Activities** – Peer Support Team members were actively involved with some patient rehabilitation and reintegration activities, facilitating trips to leisure facilities, demonstrating practical skills and assistance with employment and education facilities.

**SCI related problems** – Peer Support Team members were often approached by new and returning patients to discuss problems resulting from the consequences of spinal cord injury eg. bladder and bowel management, tissue viability, pain, spasticity and fertility. The most frequent problems identified were bladder and bowel management (40%) and pressure sores (19%). Concerns were also highlighted by patients about treatment received from non-SCI specialist service.

**Figure 6: Distribution of Peer Support Contacts**



**SIA Information** – Peer Support Team members provided details of SIA resources available – services and information (leaflets, publications, helpline, web-site) which were not exclusive to SIA members.

**Management and Education** – Peer Support Teams were often involved in SCI centre management, through a variety of activities – participation in Patient Groups, SCI Management Team meetings and service review and development projects. They were also involved in education programmes for patients, SCI centre staff and also other health care professionals visiting the SCI Centre or in other hospitals where patients were waiting to be transferred to an SCI Centre.

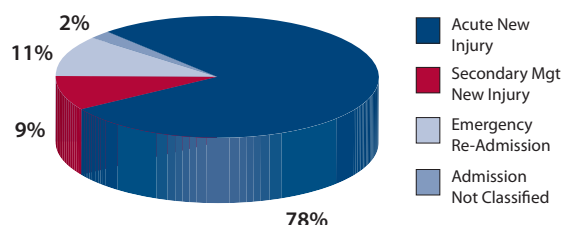
## SPINAL CORD INJURY CENTRES New In-Patients And Emergency Re-Admissions

744 patients were discharged from the 9 SCI Centres between April 1 2007 – 31 March 2008, following admission for acute or secondary management of a new spinal cord injury or re-admission for emergency treatment.

Management of acute new injuries accounted for 78% of all admissions in this patient group.

71% of the total population were male and 28% female (1% gender not given). The average age was 44 years with a range from 3 to 102 years. The largest age group was 21 – 30 years which accounted for 20% of total population.

**Figure 7: Reason for Admission**





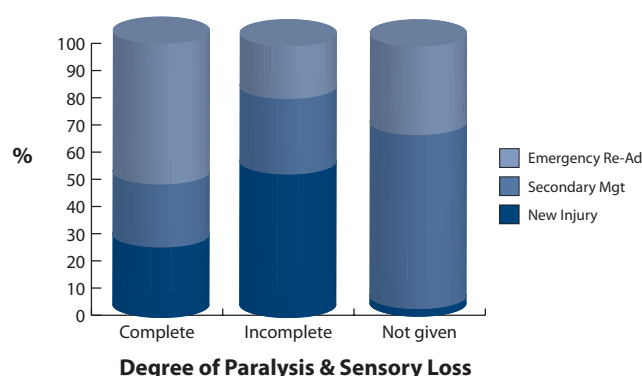
The distribution of levels of injury across the three admission groups are shown in Table 1.

**Table 1: Level of Injury**

| Type of Admission           | Level of Injury |        |         |        |        |           |
|-----------------------------|-----------------|--------|---------|--------|--------|-----------|
|                             | C1 - 4          | C5 - 8 | T1 - 12 | L1 - 5 | S1 - 5 | Not Given |
| New Injuries                | 24%             | 26%    | 37%     | 11%    | 0.1%   | 1.9%      |
| 2° Mgt of New Injuries      | 13%             | 20%    | 34%     | 18%    | 0      | 15%       |
| Emergency ReAd <sup>n</sup> | 9%              | 32%    | 38%     | 7%     | 0      | 14%       |

The most frequent injuries were at the thoracic level in all three admission groups.

**Figure 8: Severity of Injury**



71% of the population sustained a spinal cord injury through trauma and 28% of the population had spinal cord injury as a result of other disease processes. The cause of injury was not stated in 1% of the population. The most frequent cause of traumatic injury was road traffic accident (27%), followed closely by falls (26%). Non-traumatic causes included infection and malignancy.

## Key Facts

- **71% population sustained traumatic spinal cord injury**
- **Most frequent causes of injury were road traffic accidents (27%) and falls (26%)**
- **Non-traumatic SCI patients significantly older than traumatic SCI patients ( $p < 0.01$ )**

## Associated Injuries and Pre-existing Medical Conditions

24% of patients were reported to have sustained other injuries at the time of their spinal cord injury. The most common incidence were chest injuries (39%), shoulder girdle and upper limb injuries (30%) and injuries to the pelvis and lower limb (28%). 19% of the patients were reported to have sustained some degree of head injury although further classification or description of these patients was not available.

44% of the patients were reported to pre-existing medical conditions un-related to their spinal cord injury. The most common reported were cardiovascular (26%), respiratory (16%) and neurological (12%) conditions. 13% of the patients were diabetic pre-injury and 9% had a previous history of mental health problems.

## Referral and Admission Management

Detailed referral information was not available in 30% of the total patient group (24% referral information on new injuries missing).

The most common sources of referral for the entire patient group were Orthopaedic services (26%), Neurosurgery (14%) and 10% of referrals were received directly from Accident and Emergency departments.

From the available data, the average time from diagnosis of a new spinal cord injury to admission into a specialist SCI Centre was 46 days, which reflected delays in referral from the acute Trust, patients medically unfit for transfer and the capacity of SCI Centres to admit, due to restricted availability of appropriate beds.



### Key Facts

- 17% New Injuries referred within 1 day of injury
- 21% New Injuries **not** referred within 1 month of injury
- 9% New Injuries admitted within 1 day of Injury
- 41% New Injuries **not** admitted within 1 month of injury

## Complications On and During Admission

24% newly injured patients presented with complications on arrival at the SCI Centre. The most common complications were pressure sores (40%), respiratory (28%) and infection control (6%). 28% patients also incurred complications during admission although the distribution of problems was different – Respiratory (24%), infection control (22%) and pressure sores (10%). Incidence of deep vein thrombosis (DVT) was reported in 7% of the patients.

### Key Associations

- Delay from time of injury to admission to SCI Centre increased risk of complications on admission ( $p < 0.05$ )
- Strong correlation between age and number of complications on and during admission ( $p < 0.05$ )
- Patients admitted to SCI Centre with complications had increased risk of complications during admission ( $p < 0.05$ )

**Table 2: Average Length of stay**

| Admission Type                             | Level of Injury |          |          |         |         |
|--|-----------------|----------|----------|---------|---------|
|  | C1 - 4          | C5 - 8   | T1 – 12  | L1 - 5  | S1 - 5  |
| <b>New Injury</b><br>583 patients          | 140 days        | 177 days | 112 days | 84 days | 65 days |
| <b>2° Mgt of New Injury</b><br>68 patients | 95 days         | 121 days | 124 days | 98 days | -       |
| <b>Emergency Re-Adn</b><br>81 patients     | 36 days         | 53 days  | 57 days  | 39 days | -       |

An extensive range in length of stay was seen both within and across the SCI Centres.

### Key Associations

- **Highly significant increase in length of stay for patients with complications on or during admission ( $p < 0.001$ )**
- **Strong correlation between level of injury and length of stay ( $p < 0.001$ )**
- **No significant correlation between age and length of stay**

### Discharge Destination

74% of all patients were reportedly discharged to their own home, with a further 6% discharged to an interim placement ie. not their final place of residence. 1% of patients were transferred to the care of another SCI Centre to be nearer their chosen location for discharge.

6% patients were discharged to residential or nursing home care and 4% of patients were discharged to a District General Hospital for further healthcare or due to lack of available community accommodation. 2% of all patients died and discharge data was not reported in the remaining 2% of the population.

Delays in discharge were reported in 16% of the population, the most frequent cause of delay being organisation and funding of care packages and accommodation. However, 53% of the patients delayed were discharged to their own home.

### Elective Re-Admissions

909 patients were discharged from 6 SCI Centres following elective admission for on-going treatment of SCI related problems or further rehabilitation.

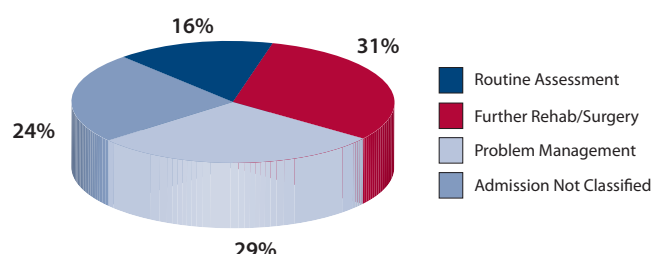
63% of this population were male and 25% female (12% gender not specified). The average age was 48 years (range 2 - 82 years) but the average male age was 43 years and the average female age was 52 years. 57% of the Re-Admissions population had sustained a spinal cord injury through trauma and 15% of the population had spinal cord injury as a result of other disease processes. The cause of injury was not stated in 28% of the population.

**Table 3: Level of Injury**

| C1 - 4 | C5 - 8 | T1 - 12 | L1 - 5 | S1 - 5 | Not Given |
|--------|--------|---------|--------|--------|-----------|
| 13%    | 30%    | 45%     | 8%     | 0.1%   | 3.9%      |

43% of the population had sustained SCI resulting in complete loss of voluntary muscle power and sensation. 24% reported some degree of neurological function below the level of their injury and 33% provided no information regarding severity of injury.

**Figure 9: Reason for Admission**

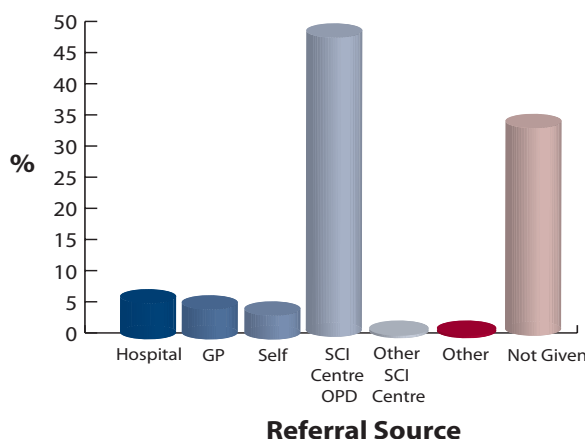


The 3 categories for admission were almost equally divided between routine assessment, further rehabilitation or surgery and problem management. The reason for admission was not classified for 16% of the patient group.

50% of the Re-Admission patients were identified through planned follow-up in the SCI Centre Out-Patient department.

The most frequent problems requiring admission to the SCI Centre were bladder (14%), respiratory complications, bowel management (3%), pressure sores (2%), spasticity (2%) and pain (1%).

**Figure 10: Referral Source**



## Key Facts

- 50% of Elective Re-Admission patients identified through planned follow-up
- 31% Elective Re-Admissions for further rehabilitation or surgery
- 29% Elective Re-Admissions for management of SCI related problems
- Average Elective Re-Admission stay - 28 days (Range 1 – 485 days)
- Total bed days required for 909 Elective Re-admissions - 25,452

## Out-Patient Activity

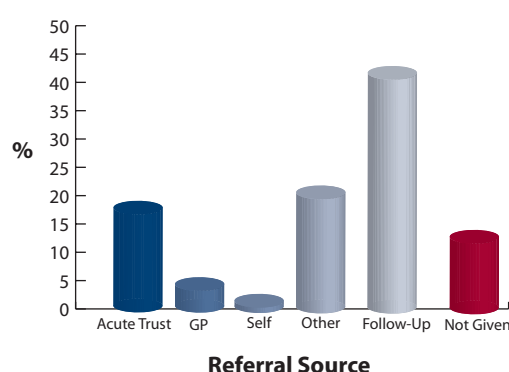
974 Out-patient attendances between 1 September – 31 December 2008 at 4 Specialist Spinal Cord Injury Centres were reviewed.

72% of the Out-Patient population were male and 27% female (1% gender not specified). 66% of this population had sustained a spinal cord injury through trauma and 28% of the population had spinal cord injury as a result of other disease processes. The cause of injury was not stated in 6% of the population. The average age was 49 years (range 5 – 89 years) and the largest age group was 41 – 50 years. There was no significant difference between the age of the traumatic injury group (average 48 years) and the non-traumatic injury group (average 49 years).

**Table 4: Level of Injury**

| C1 - 4 | C5 - 8 | T1 - 12 | L1 - 5 | S1 - 5 | Not Given |
|--------|--------|---------|--------|--------|-----------|
| 10%    | 29%    | 44%     | 12%    | 0.1%   | 4.9%      |

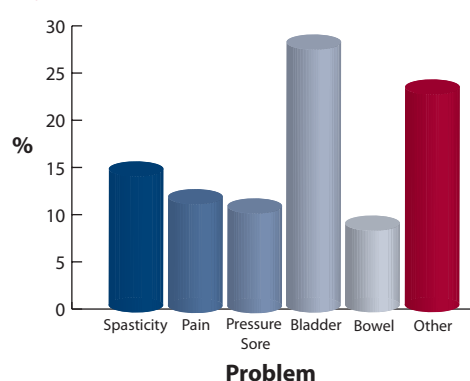
**Figure 11: Out Patient Referral Source**



The distribution of referral sources is shown in Figure 11. A large proportion (43%) of the out-patient activity related to patients in the planned review programme which forms part of the SCI Centre commitment to life long support.

72% of all the patients seen in the out-patient department reported significant clinical problems, highlighting the importance of systematic life-long review programmes. The most frequent problems reported were bladder related (29%) and spasticity (15%). Other problems (24%) included neurological, musculo-skeletal and psychological issues.

**Figure 12: Clinical Problems**



## Key Facts

- **46% Out-Patient activity is planned patient review**
- **29% Out-Patients required further active treatment**
- **22% Out-Patients required referral to other services**

## Facilities and Staffing Bed Management

The number of beds available within the service across the 9 SCI Centres increased in 2008, from 417 to 425 beds and all beds were funded and staffed.

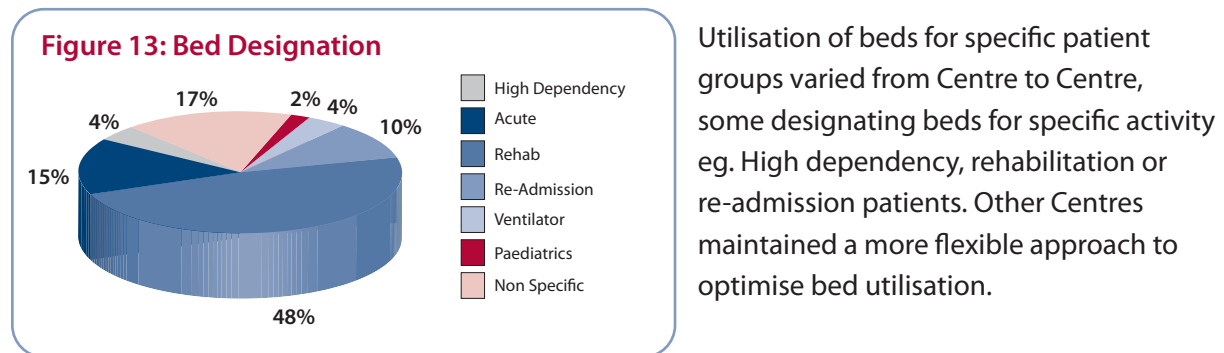


Figure 13 demonstrates the designation of beds for particular functions across the national bed availability.

Accurate information to assess daily bed utilisation and occupancy was difficult to retrieve across the 9 Centres. All of the SCI Centre beds fell under the host Trust bed management policy, and as such could be used by patients requiring admission under the care of other services eg. trauma, orthopaedics, general medicine and surgery. Conversely, SCI patients could also be admitted into other non-SCI beds within the host trust, in particular HDU or ICU beds. Detailed information on host Trust bed occupancy by SCI patients was not retrieved but 969 occupied SCI bed days were taken up by non-SCI patients in three of the SCI Centres, which represents 1.5% of the available bed days across those three SCI Centres.

## Change in Facilities and Staffing

Service and SCI Team configuration varied across the 9 SCI Centres. A small number of additional junior and senior posts had been established during the previous year in medical, nursing, therapy and management teams across 4 of the SCI Centres but cuts had also been made in nursing and therapy teams across 3 of the Centres. Host Trust cost pressures had been imposed through lack of replacement cover for maternity leave, re-deployment of staff across the organisation and substantial reductions in agency nursing budgets.

Bids for service developments to augment clinical and administration services (additional specialist consultant medical and nursing staff; new clinics for out-patient and outreach support; re-organisation of discharge planning process) had been prepared but not agreed for the new financial year.

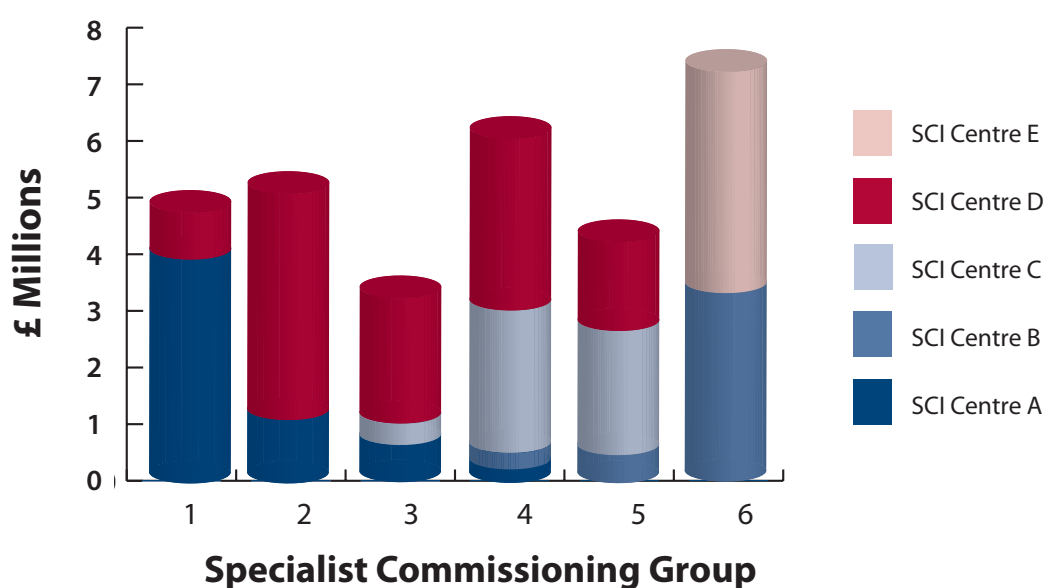
### Key Facts

- **1% Increase in available bed capacity over financial year 2007/08**
- **969 SCI bed days utilised by non-SCI patients**
- **Host Trust cost pressures reduced SCI Centre staffing**

## SERVICE COMMISSIONERS

Responses were received from 6 out of the 10 Specialised Commissioning Groups (SCG'S) who had contracted activity with 5 out of the 9 SCI Centres across England and Wales. Each of the SCG's had commissioned activity in more than 1 SCI Centre and one SCG had contracted services from 4 separate SCI Centres. The contracted activity for spinal cord injury by the 6 Specialist Commissioning Groups across the 5 Centres totalled £32,215,053.

**Figure 14: Commissioning Patterns**



It was not possible to equate the funds paid to specific patient activity, due to the variance in commissioning arrangements and currencies, some being calculated through occupied bed days and others through episodes of care. Each of the SCG's reported that they had not commissioned treatment of SCI patients in other NHS Centres. Where treatment occurred, it would often be funded through larger contracts managed by the patient's PCT.

### Key Facts

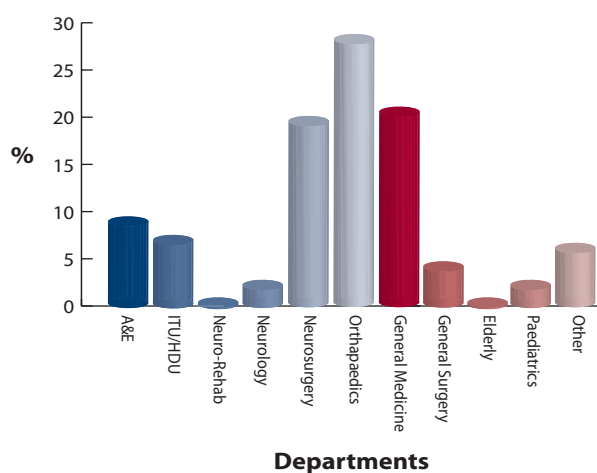
- No national standardised currency for commissioning
- Unable to differentiate SCI activity within Host Trust activity
- Limited contract monitoring information available

## OTHER NHS SERVICES

Pro formas were sent to the Chief Executives of 170 Acute NHS Trusts. 15 Trusts responded (8%), of which 9 Trusts (5%) provided information on SCI patients who had been treated by their organisation.

253 patients had been treated across the 9 organisations in the departments shown in Figure 15. Other departments managing SCI patients were oncology, plastics, pain management, obstetrics and colorectal services.

**Figure 15: Departments Treating SCI Patients**



Details of referral source and rationale were only available for 20% of the patient group but 17% of the total population (43 patients) were admitted for initial management of their spinal cord injury and only 6 were known to have been referred on to a specialist SCI Centre.

### Key Facts

- **SCI Patients use diverse range of other NHS services**
- **Identification of SCI Patients problematic and information not available as routine**

## 5. Discussion

The population characteristics (gender, age, levels and severity of injury) are similar in all patient groups reviewed in this study, with the exception of a larger number of older patients with long standing injuries completing the on-line user survey. Future surveys should seek to include experiences and desires of newly injured patients to embrace more recent experiences and reintegration issues. The populations also have similar characteristics to those reported by the Queen Elizabeth National Spinal Injuries Centre in Glasgow for the same year, adding confidence that the study sample is representative.



It is recognised that the desired model for management of acute spinal cord injury addresses the requirements of the World Health Organisation Convention on the Rights of Persons with Disability<sup>7</sup> ie early identification of impairment and intervention to minimise and prevent further disability, in order to achieve lifelong health and well-being. This study suggests that the existing SCI service is striving to achieve this for acute SCI sustained as a result of trauma but results of the on-line user survey would suggest that further work is required to bring this in line for patients who have sustained SCI as a result of other disease processes.

A high percentage of each patient group in the study reported medical conditions additional and unrelated to their spinal cord injury. The National Service Framework for Long Term Conditions<sup>5</sup> requires that provision of healthcare to patients with long-term neurological conditions, in any healthcare setting, should not compromise management of the patient's neurological condition or personal care. It is important, therefore, that the specialist SCI Centres provide an accessible service interface for their patients and other health care providers, to ensure that any health care need is managed within the context of their spinal cord injury.

It is important to recognise the increasing pressure on the specialist SCI Centres to provide extended services to a growing population whilst complying with their host Trust bed and financial management initiatives. Imposed cost pressures have resulted in reduced staffing and delays in proposed service developments, despite direct funding streams from the service commissioners. Use of SCI beds by non SCI patients prevents access for SCI patients and also presents issues in relation to governance regarding the skill set for SCI Centre staff for the management of some non SCI patients. Further blockage of SCI beds results from delayed agreement and funding of more complex care packages to enable community reintegration for SCI patients.

This study quantified the difficulties in retrieval of basic patient information across the service. Retrospective data collection was required to review in-patient activity which proved complex and problematic, such that substantial information was not available. The prospective data collection process to monitor out-patient activity greatly improved the quality and quantity of data required. International data sets and information management software, specific to spinal cord injury, have been developed and recognised but implementation requires extensive investment and may not be supported by the SCI Centre host Trust information strategy.

Throughout the course of the project, there have been several relevant developments made in associated work streams. The South of England Spinal Cord Injury Board, configured following an extensive review of specialist SCI services in the South of England, has commenced a work plan to cover many areas identified in the study. The Board and its relevant sub-groups are in the process of reviewing the service standards devised in 2003 for the 3 SCI Centres in the South of England, investigating an appropriate model for an acute outreach service, considering a minimum data set and information management system and developing standardised currencies to support the commissioning process.

Other organisations have devised or revised standards relevant to spinal cord injury patients (British Society of Rehabilitation Medicine<sup>12</sup>, UK Rehabilitation Council and Commission on Accreditation of Rehabilitation Facilities<sup>13</sup>) which should be considered in the development of national service standards in Phase 3.

All of the SCI Centres were involved in aspects of research and investigation, ranging from basic science programmes, clinical management, to service re-configuration but resources and capacity vary considerably between Centres. The UK Spinal Cord Injury Research Network is seeking to support collaborative research development through provision of expertise and funding. The charity ASPIRE is undertaking a review of the use of interim housing to facilitate discharge from SCI Centres and Spinal Research continues to support research into new therapies to limit or reverse nerve damage, which are planned to move into clinical trials in the near future. These trials will require facilities and expertise that are currently not available at all the SCI Centres. Research forms the basis of the SCI Service of the future and as such, all service developments should incorporate facilities and practices which enable implementation and evaluation of evidence-based innovation in spinal cord injury management.

## 6. Recommendations

This extensive review has demonstrated the importance of specialist management for people with spinal cord injury to address their complex and discrete healthcare requirements, confirmed a patient population failing to gain access to the service and highlighted the disadvantages of not gaining timely and appropriate access to specialist spinal cord injury care.

### SIA User Survey

*'My GP is my only health expert .....*

*.... asked local rehab centre to review me and they refused.*

*My GP feels out of their depth and I feel no-one gives a damn'*

August 2008

Each of the patient populations reviewed in this study experienced health problems unrelated to their spinal cord injury and required treatment from other health care services. The specialist spinal cord injury centres must therefore provide an accessible service interface for their patients, to ensure that any health care need is managed within the context of their spinal cord injury.

Retrieval of information across the service was complex and problematic. This report highlights particular areas of information deficit, in order that prospective data collection may be improved, to ensure the required capacity planning, service procurement and funding, and programme development are adequately addressed.

Scientific advances continue, which in time may impact on initial and late stage management of spinal cord injury, to reduce impairment and enhance functional recovery of the central nervous system. All future service planning must incorporate facilities and practices which enable implementation and evaluation of evidence-based innovation in spinal cord injury management.

The Spinal Injuries Association advocates that the following standards should be requirements for a future specialist spinal cord injury service:-

## Capacity and Location

Every newly injured patient gains access to specialist SCI service within 24hours  
Life-long access for all SCI patients to specialist SCI services in appropriate location

## National Model of Treatment

National protocol for treatment and care of SCI people  
SCI people treated by dedicated, trained specialist SCI Team with required facilities and resources

## Information Management

National information management system to collect incidence and prevalence data  
Compatible electronic patient records across SCI Centre

## Funding

Financial transparency and consistency  
Single body to monitor, evaluate and commission SCI service

In the immediate future, key areas for research and service development will enhance the patient experience, improve and quantify clinical outcomes and increase service efficiency. The target areas for development in Phase 3 are:-

## CARE PATHWAYS and STANDARDS OF CLINICAL MANAGEMENT

- To develop national guidelines for clinical management of SCI patients in NHS services
- To review, develop and implement clinical pathways for acute admission and lifelong support of SCI patients in specialist SCI Centres and other NHS services
- To identify and adopt standardised clinical outcome measures to support and evaluate patient care pathways
- To undertake national audit of practice

## INFORMATION MANAGEMENT

- To develop minimum data set for all patients managed by SCI Centres
- To develop and implement compatible data collection methods in all SCI Centres
- To review methods for SCI patient identification in other NHS services

## FUNDING

- To standardise and adopt a national commissioning framework and currency for spinal cord injury
- To review SCI Centre Host Trust utilisation of specialised commissioning funding

## CLINICAL COMPLICATIONS

- To conduct a prospective review of complications for new SCI patients and patients already under care of specialist SCI service

Further research is also required to provide evidence to support a preferred model of care for the management of acute new injuries and to examine the factors contributing to variance in length of stay, utilising the selected measures developed to compare meaningful outcomes.

In order to maintain continuity and momentum, it is essential that collaboration of all relevant stakeholder groups is continued and further developed in Phase 3 as soon as possible. The proposed work plan falls in line with recommendations from the Carter Review<sup>4</sup>, which include formation of clinical networks and strengthened integrated pathways, national clinical databases, improved performance management and raised profile for commissioning.

Partnership agencies to assist in addressing these goals should include all SCI Centres in UK, Strategic Health Authorities, Specialised Commissioners, South of England SCI Board, British Association of Spinal Cord Injury Specialists (BASCIS), Multidisciplinary Association of Spinal Cord Injury Professionals (MASCIP), SCI UK, UK Spinal Cord Injury Research Network, the National Institute for Health and Clinical Excellence and the Department of Health.

This study provided a comprehensive baseline overview of the requirements and provision of specialist spinal cord injury services during one financial year. The data have quantified anecdotal reports of restricted or delayed access to services and demonstrated the importance of early referral and admission to a specialist Spinal Cord Injury Centre to prevent complications and achieve successful discharge to the patients chosen environment.

Key themes run throughout the report – successful outcome following timely access to specialist SCI services; demand exceeding availability; increased financial pressures causing service reduction and constraining service development; lack of co-ordinated care across services, compounded by inadequate information management. Failure to address these issues in a pro-active and systematic way will result in undesirable patient experiences, poor clinical outcomes and inefficient use of NHS resources. Collaborative development of a national spinal cord injury service, based on common principles and standards of care, with clearly defined pathways and networks to interface with other health care services for initial management and life long support, will ensure a universal lifelong improvement for people with spinal cord injury.

The SIA 'Campaign for Change' and the creation of the All Party Parliamentary Group on Spinal Cord Injury have already raised national awareness of the issues facing people with spinal cord injury and the specialist spinal cord injury service they require. This report demonstrates the strength of collaborative working and provides a further evidence base to support the work plan for the All Party Parliamentary Group and other relevant groups, including the South of England Spinal Cord Injury Board, National Specialised Commissioning Group and the Spinal Injuries Association which will continue to campaign to 'Preserve and Develop a National Spinal Cord Injury Service' which is 'Fit for Purpose' for all those who will require it in the 21st century.

**Fiona Barr PhD MCSP SRP**  
**Research Project Manager**  
**May 2009**

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# Spinal Injuries Centres

## **Duke of Cornwall Spinal Treatment Centre**

Salisbury District Hospital  
Odstock Road  
Salisbury  
SP2 8BJ

## **Golden Jubilee Spinal Cord Injuries Centre**

James Cook University Hospital  
Marton Road  
Middlesbrough  
TS4 3BW

## **London Spinal Injuries Centre**

Royal National Orthopaedic Hospital NHS Trust  
Stanmore  
Middlesex  
HA7 4LP

## **Midlands Centre for Spinal Injuries**

Robert Jones & Agnes Hunt  
Orthopaedic Hospital  
Oswestry  
Shropshire  
SY10 7AG

## **National Spinal Injuries Centre**

Stoke Mandeville Hospital  
Mandeville Road  
Aylesbury  
HP21 8AL

## **The Princess Royal Spinal Injuries Centre**

Northern General Hospital  
Sheffield  
South Yorkshire  
S5 7AU

## **Queen Elizabeth National Spinal Injuries Unit for Scotland**

1345 Govan Road  
Glasgow  
G51 4TF

## **North West Regional Spinal Injuries Centre**

Southport & Formby District General Hospital  
Town Lane  
Southport, Merseyside  
PR8 6PN

## **Spinal Cord Injuries Unit**

Musgrave Park Hospital  
Belfast  
BT9 7JB

## **Welsh Spinal Injuries & Neurological**

Rehabilitation Centre  
Rookwood Hospital  
Fairwater Road  
Llandaff, Cardiff  
CF5 2YN

## **Yorkshire Regional Spinal Injuries Centre**

Pinderfields General Hospital  
Aberford Road  
Wakefield  
WF1 4DG

## **Supported by**

British Association of Spinal Cord Injury Specialists (BASCIS)  
Multidisciplinary Association of Spinal Cord Injury Professionals (MASCIP)



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