The Audit, Information & Analysis Unit

Audit of Spinal Cord Injured, Ventilator Dependent Patients Referred to a Spinal Cord Injury Centre in the South of England

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CONTENTS

Page

FIGURES

Page

TABLES

Page

Definitions

'n'	The total number of data points. For this audit, the number of patients.
Mean	The average value of a range of data points obtained by adding all the points and dividing by the total number of data points (n).
Median	This is the midpoint of all the data points when they are arranged in order from smallest to largest. If the number of points is even then the median is the average of the two middle data points. This value is less influenced by outliers than the mean.
Mode	This is the value which occurs most often in a range of data points. This value is not influenced by outliers.

Executive Summary

Introduction

There is little published work documenting the incidence and care of spinal cord injured ventilator dependent patients at a regional level. Anecdotal reports suggest many problems with the care pathway, particularly for newly injured patients, including delayed referral, inadequate weaning, delayed admission to a Spinal Cord Injury Centre (SCIC) and avoidable complications such as pressure ulcers. Reports from a London Major Trauma Centre in 2008-09 suggested that significant numbers of these patients occupy intensive care (ITU) beds whilst waiting for transfer to a specialist rehabilitation facility. This is an important clinical and service development issue particularly with the ongoing development of the London Trauma Network which will potentially concentrate the number of newly injured patients in a smaller number of trauma centres. It is also important that patients with complex nursing and clinical needs are treated appropriately and in accordance with recognised standards where they exist.

Key issues for the care of the newly spinal cord injured ventilator dependent patient include: the use of a standard protocol to maximise the chance of successful weaning; timely referral and admission to a specialist SCIC; avoidable complications such as pressure ulcers which can impact on a patient's rehabilitation and length of stay and also on bed capacity at the SCIC. Anecdotal experience suggests that capacity within SCICs is inadequate and does not meet demand but there are currently no data available to quantify this or the delays in admission that are also seen. Early outreach intervention by the specialist spinal cord injury team to the referring trauma centre may help promote good practice, improve outcomes and reduce the risk of avoidable complications.

Respiratory Information for Spinal Cord Injury UK (RISCI UK) is a multidisciplinary group developed by clinicians to formulate national standards of care for spinal cord injured patients requiring respiratory support before and during admission to a SCIC and after discharge. This includes but is not limited to invasive ventilation. Guidelines have been developed for ventilation and facilitated weaning[1, 2, 3] but they have tended to be adopted within specialist centres and it is not known if they are recognised or adhered to outside of the SCI centres.

Methodology

This was a three month prospective audit looking at spinal cord injured ventilator dependent patients referred to the three SCICs in the South of England. A snapshot of the number of ventilated patients who were on a waiting list or were an inpatient at a SCIC was taken at the start of the data collection period and again at the end. During this time data were also collected prospectively on those who were inpatients at a SCIC at the audit start date, those on the waiting list and those who were referred during the audit period whether they were admitted or not. Further data were collected on patient outcomes such as weaning, starting rehabilitation, complications and discharge. The audit looked at both newly injured patients and those with an existing spinal cord injury.

Data collection leads were identified at each SCIC. The proformas including the initial and final snapshot forms and the prospective spreadsheet were developed with the clinical and commissioning leads and agreed by the Service and Standards Subgroup of the South of England Spinal Cord Injuries Board. Input into this process was sought from RISCI UK and from clinicians at Southport and Ormskirk Hospital NHS Trust which has extensive experience in the care of spinal cord injured ventilator dependent patients.

A representative from the Spinal Injuries Association sits on the Service and Standards Subgroup and the South of England Spinal Cord Injuries Board so the study has had patient engagement from the scoping stage through to the development of the recommendations and action plan and final sign off by the Board.

Results

- 87% of the audit population had a new spinal cord injury.
- The audit population was 77% male and ages ranged from 22 to 88 years of age at the time of referral.
- 33% of patients were injured at C4.
- 29% of patients admitted to a SCIC had pressure ulcers and 41% had other complications.
- The initial snapshot identified 13 patients: **6 were inpatients at a SCIC and 7 were on the waiting list of one or more centre.**
- **73% of newly injured patients were ventilated on the day of injury.** The number of **days from injury to ventilation ranged from 0 to 28 days with a mean of 2 days and both median and mode values of 0 days.**
- **Time from injury to referral ranged from 0 to 90 days with a mean time of 20 days and a median of 11 days.**
- For newly injured patients admitted during the audit period, **time from referral to admission ranged from 0 days to over 6 months with a mean of 58 and a median of 51 days.**
- For the patients weaned during the audit period the **total time on ventilator support ranged from 10 to 127 days with a mean of 79 and a median of 84 days.**
- The final snapshot identified 21 patients: **11 were inpatients at one of the SCICs and 10 were on the waiting list of one or more centre.** One patient who was on the waiting list on the 1st January 2010 was still on it on the 31st March 2010.

Conclusions

- This audit has been successful in meeting its aims and has gathered key data on thirty ventilated patients with both new and existing spinal cord injuries. This information will be invaluable to the Spinal Cord Injuries Board and Consortium in gaining a good understanding of this small but high complexity and high cost patient cohort and will inform future service planning.

- It has highlighted the excellent work done by the current outreach teams who, on top of the cohort identified in this audit, have supported Acute Trusts to wean ventilated patients in their ITU and initiate appropriate care to minimise the risk of complications before transfer to a SCIC which can avoid delays in transfer and so means that the start of their rehabilitation programme is not delayed.

- At a regional level the number of patients sustaining ventilator dependent spinal cord injury is relatively small and this supports the current model of patients receiving rehabilitation in a specialist SCIC. However the times seen from referral to admission are excessive suggesting that capacity at the SCICs does not meet demand.

- Referrals from trauma centres to SCICs are often delayed and the reason for this is not clear.

- Avoidable complications are common and impact on a patient's rehabilitation and length of stay and also on capacity at the SCICs. Weaning from ventilation is frequently possible but can take a significant period of time (total time on ventilation in patients that weaned ranged from ten to 127 days with a mean of 79 days).

- The audit has found evidence of flexible bed management to support the admission of ventilated patients. Whilst this ability to utilise resources flexibly is necessary, centres must be supported to be able to admit patients requiring all levels of support to begin expert treatment as soon as possible. If this cycle of delayed admissions, extended length of stay and bed blocking can be broken patients can have the best possible outcomes and centres can function efficiently and cost-effectively.

Recommendations

1. It is essential that Trusts, clinicians and commissioners ensure that future tariffs and contracts reflect the true cost of treating patients according to their level of dependency and achieving best outcomes so that there are no financial disincentives to admit a ventilated patient.

2. Greater capacity is needed within the SCICs to meet the demand for specialist rehabilitation for patients with ventilator dependent spinal cord injury. This would improve clinical care and efficiency by allowing early treatment by a specialist team to maximise chances of weaning, reduce risk of complications and reduce overall length of hospital stay and associated costs. Additionally, SCICs should manage resources flexibly to meet clinical priorities and the prevailing case mix.

3. SCICs should work with Trauma Centres/Acute Trusts to ensure timely contact with and referral to a SCIC are made at the earliest opportunity and in line with the South of England Guidelines and Major Trauma Centre contracts.

4. The South of England Spinal Cord Injuries Board should roll out the use of the referral website and dataset across the south of England. The SCICs should encourage and assist referring hospitals to complete the on-line dataset for all new spinal cord injured patients. This will provide the essential data on service demand which the South of England Board requires for planning purposes.

5. As there are currently no published national guidelines for weaning, clinicians should work with organisations such as RISCI UK to develop and disseminate them. This would help non-specialist centres and trauma units to initiate weaning with liaison and clinical support from their local SCIC.

6. SCICs should record and monitor on a regular basis waiting times from injury and referral to admission for all patients. Commissioners should receive from SCICs regular reports of the numbers of spinal cord injured patients awaiting admission and the length of time waiting. These reports should indicate how many patients are ventilated.

7. SCICs should record and monitor on a regular basis all ventilated patients referred and admitted with pressure ulcers or other avoidable complications.

8. A further study could be commissioned to investigate if there are spinal cord injured ventilated patients in Acute Trust ITUs who are not being referred to a SCIC or managed in conjunction with a specialist spinal cord injury multidisciplinary team.

9. A further long term study could be commissioned to track outcomes and costs against the length of total hospital stay in the medium and long terms as well as the costs and outcomes for models of service delivery in the community for patients once discharged from hospital.

10. A further study could be commissioned to quantify the work of the SCIC outreach services, how the Centres work together to avoid duplication and the impact on patient outcomes. As RNOH will also be implementing an Outreach Service there could potentially be an increase in referrals to centres for both ventilated patients and patients for acute rehabilitation so this will also need to be monitored.

Clinical and Commissioning Prioritisation of Action Points

	Action	Priority		
		High	Medium	Low
1.	SCICs should work with Acute Trusts and Trauma centres to encourage timely contact with and referral to a SCIC. **SCICs, Acute Trusts**	✓		
2.	The use of the referral website should be rolled out across the South of England and SCICs should encourage and assist referring Trusts to complete the online dataset for all new referrals. **Spinal Cord Injuries Board, SCICs, Acute Trusts**	✓		
3.	The South of England Board and/or the NSCISB should work with clinicians and RISCI UK to develop and disseminate national guidelines for the weaning of ventilator dependent spinal cord injured patients. **Spinal Cord Injuries Board, Clinicians, RISCI UK**	✓		
4.	SCICs should provide regular information to the South of England Board and Commissioners on the number of SCI patients awaiting admission to a SCIC and the length of time waiting. This should specifically identify ventilated patients. **SCICs**	✓		
5.	SCICs should record and monitor all patients admitted with pressure ulcers and other avoidable complications. This should specifically identify ventilated patients. **SCICs**	✓		
6.	There should be consideration of what further pieces of work may be required in the medium and long term and this may be in the South of England or as part of the national work programme of the NSCISB. This may involve looking at the work of the Outreach Services, SCI patients in acute Trust ITUs or a longer term study of outcomes. **Spinal Cord Injuries Board**		✓	

1. Introduction and Background

There is little published work documenting the incidence and care of spinal cord injured ventilator dependent patients at a regional level. Anecdotal reports suggest many problems with the care pathway, particularly for newly injured patients, including delayed referral, inadequate weaning, delayed admission to a Spinal Cord Injury Centre (SCIC) and avoidable complications such as pressure ulcers. Reports from a London Major Trauma Centre in 2008-09 suggested that significant numbers of these patients occupy intensive care (ITU) beds whilst waiting for transfer to a specialist rehabilitation facility. This is an important clinical and service development issue particularly with the ongoing development of the London Trauma Network which will potentially concentrate the number of newly injured patients in a smaller number of trauma centres. It is also important that patients with complex nursing and clinical needs are treated appropriately and in accordance with recognised standards where they exist. This study was commissioned by the South of England Spinal Cord Injuries Board to investigate the numbers of spinal cord injured patients requiring ventilation referred to a SCIC, waiting times before admission and total time spent on ventilatory support.

Initial treatment at an acute hospital, such as ventilation, is funded under local contracts and not through the South of England Spinal Cord Injury Consortium however this care clearly impacts directly on a patient's continuing care pathway and eventual outcomes and therefore on strategy and service planning for the SCICs. It is also a key area in ensuring all patients are being equally and appropriately treated and in accordance with the recognised standards where they exist. Throughout this report 'acute hospital' is used to refer to any hospital treating a spinal cord injured patient that is not a Spinal Cord Injury Centre.

Key issues for the care of the newly spinal cord injured ventilator dependent patient include: the use of a standard protocol to maximise the chance of successful weaning; timely referral and admission to a specialist SCIC; avoidable complications such as pressure ulcers which can impact on a patient's rehabilitation and length of stay and also on bed capacity at the SCIC. Anecdotal experience suggests that capacity within SCICs is inadequate and does not meet demand but there are currently no data available to quantify this or the delays in admission that are also seen. Early outreach intervention by the specialist spinal cord injury team to the referring trauma centre may help promote good practice, improve outcomes and reduce the risk of avoidable complications. It is accepted that the earlier a spinal cord injured patient can begin rehabilitation the more likely they are to have a positive outcome so any measures that can mitigate such delays and complications could bring significant benefits to patients and efficiencies to SCICs.

Respiratory Information for Spinal Cord Injury UK (RISCI UK) is a multidisciplinary group developed by clinicians to formulate national standards of care for spinal cord injured patients requiring respiratory support before and during admission to a SCIC and after discharge. This includes but is not limited to invasive ventilation. Guidelines have been developed for ventilation and facilitated weaning [1, 2, 3] but they have tended to be adopted within specialist centres and it is not known if they are widely recognised or adhered to outside of the SCICs. The SCIC at Southport in the North West of England has been at the forefront of much of this work as it has the biggest ventilator unit in the country but again, it is not known if their clinical practice is replicated throughout the country.

For the purposes of this audit ventilator dependency is defined as:

- Ventilator dependency via intubation or tracheostomy secondary to high spinal cord injury rather than associated injuries (e.g. chest trauma)
- Likely to require ventilatory support for more than eight hours a day for a period of at least three months

- Has the potential to wean from ventilatory support under the supervision of an experienced respiratory team within a spinal cord injury centre.

Spinal cord injured patients meeting at least two of these criteria were included in this study.

1.1 Aims

- To ascertain the number and status of ventilator dependent patients on the waiting list for transfer to a SCIC.
- To ascertain the number of patients being referred and admitted to a SCIC whilst still ventilated and to understand how this impacts on capacity and patient outcome.
- To ascertain the waiting times from injury to referral to a SCIC and from referral to admission.
- To ascertain the frequency of complications including avoidable complications such as pressure ulcers.

1.2 Potential Impact

- This is intended as a preliminary piece of work to understand the nature and scale of the problem and could be developed into a larger study looking at all acute hospitals with intensive care units in the South East of England if felt necessary.
- The confirmation and wider adoption of existing guidelines for consistent treatment and referral of ventilated spinal cord injured patients to a SCIC or potentially the development of new national guidance.

1.3 Guidelines/Standards

- Southport and Ormskirk Hospital NHS Trust Ventilator Free Breathing Weaning Guidelines (updated 2006): Southport has one of the largest units for ventilated patients in the UK and has developed guidelines for transfer and weaning of patients.

- Salisbury has also developed an evidence based guideline: Weaning from Mechanical Ventilation Support (2007). The SCIC is also in the final stages of agreeing local standards for “Spinal cord injured patients with long and short term ventilator and/or airway management needs”.

- Spinal Cord Injury Rehabilitation Evidence (SCIRE) version 2. Chapter 8 Respiratory Management following Spinal Cord Injury (2008)

2. Methodology

This was a three month prospective audit looking at spinal cord injured ventilator dependent patients referred to the three SCICs in the South of England. A snapshot of the number of ventilated patients who were on a waiting list or were an inpatient at a SCIC was taken at the start of the data collection period and again at the end. During this time data were also collected prospectively on those who were inpatients at a SCIC at the audit start date, those on the waiting list and those who were referred during the audit period whether they were admitted or not. Further data were collected on patient outcomes such as weaning, starting rehabilitation, complications and discharge. The audit looked at both newly injured patients and those with an existing spinal cord injury.

Although the benefit of involving all ITUs in the South East of England would have been to help understand the numbers of patients who were not even referred to a SCIC it was felt that a study of this size (60 adult ITU and another 7 PICU) would be difficult to manage. Previous studies of this type have suggested that the response rate could be poor and the audit may be likely to be subject to serious delays and slippage. It was therefore decided to run this shorter term preliminary piece of work focussed on the three SCICs which would be much easier to control and could collect robust data to identify the issues. The results could then be used to develop a larger piece of work involving Acute Trusts if that was felt to be necessary and appropriate.

Data collection leads were identified at each SCIC. The proformas including the initial and final snapshot forms and the prospective spreadsheet were developed with the clinical and commissioning leads and agreed by the Service and Standards Subgroup of the South of England Spinal Cord Injuries Board. Input into this process was sought from RISCI UK and from clinicians at Southport and Ormskirk Hospital NHS Trust which has extensive experience in the care of spinal cord injured ventilator dependent patients.

A representative from the Spinal Injuries Association sits on the Service and Standards Subgroup and the South of England Spinal Cord Injuries Board so the study has had patient engagement from the scoping stage through to the development of the recommendations and action plan and final sign off by the Board.

2.1 Participation

The Three Spinal Cord Injury Centres in the South of England participated fully in this study:

- National Spinal Injuries Centre, Stoke Mandeville - Buckinghamshire Hospitals NHS Trust
- London Spinal Cord Injury Centre - Royal National Orthopaedic Hospital NHS Trust
- Duke of Cornwall Spinal Treatment Centre - Salisbury NHS Foundation Trust

2.2 Timescale

The initial snapshot of inpatients and patients on the waiting list was taken on the 1st January 2010. The prospective data collection ran for three months until the 31st March 2010 when the final snapshot was taken. Data were returned to the AIAU Project Coordinator by the middle of April 2010.

3. Results

The audit identified a total of 30 individual patients ventilated either because of a new spinal cord injury, because of complications arising from an existing injury or because of a requirement for peri-operative support for elective surgery for a patient with an existing injury. Of these 30 patients, six were referred to more than one SCIC (five were referred to two centres and one patient was referred to all three SCICs) giving a total of 37 different referrals.

3.1 Patient Details

3.1.1 Demographics

The majority of the audit population was male (77%, n=23) and just under a quarter were female (23%, n=7). This is not surprising and reflects previous studies which also found the majority of spinal cord injured patients to be male.

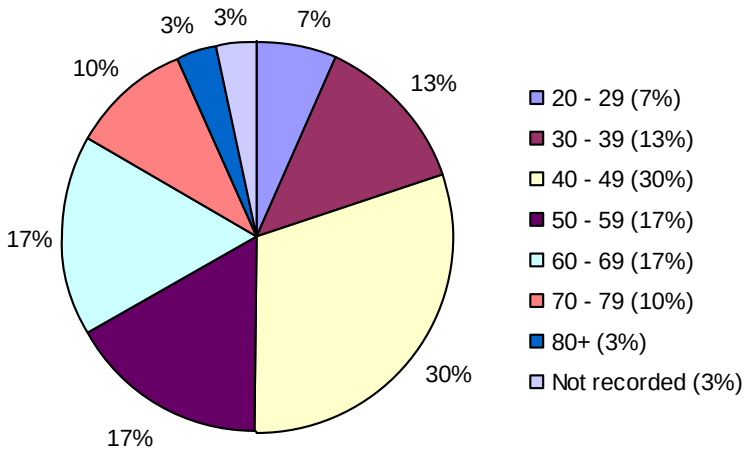
The audit population ranged from 22 to 88 years of age at the time of their referral. The average ages of the males were higher than the females although this comparison should be treated with caution due to the small number of female patients.

Table 1 - Average ages of ventilated patients

	Range	Mean Age	Median Age
Total Population	22 – 88	51	48
Male	24 – 88	54	53
Female	22 – 55	39	39

The ages of the audit population were normally distributed and the largest single group (30%, n=9) was between 40 and 49 years of age. For one patient this information was not recorded.

Figure 1 - Age breakdown of total audit population

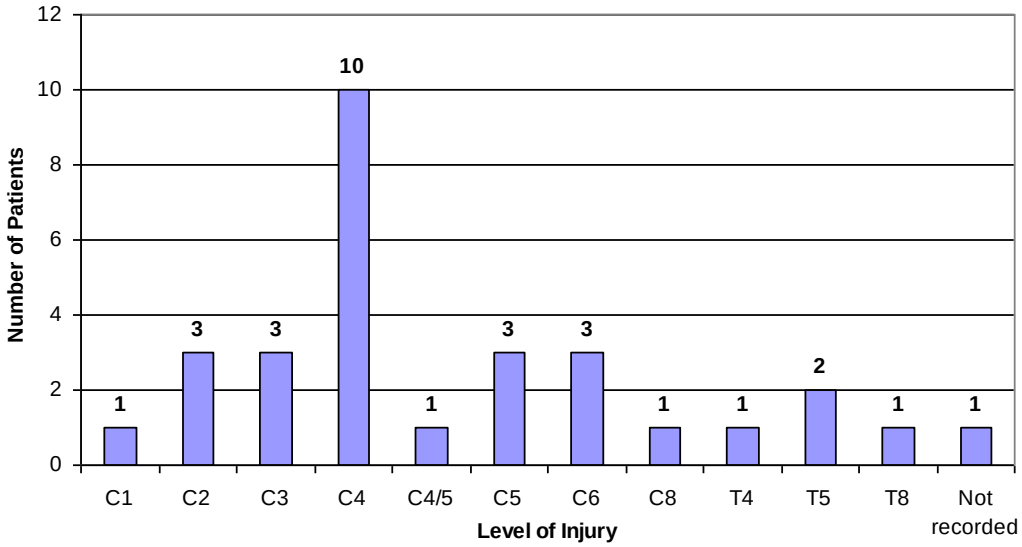


3.1.2 Level of Injury

A third of patients (n=10) were injured at C4 and for one patient this information was not recorded.

Lesions at C4 and above cause loss of diaphragm function among other issues, so ventilation is often required either for a substantial period of time or permanently. Although, for some patients, weaning is possible to allow independent breathing when upright, ventilatory support can remain necessary when lying, for example during the night.

Figure 2 - Level of injury of audit population



Some of the patients appeared to have relatively low injuries of the thoracic spine. The patient injured at T8 had an existing injury but the three patients injured at T4 and T5 were all newly injured patients who required ventilation. Depending on other factors, thoracic lesions often have a good chance of timely weaning but if this opportunity is not taken and a patient is left on ventilation for a significant period of time it can have a massive impact on their psychological and emotional well being. This can then also impact on a patient's willingness and ability to engage with further therapy and rehabilitation.

3.1.3 Source of Referral

Patients were referred to the SCICs from across the South of England as would be expected as well as from other areas such as Cambridgeshire and the Midlands. The table below shows all referrals including where duplicate referrals were made to multiple centres (n=37).

Table 2 - Referring hospital by Spinal Cord Injury Centre

Referring Hospital	DOC	NSIC	RNOH
East of England			
Addenbrooke's Hospital		3	
Watford General Hospital		1	2
London			
King's College Hospital	1	3	3
St George's Hospital		2	
Mayday University Hospital		2	
National Hospital for Neurology & Neurosurgery			1
Royal London Hospital		1	1

North Middlesex University Hospital		2	1
South East Coast			
The Princess Royal Hospital	1		
Royal Sussex County Hospital	1		1
South Central			
St Mary's Hospital, Isle of Wight	1		
South West			
Poole Hospital	1		
Salisbury District Hospital	3		
East Midlands			
Northampton General Hospital		1	
West Midlands			
Queen Elizabeth Hospital, Birmingham	1		1
Russells Hall Hospital		1	
Other			
Repatriation from overseas		1	
N/A elective admission from home	1		
Total	**10**	**17**	**10**

As can be seen above the referrals do appear to split along rough geographic catchment areas with referrals from hospitals in the South East Coast, South Central or South West regions tending to go to Salisbury and referrals from the Midlands to Stoke Mandeville. There is of course significant overlap between Stoke Mandeville and RNOH with referrals from London and East of England hospitals due to their geographic proximity and the population density in the South East. Some hospitals prefer to make referrals to multiple sites to optimise the chance of getting a bed for their patient as quickly as possible.

3.1.4 Pressure Ulcers and Complications

Pressure ulcers are a very serious problem and are caused by continuous pressure on a part of the body particularly where there is a bony prominence such as the bottom of the spine, the heel, the shoulders or the back of the head. They can develop very quickly and spinal cord injured patients are at increased risk because of their lack of mobility and sensation. Expertise in skin management is essential in both preventing ulcers from developing and managing the healing process if they do. Pressure ulcers are categorised into grades 1 to 4 depending on the severity with the most serious grades (3 and 4) showing full thickness skin and/or tissue loss. In areas with significant subcutaneous fat, wounds can be extremely deep and grade four ulcers will have exposed tendon, muscle or bone. Pressure ulcers can require complete bed rest for a number of months to allow for healing, delaying the start of a rehabilitation programme and causing another patient to have to wait for a bed.

In total there were 17 ventilated patients who were either inpatient in a SCIC as of the 1st January 2010 or were admitted during the audit period: of these just under a third (n=5) had pressure ulcers on admission; ten patients had no pressure ulcers and for two patients this information was not recorded. Of the ulcers recorded one was on the occipital bone, one was on the patient's heel and one was on the sacrum. The sites for the other two patients were not recorded. Four of the ulcers were grade 3 or 4 and one was described as small.

Table 3 - Pressure ulcers

Patient Audit Number	Site of Ulcer	Grade
2	Occipital	3
1	Not recorded	Small

14	Not recorded	3/4
26	Heel	3
27	Sacrum	4

For more information on waiting times for patients with pressure ulcers please see **section 3.3.3**.

Of the 17 admitted patients seven had other complications, eight did not have any and for two patients it was not recorded. Other complications included diarrhoea, chest trauma, one patient who was *C. Difficile* positive and one patient who had gross hyperextension of the neck due to mismanagement at the local hospital.

Table 4 - Complications

Patient Audit Number	Complications
7	*C. Difficile* positive
11	Hip replacement stuck solid, gross hyperextension of neck
13	Diarrhoea
15	Multisystem failure
16	Chest trauma
17	Obstructive sleep apnoea
18	Multiple injuries after serious accident

3.1.5 New or Existing Injuries

The majority of the audit population (87%, n=26) were newly injured patients who were ventilated at the time of their accident or very shortly afterwards. However there was also a small cohort (13%, n=4) of patients who had old injuries. These patients were ventilated for various reasons including multisystem failure, pneumonia and for peri-operative care for elective surgery. For more information on these two groups of patients separately please see **sections 3.2 and 3.3**.

3.2 Initial Snapshot

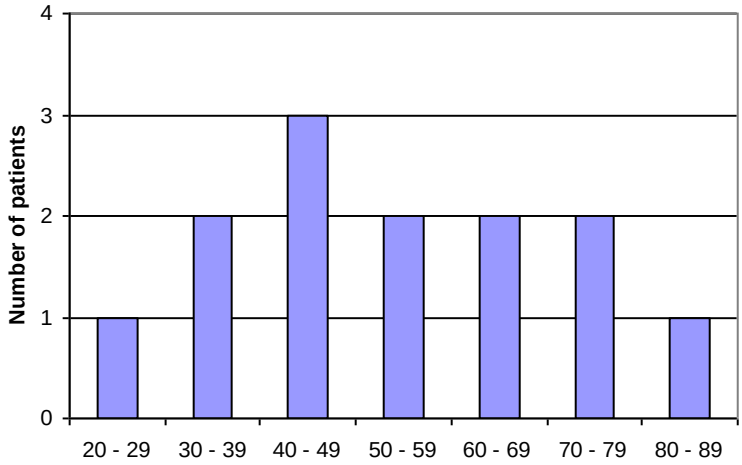
At the start of the data collection period on the 1st January 2010 a snapshot was taken of all spinal cord injured ventilator dependent patients who were either inpatients at one of the three SCICs in the South of England or on a waiting list. It was hoped that this would give an understanding of the numbers of patients involved, the levels of injury and an idea of the lengths of time patients were waiting for referral and admission to a SCIC.

The initial snapshot identified 13 individual patients of whom six were inpatients at one of the three SCICs and seven were on a waiting list. Three patients were on the waiting list of more than one centre. One patient had an existing injury and was ventilated for peri-operative care and the rest were newly injured patients.

3.2.1 Initial Snapshot Gender and Age

The majority of patients on the initial snapshot were male (n=10) with three female patients. Ages ranged from 24 – 88 years of age with a mean age of 53 yeas and a median of 51 years.

Figure 3 - Ages of patients on initial snapshot (01/01/10)

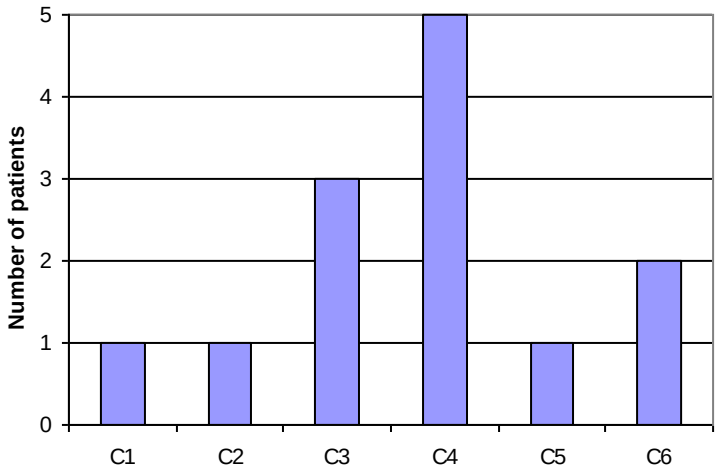


The largest single group was aged between 40 and 49 years old (n=3) but the cohort was evenly split across the ages groups from 30 to 79 years old.

3.2.2 Initial Snapshot Level of Injury

The largest proportion of patients (n=5) were injured at C4.

Figure 4 - Level of injury of patients on initial snapshot (01/01/10)



3.2.3 Initial Snapshot Waiting Times

The length of time the twelve newly injured patients were on ventilation before they were referred to a SCIC ranged from 0 – 45 days with a mean time of 16 days and a median of 13 days. One patient was referred on the day of ventilation but only one other patient was referred within a week of ventilation. For patients with multiple referrals only the first was used to calculate the time on ventilation before any referral was made. Three patients were ventilated after referral and in one case the date of referral was not known.

As of the 1st January 2010 the length of time on ventilation for the newly injured patients ranged from four to 278 days with a mean time of 95 days and a median of 60 days showing how the data were skewed by the large outliers. Two patients had been ventilated for more than six months (278 days and 188 days) and another one had been ventilated for just less than six months (172 days).

The length of time on the waiting list was calculated as of the 1st January 2010 for those newly injured patients who were not admitted before then. For patients with multiple referrals only the first was used to calculate the total waiting time. The time on waiting list ranged from 0 days to 188 days with a mean time of 58 days and a median of 50 days, again showing how the outliers have skewed the data. One patient was on a waiting list for over six months (188 days) before being admitted to a SCIC.

For more detailed information on total waiting times please see **section 3.3.1**.

3.3 Prospective Data Collection

The prospective data collection spreadsheet gathered information on the patients identified by the initial snapshot and also on all new referrals and admissions of ventilated patients to a SCIC between the 1st January 2010 and 31st March 2010. This was 30 patients in total. Data were also collected on patient outcomes such as if they were weaned off of ventilation, started rehabilitation or were discharged to another service.

3.3.1 Waiting Times

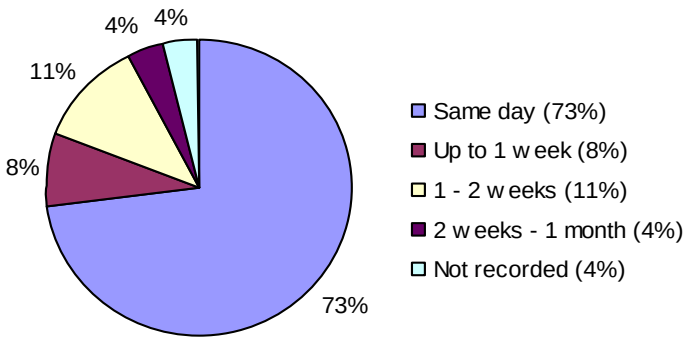
Waiting times were calculated from injury to ventilation and from ventilation to referral for the total audit population and from referral to admission for those patients that were admitted. For those that were not admitted the total waiting time was calculated up to 31st March 2010. Total time on ventilation was also calculated and for those who were not weaned during the audit period this was also calculated up to the 31st March 2010.

So as to gain information on how spinal cord injured patients are treated in the immediate aftermath of their injury the cohort was split into the newly injured patients (n=26) and those who had existing injuries (n=4).

Time from injury to ventilation

For newly injured patients only, almost three quarters (n=19, 73%) were ventilated on the day of injury. The number of days between injury and ventilation ranged from 0 to 28 days with a mean of two days and a median and mode of 0 days. For one patient the dates of injury and ventilation were not recorded.

Figure 5 - Time from injury to ventilation for newly injured patients



For the six patients ventilated between one and 28 days after their injury, five were injured between C4 and C6. One patient was injured at T4.

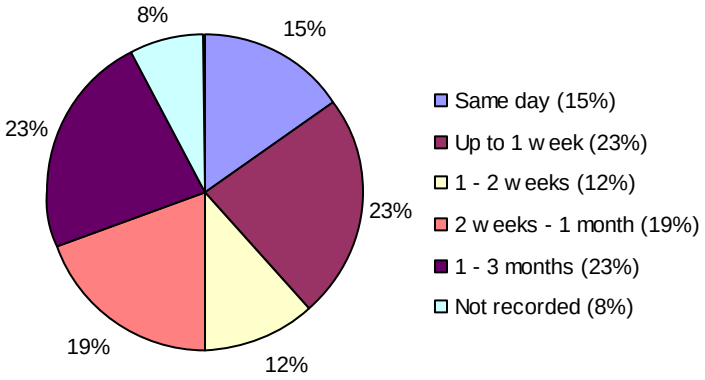
Table 5 - Details of patients ventilated after day of injury

Patient Audit Number	Level of Injury	Time from Injury to Ventilation (days)	Reason for ventilation
5	C5	8	Transferred for surgical fixation. Ventilated post-op
11	C4	12	Pneumonia
13	C6	10	Not recorded
17	C4/5	5	Ventilatory support for previous obstructive sleep apnoea
19	C6	28	Post stabilisation
20	T4	1	Full support (locked in syndrome)

Time from injury to referral

For newly injured patients the time from injury to referral ranged from 0 to 90 days with a mean time of 20 days and a median of eleven. For one patient the date of injury was not recorded and for one patient the date of referral was not recorded.

Figure 6 - Time from injury to referral for newly injured patients

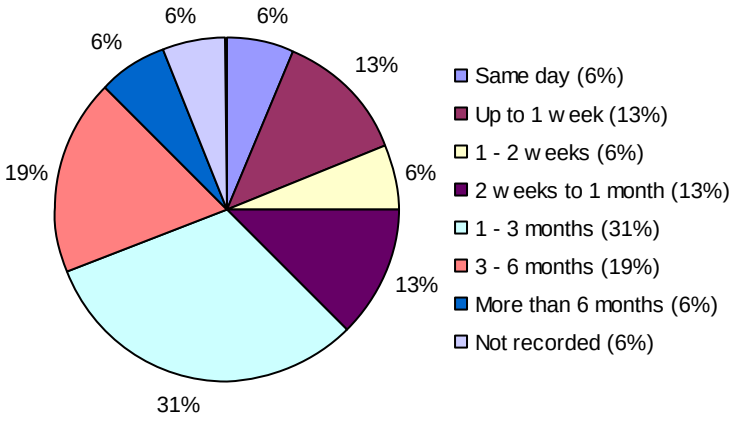


Patient 8, injured at C2 with complete neurological deficit and no other injuries, was not referred to a SCIC until 90 days after injury. The patient was admitted to a neurology centre and ventilated on the day of injury but no details were given about why the referral took three months or why only one SCIC was contacted. This patient had not been admitted to a SCIC by the end of the audit period.

Time from referral to admission

Of the 26 newly injured patients, 16 were admitted either before or during the audit period. The waiting times from referral to admission ranged from 0 days to over six months (188 days) with a mean time of 58 days and a median of 51. A quarter of these patients (n=4) were admitted within two weeks but five waited longer than one month for admission to a SCIC and another four waited for three months or longer. For one patient the date of referral was not recorded.

Figure 7 - Time from referral to admission for newly injured patients



A further nine newly injured patients were not admitted during the audit period and were still on the waiting list as of the 31st March. The waiting times for these patients were calculated up to the 31st March and they ranged from two to 101 days with a mean time of 50 days and a median of 39.

Table 6 - Time on waiting list for those not admitted (up to 31/03/10)

Patient Audit Number	Time on ventilation (days)
8	34
9	29
19	101
20	85
21	71
22	71
23	39
24	21
25	2

One newly injured patient was referred to a neurology centre for neuro-rehabilitation after discussion with the SCIC.

An aspect of the care pathway that requires further study is whether long lengths of stay at an Acute Trust whilst on ventilatory support prior to admission to a SCIC can adversely impact on patient outcomes as is often believed. Certainly this study found cases where patients who had long lengths of stay in Acute Trust ITUs were not able to be weaned even after several months in a SCIC:

- Patient 4, injured at C3, waited in an Acute Trust ITU for over six months before transfer to a SCIC. The patient had other complications and was undoubtedly a complex case but there was a ten day delay before referral to a SCIC where expert advice should have been sought and may have been able to expedite a transfer. This patient was ventilated for over ten months (323 days) in total at the Acute Trust and the SCIC and ultimately could not be weaned.

- Patient 11 was also injured at C4 and was ventilated 12 days after injury. Although referred to a SCIC the day after injury the patient was not admitted until 144 days

later. After another seven months at the SCIC the patient was still ventilated and although tolerating brief spells away from ventilatory support it was not clear if full weaning would be possible.

Of the four patients with existing injuries: one was already on the spinal unit, one was ventilated on admission to the spinal unit for surgery, one was on a waiting list and one did not have any details recorded. The patient on the waiting list had been waiting for 34 days as of the 31st March 2010.

3.3.2 Total Time on Ventilation

Five newly injured patients were weaned during the audit period and their total time on ventilation ranged from ten to 127 days with a mean of 79 days and a median of 84 days.

Table 7 - Waiting times for weaned patients with new injuries (days)

Patient Audit Number	Time from injury to ventilation	Time from injury to referral	Time from referral to admission	Total time on ventilation
2	0	36	92	116
3	0	5	62	84
13	10	3	55	127
16	0	0	14	10
17	5	12	18	62

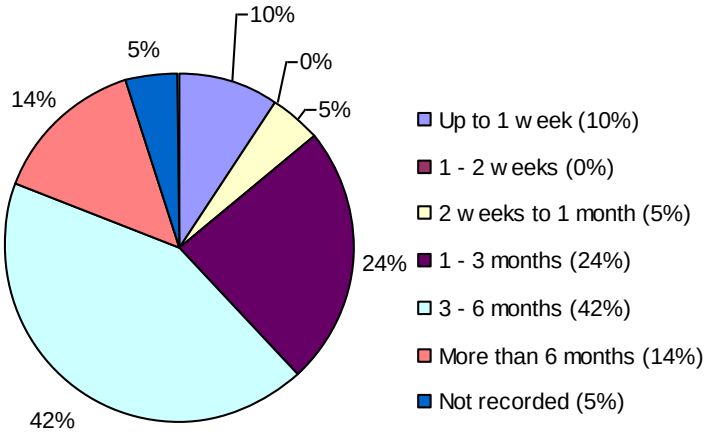
As can be seen in the table above, patients 2 and 16 were weaned at the acute Trust ITU with support from the SCIC. Once weaned these patients were then admitted to the SCIC in 12 days and four days respectively. This shows that if patients can be weaned before transfer it is often much quicker to gain admission to a rehabilitation bed in a SCIC than if they require a more specialised respiratory bed:

- Patient 16 was injured at T5 and the SCIC team was involved in their management from the day of injury. The short time on ventilation demonstrates that patients with injuries at this level can often be successfully weaned at an early stage and in this case the patient was able to commence rehabilitation within two weeks of injury.

- Patient 3 was injured at C4 and referred to a SCIC five days after injury. Unfortunately they were not able to admit. A referral to an alternative SCIC was not made for another 20 days potentially missing beds in this time and the patient waited two months for admission to a specialist facility. Once there, the patient was weaned after 17 days suggesting that the patient could have been weaned at an earlier point and that an earlier admission could have cut the time this patient spent on ventilator support.

For the other 21 newly injured patients the time on ventilation was calculated up to the 31st March: this ranged from 2 days to over ten months (323 days) with a mean of 120 days and a median of 111 days. For one patient the time was calculated up to when they were discharged to a nursing home still ventilated and for one patient it was calculated until their death. For one patient the date of ventilation was not recorded.

Figure 8 - Total time on ventilation up to 31/03/10 (for those newly injured patients who were not weaned)



Of the four patients with existing injuries, one patient was weaned after 13 days. Two were still ventilated and had been for 39 days and 146 days. For one patient this information was not available.

3.3.3 Patients with Pressure Ulcers

Five patients were admitted to an SCIC with a pressure ulcer and one of these was a patient with an existing injury. For the other four patients, time from referral to admission ranged from one to 92 days with a mean time of 55 days and a median of 64 days. The mean value is lower than that of the group of patients admitted without pressure ulcers but the median value was significantly higher.

Table 8 - Average times from referral to admission (newly injured patients only)

Patients with pressure ulcers		Patients without pressure ulcers	
Mean	**Median**	**Mean**	**Median**
55	**64**	59	**42**

Total time on ventilation was also looked at for the four patients with new injuries. One of these patients was weaned during the audit after 116 days on ventilation but the other three patients were still ventilated at the end of the audit period. For these three patients, time on ventilation ranged from 83 days to 137 days with a mean of 103 days.

The very small number of patients means that these results should be interpreted with caution but for this sample there does not appear to be any evidence that patients with pressure ulcers were ventilated for longer. However the median values did suggest that the time from referral to admission was longer for patients with pressure ulcers. Clearly though this study was not long enough to look at total lengths of stay. For patients with pressure ulcers the expectation would be that length of stay would be longer due to the requirement for total bed rest whilst healing. Longer term studies are required to gather data and investigate this further.

3.3.4 Patient Outcomes

As mentioned before 30 spinal cord injured ventilated patients were identified by the audit. Of these 13 were known to the SCICs as of the 1st January 2010 either as inpatients or by

being on the waiting list. A further 16 patients joined the waiting list during the audit period and one patient was already on the spinal unit undergoing rehabilitation when they suffered multiple organ failure and required ventilatory support.

Of these 30 patients, 26 had new injuries and four had existing injuries. Of the newly injured patients, five were already inpatient at the start of the audit and a further eleven patients were admitted during the audit. One patient was put on the waiting list of one of the SCICs but after discussion between the acute hospital and a Rehabilitation Consultant it was felt that neuro-rehabilitation would be a more appropriate treatment option. Nine patients were still on the waiting list as of the 31st March.

Where outcomes were available, five patients were weaned and had started rehabilitation, one patient died and one patient was discharged during the audit period although this patient was not weaned but was discharged to a nursing home still ventilated.

Of the four patients with existing injuries, two were inpatients, one was still on the waiting list and for the other no information was available. Of the two inpatients, one was weaned and one was still ventilated as of the 31st March.

For a more detailed map of numbers of patients on the waiting lists, admissions and outcomes please see **Appendix A**.

3.4 Final Snapshot

At the 31st March 2010, 21 individual ventilated patients were identified: eleven of these were inpatients and ten were on the waiting list. As will be discussed further in **section 4** one SCIC applied for additional funding to open extra ventilator beds to allow admission of additional patients who had been waiting a long time. One patient who was on the waiting list on the 1st January was still on the waiting list on 31st March. Two patients were on the waiting lists of more than one SCIC.

Two patients on the waiting list for Stoke Mandeville had been accepted for transfer but were awaiting beds. For more detailed information on numbers on waiting lists, admissions and outcomes please see **Appendix A**.

3.5 Cost of Care

To gain a clearer picture of the total resources required to treat these patients it was decided to look at the costs involved in each stage of their care at both acute hospital and SCIC. South East Coast SCG was able to provide information on the SCIC costs for all consortium patients and also the acute hospital costs for South East Coast patients only.

As can be seen from both of these case studies the cost of treating ventilated patients can vary widely particularly at acute hospitals and the costs mount up to very large sums of money in a relatively short time.

As can be seen in both of these examples, costs at a SCIC can be cheaper than at an acute hospital or Major Trauma Centre ITU, even given the level of specialist expertise and multidisciplinary care available at a SCIC. Clearly there are financial considerations as well as clinical ones in the timely transfer of ventilator dependent spinal cord injured patients to a SCIC.

Case Study 1

51 year old male injured at C6.
This patient was admitted to a neurological centre on the day of injury and was **referred to a SCIC after three days**. He was put on a ventilator 10 days after injury and moved to the ITU at an acute hospital 34 days after injury. He was **admitted to the SCIC 58 days after his injury (55 days after the referral)**. The SCIC recorded the patient as having diarrhoea and the delay in admission to the SCIC may have been because of a hospital acquired infection.

Costs prior to SCIC admission - **£73,587** (£1291/day)

The patient was weaned after being at the SCIC for 67 days (**in total 127 days on ventilation**) and was still an inpatient as of 30th June 2010.

SCIC costs up to 30th June - **£153,890**

This breaks down as:
Ventilated bed costs – 67 days - **£63,650** (£950/day)
Standard bed costs – 188 days - **£90,240** (£480/day)

Total costs up to 30th June - **£227,477**

Case Study 2

72 year old male injured at T5.
This patient was admitted to a major trauma centre and ventilated on day of injury where he received multi-organ support. **He was referred to a SCIC on the day of injury. He was then referred to a second SCIC 14 days after injury and the third 24 days after injury.** He was transferred to an acute hospital 18 days after injury and remained there for another 51 days before **admission to a SCIC (69 days after injury)**.

Costs prior to SCIC admission - **£127,344** (£1845.57/day)

The patient was still inpatient and ventilated after 51 days at the SCIC up to 30th June 2010. **At that point he had been ventilated for a total of 120 days.**

SCIC costs up to 30th June 2010 - **£48,450** (£950/day)

Total costs - **£175,794**

For the patient in case study 2 the pathway seemed to work well initially: the patient was admitted to a Major Trauma Centre where he was ventilated and referral to a SCIC was made, both on the day of injury. When that SCIC could not admit him, further referrals were made but the patient was then transferred to a District General Hospital and had contracted pneumonia, lessening the likelihood of weaning. Eventual admission to a SCIC was over two months after injury and early weaning was not possible.

4. Discussion

This audit has collected important data on a group of patients that had not been investigated before. These patients require very intensive, complex and costly care and have a high likelihood of succumbing to avoidable complications if treated inappropriately or if long delays before admission to a SCIC occur. The data provide important information with implications for service development and clinical practice.

4.1 Waiting Times

The data collected have shown a mean time from injury to referral of 20 days and while the median is lower at eleven days this is still unacceptably long. In total six patients waited longer than one month for referral to a SCIC with the longest wait almost three months (90 days). While the pressure on beds for ventilated patients can cause understandable but still unacceptable delays in admission there is no reason for any delay in contacting a specialist SCIC for advice on management of the patient or if possible to involve outreach services. The importance of early communication with a SCIC cannot be emphasised enough; even if immediate transfer is not felt to be appropriate because of co-existing conditions or injuries, SCIC teams must be involved in decisions about the management of spinal cord injured patients from the very beginning to ensure they access the correct pathway and to optimise potential outcomes. It is understood that for some patients weaning may not be possible because of other factors but early conversations optimise the potential for weaning and where this is not possible can help to avoid other complications and get the appropriate pathway initiated early. The contracts of the London Major Trauma Centres already include a target to make contract with a SCIC within four hours of the arrival of a spinal cord injured patient. The South of England Spinal Cord Injuries Board has also agreed a programme of rolling this out to all Trusts across the South of England.

Waiting times from referral to admission ranged widely but the mean time was nearly two months (58 days) and the median only slightly lower at 51 days. Co-morbidities can delay transfer and some of these patients will have had contact with and support from outreach teams and respiratory consultants. However the concern is that some of these patients will have had no specialist input into their management or therapy before admission to a SCIC.

4.2 Capacity and Procurement

Clearly there are capacity issues in SCICs, particularly around respiratory beds. This is due to the greater resources, particularly in staffing, that these patients require in the SCICs compared with a patient breathing independently. The number of these patients who survive their initial injury has increased over time due to improved techniques for management both at the point of injury and in the first 48 hours following this. The increase in number of ventilated patients who were inpatient in a SCIC from the initial to final snapshots is partly down to the fact that Salisbury deployed additional resources to support the admission of three ventilated patients who had been on the waiting list for a long period.

However this is not just an issue for the SCICs: the efficient use of capacity in Acute Trust ITUs, which often work with a very high turnover, is also compromised by ventilator dependent spinal cord injured patients for whom weaning has not been attempted or is not appropriate. The transfer of a patient to a SCIC frees up a bed for another patient requiring intensive care.

Additionally, the situation is not caused solely by ‘front end’ problems. Throughput of patients is essential in both ITU and SCIC and ‘bed blocking’ by those patients who have

avoidable complications, particularly if still ventilated, and discharges which are delayed for non-clinical reasons such as housing or continuing care packages prevent the timely admission of new patients. This then perpetuates the unhealthy and costly cycle both in the referring trauma centre or Acute Trust and within the SCIC.

The old-fashioned contract 'currencies' currently in use do not accurately reflect the true cost of treating patients. For example at one SCIC, commissioners pay the same arbitrary bed day rate regardless of whether the patient is a newly injured tetraplegic on ventilation, a paraplegic nearing the end of rehabilitation, or an 'old' SCI patient admitted overnight for a minor procedure and effectively looking after himself. This builds perverse incentives into the system as the Trust loses money on higher dependency patients. It makes it very difficult for the SCIC to manage the case-mix with sufficient flexibility to meet the current demand. The problem is compounded by the lack of data due to poor information management in the recent past.

The new Commissioning Classifications (currencies) being developed for spinal cord injury services assign patients to groups according to the level of injury, need and resources required. The longer spells such as the initial spell following injury are broken down into packages, such as recovery and rehabilitation. Common definitions will apply to the packages across the SCICs in England and there will be a common approach to what is included or excluded from the packages so they will mean the same in every SCIC. The new currencies will reflect factors such as level of injury, presence of pressure ulcers or the requirement for ventilatory support. The packages are being costed in line with the latest Department of Health guidance.

The development of the South of England Database (to record, among other things, issues that arise during the period between injury and admission to the SCIC) and the National Spinal Cord Injury Database will facilitate the collection of data. A dataset has been agreed through the South of England Spinal Cord Injuries Board for referring Acute Trusts to submit to the SCIC on arrival/diagnosis of a newly injured patient. A web-site will be available shortly onto which the referral dataset can be entered which is being piloted in London. This will enable the South of England Board to receive data on the numbers of patients injured, how quickly they are referred and how long they wait for admission to the SCIC. Ventilated patients will be separately identifiable.

Basing payment on packages will provide SCICs with incentives to deliver packages with the most efficient use of resources as they will no longer be paid by the day. The next step will be the development of tariffs based on outcomes. *Weaning* a ventilated patient (where clinically appropriate) or *healing* a pressure sore could be examples of outcomes that could be paid for. Possibly *preventing* pressure sores in the first place (by providing outreach to acute hospitals) could be an outcome. CQUIN targets are also being developed which are focused towards improved communication and collaboration between Acute Trusts and SCICs and trying to reduce avoidable complications.

4.3 Outreach Service

This audit has not captured the nature of the current close working relationships between trauma centre/acute hospital and SCIC outreach services that help facilitate successful weaning before admission to a SCIC meaning those patients were not part of the audit population. Outreach services have been developed and are now functioning from Salisbury and Stoke Mandeville and RNOH plans to implement an outreach service from October 2010. Anecdotal evidence suggests the importance of this work cannot be overstated. Outreach can ensure consistency of care in an acute ITU setting so that patients reach the SCIC in the best possible physiological and emotional condition to engage in their

continuing care. An example of this is the work done by the outreach nurse at Stoke Mandeville: she made a series of visits to a ventilated patient at Addenbrooke's and supported that patient to be weaned at Addenbrooke's, enabling transfer to the SCIC to begin rehabilitation without delay. This aspect of the service is very important because if patients are weaned it increases their chances of a shorter wait for admission into a rehabilitation bed rather than a longer wait for a more specialised respiratory bed. More work should be done to quantify in a more systematic way how this service improves outcomes.

A number of ventilated patients admitted to a SCIC had pressure ulcers (29%, n=5) and another 41% (n=7) had other complications. These issues, whether unavoidable or not, can not only lead to delays in starting rehab which can impact on eventual physiological outcomes but also impact in other ways such as on a patient's psychological wellbeing. Early access to appropriate specialised multidisciplinary support is essential. One of the aims of an outreach service is to provide this support and advise ITU teams on aspects of care for spinal cord injured patients that they may not have had much experience of such as skin and bowel management.

As can be seen in **table 2**, referrals to the three SCICs in the South of England tend to be along geographic lines as would be expected. Where outreach services have already been put in place, links have been made with Acute Trusts in the area and relationships developed which enable close working for the benefit of patients. When the outreach service at RNOH is also started the three services will have to work closely with each other to prevent duplication of work and to cover the widest possible area. Some Acute Trusts still refer to all three centres in the hope of getting a bed for their patients as quickly as possible and the outreach services play an important role in managing these referrals with close liaison and quick information sharing to allow any centre to respond once a bed becomes available.

4.4 New and Existing Injuries

The majority of the audit population were newly injured patients requiring respiratory support but a small number of patients had existing injuries and these groups generally had different reasons for ventilation and admission. However, once ventilated they require the same level and intensity of care as the newly injured patients and also require specialist expertise to manage their condition.

4.5 Spinal Cord Injured Patients in Acute Trusts

One area which remains a concern, which is not captured in this audit, is the issue of ventilated spinal cord injured patients who are not referred to a SCIC and where the referring hospital does not make any contact with a SCIC for advice on their management. Given the very specialist nature of the care required it is to be hoped that there are no patients in this situation but some of the long delays in contacting a SCIC and in referral seen in this audit suggest that this is possible. The fact that currently no data are available on the incidence and prevalence of these patients suggest that it could be happening which is of clear concern. It is hoped that the development of outreach services and better communication and educational links with Acute Trusts will make this less likely.

4.6 National Spinal Cord Injury Strategy Board

Following parliamentary discussions relating to the Health Bill and publication of the Spinal Injuries Association (SIA) Report 'Preserving & Developing a National Spinal Cord Injury Service'[4], a meeting of the Specialised Commissioning Group (SCG) Directors agreed to establish a national Board as a step forward in improving outcomes for patients and service provision. The National Spinal Cord Injury Strategy Board (NSCISB) met for the first time in March 2010 with a membership of representatives from the ten SCGs in England, the eight SCICs in England, MASCIP, BASCIS and SIA. Commissioners from Wales and Scotland were also invited to attend.

Since then the NSCISB has approved a policy document[5] about planning for spinal cord injury in trauma services which has been communicated to SCGs, Acute Trusts and PCTs across England.

As part of the national programme a work stream was agreed to look at clinical care pathways for the acute care and lifelong management and support of spinal cord injured patients. The aim of this work will be to develop consistent national pathways which will streamline patient management and provide an evidence based process and clinical guidelines to ensure early identification of injury and timely intervention by specialised SCI teams. As discussed previously these early interventions can impact enormously on eventual outcomes so it is vital that they are carried out by or under the supervision of appropriately skilled and experienced SCI teams to minimise and prevent further disability and optimise outcomes. This project will have a sub-group looking specifically at ventilator dependent spinal cord injured patients and the particularly complex requirements of this patient group.

This work will develop national pathways for adoption and implementation by all Acute Trusts and SCI Centres and will ultimately be added to the Map of Medicine so that all spinal cord injured patients across England can be certain of the same high quality, timely care in the correct setting with the support of the correct multidisciplinary team and related to lifelong individual need.

5. Conclusions

This audit has been successful in meeting its aims and has gathered key data on30 ventilator dependent patients with both new and existing spinal cord injuries. This information will be invaluable to the Spinal Cord Injuries Board and Consortium in gaining a good understanding of this small but high complexity and high cost patient cohort and will inform future service planning. It has also highlighted the excellent work done by the current outreach teams who, on top of the cohort identified in this audit, have supported Acute Trusts to wean ventilated patients in their ITU and initiate appropriate care to minimise the risk of complications before transfer to a SCIC. This can avoid delays in transfer and so means that the start of the patient's rehabilitation programme is not delayed.

At a regional level the number of patients sustaining ventilator dependent spinal cord injury is relatively small and this supports the current model of patients receiving rehabilitation in a specialist SCIC. However the times seen from referral to admission are excessive suggesting that capacity at the SCICs does not meet demand. Referrals from trauma centres to SCICs are often delayed and the reason for this is not always clear. Avoidable complications are common and impact on a patient's rehabilitation and length of stay and also on bed capacity at the SCICs. Weaning from ventilation is frequently possible but can take a significant period of time as seen by the results of this audit (total time on ventilation in patients that weaned ranged from ten to 127 days with a mean of 79 days).

Unsurprisingly when looking at the South of England, an area which covers approximately half of the population of England but has around a third of the total beds for spinal cord injured patients, the audit has found long waiting times and issues around capacity which were previously known or suspected but not quantified. Issues around bed usage were also uncovered as rehabilitation beds were closed to allow admission of ventilated patients. Whilst this level of flexibility may be necessary, centres must be supported to be able to admit patients requiring all levels of support to begin expert treatment as soon as possible. Issues around capacity are only part of the problem: SCICs and Acute Trusts need to find smarter ways of working together to ensure firstly that patients can access the correct care pathway and then that the pathway works to enable the smooth flow of information and of patients. If this cycle of delayed admissions, extended length of stay and bed blocking can be broken patients can have the best possible outcomes and centres can function efficiently and cost-effectively.

6. Recommendations

1. It is essential that Trusts, clinicians and commissioners ensure that future tariffs and contracts reflect the true cost of treating patients according to their level of dependency and achieving best outcomes so that there are no financial disincentives to admit a ventilated patient.

2. Greater capacity is needed within the SCICs to meet the demand for specialist rehabilitation for patients with ventilator dependent spinal cord injury. This would improve clinical care and efficiency by allowing early treatment by a specialist team to maximise chances of weaning, reduce risk of complications and reduce overall length of hospital stay and associated costs. Additionally, SCICs should manage resources flexibly to meet clinical priorities and the prevailing case mix.

3. SCICs should work with Trauma Centres/Acute Trusts to ensure timely contact with and referral to a SCIC are made at the earliest opportunity and in line with the South of England Guidelines and Major Trauma Centre contracts.

4. The South of England Spinal Cord Injuries Board should roll out the use of the referral website and dataset across the south of England. The SCICs should encourage and assist referring hospitals to complete the on-line dataset for all new spinal cord injured patients. This will provide the essential data on service demand which the South of England Board requires for planning purposes.

5. As there are currently no published national guidelines for weaning, clinicians should work with organisations such as RISCI UK to develop and disseminate them. This would help non-specialist centres and trauma units to initiate weaning with liaison and clinical support from their local SCIC.

6. SCICs should record and monitor on a regular basis waiting times from injury and referral to admission for all patients. Commissioners should receive from SCICs regular reports of the numbers of spinal cord injured patients awaiting admission and the length of time waiting. These reports should indicate how many patients are ventilated.

7. SCICs should record and monitor on a regular basis all ventilated patients referred and admitted with pressure ulcers or other avoidable complications.

8. A further study could be commissioned to investigate if there are spinal cord injured ventilated patients in Acute Trust ITUs who are not being referred to a SCIC or managed in conjunction with a specialist spinal cord injury multidisciplinary team.

9. A further long term study could be commissioned to track outcomes and costs against the length of total hospital stay in the medium and long term as well as the costs and outcomes for models of service delivery in the community for patients once discharged from hospital.

10. A further study could be commissioned to quantify the work of the SCIC outreach services, how the Centres work together to avoid duplication and the impact on patient outcomes. As RNOH will also be implementing an Outreach Service there could potentially be an increase in referrals to centres for both ventilated patients and patients for acute rehabilitation so this will also need to be monitored.

7. Clinical and Commissioning Prioritisation of Action Points

	Action	Priority		
		High	Medium	Low
1.	SCICs should work with Acute Trusts and Trauma centres to encourage timely contact with and referral to a SCIC.	✓		
	SCICs, Acute Trusts			
2.	The use of the referral website should be rolled out across the South of England and SCICs should encourage and assist referring Trusts to complete the online dataset for all new referrals.	✓		
	Spinal Cord Injuries Board, SCICs, Acute Trusts			
3.	The South of England Board and/or the NSCISB should work with clinicians and RISCI UK to develop and disseminate national guidelines for the weaning of ventilator dependent spinal cord injured patients.	✓		
	Spinal Cord Injuries Board, Clinicians, RISCI UK			
4.	SCICs should provide regular information to the South of England Board and Commissioners on the number of SCI patients awaiting admission to a SCIC and the length of time waiting. This should specifically identify ventilated patients.	✓		
	SCICs			
5.	SCICs should record and monitor all patients admitted with pressure ulcers and other avoidable complications. This should specifically identify ventilated patients.	✓		
	SCICs			
6.	There should be consideration of what further pieces of work may be required in the medium and long term and this may be in the South of England or as part of the national work programme of the NSCISB. This may involve looking at the work of the Outreach Services, SCI patients in acute Trust ITUs or a longer term study of outcomes.		✓	
	Spinal Cord Injuries Board			

8. Dissemination

This report will be disseminated within the East of England, London and South East Coast regions unless otherwise stated:

A full report to: the participating Spinal Cord Injury Centres in the South of England; the Spinal Cord Injury Board; the National Spinal Cord Injury Strategy Board; MASCIP; BASCIS; the London Trauma Network Board; RISCI UK; East of England SCG, London SCG, South East Coast SCG, South Central SCG and South West SCG Leads; Teresa Moss, Director of the National Specialised Commissioning Team; Clinical Audit Managers and any other persons who have expressed an interest in this report.

An Executive Summary to: Acute Trust Chief Executives; Acute Trust Medical Directors; SHA Directors of Public Health; PCT Chief Executives; SCG Directors of Public Health.

Recipients of this report are encouraged to disseminate the report more widely.

The full report will be available on the South East Coast SCG web site:
http://www.secscg.nhs.uk

9. References

1. *Ventilator Free Breathing (VFB) Weaning Guidelines.* Southport and Ormskirk Hospital NHS Trust Regional Spinal Injuries Unit, updated 2006.

2. *Weaning from Mechanical Ventilation Support.* Duke of Cornwall Spinal Treatment Centre, 2007.

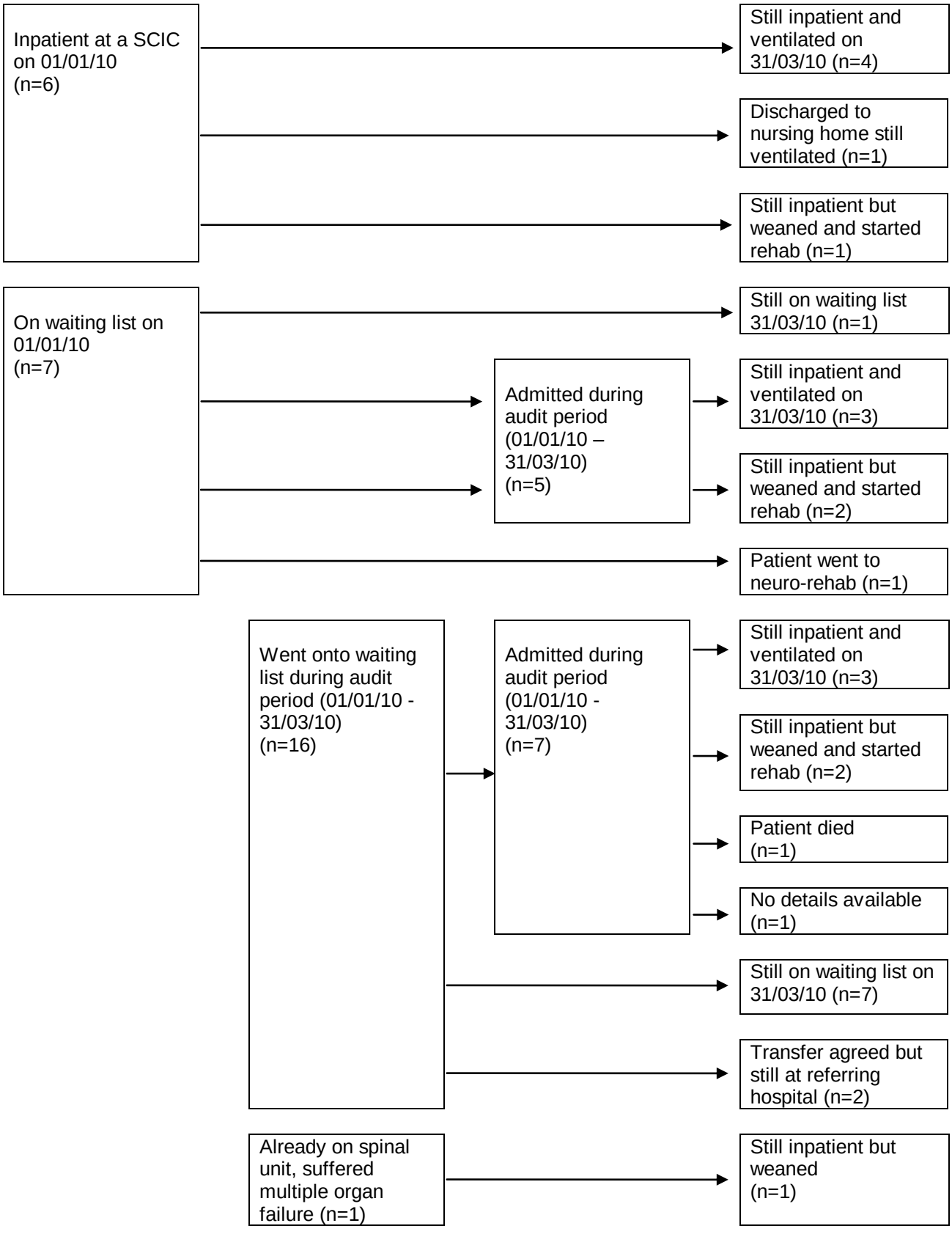
3. *Spinal Cord Injury Rehabilitation Evidence (SCIRE) version 2. Chapter 8 Respiratory Management following Spinal Cord Injury.* 2008.

4. *Preserving & Developing a National Spinal Cord Injury Service.* Spinal Injuries Association, May 2009.

5. *Meeting the Needs of People with Spinal Cord Injury in Planning for Trauma.* National Spinal Cord Injury Strategy Board, May 2010.

Appendix A

Breakdown of patient outcomes as of 31st March 2010



Appendix B

Audit Proformas

Initial Snapshot of ventilator dependent spinal cord injured patients

Name of Centre: ……

Please use this form to record all ventilator dependent spinal cord injured patients who are either in-patient at your centre or on your waiting list as of **1st January 2010**.

Patient Identifier	Date of birth	Sex	PCT/ GP postcode	Status (in patient or on waiting list)	Date of Injury	Level of injury	Date ventilated	Date of referral	Referring hospital	Date of transfer if inpatient	Length of time on waiting list

Please return this form to:

Carrie Gardner
AIAU Project Coordinator
London Specialised Commissioning Group
16th Floor, Portland House
Stag Place
London
SW1E 5RS

Carrie.gardner@londonscg.nhs.uk

Prospective Data Collection Spreadsheet

Admissions

Spinal Cord Injury Centre:

	Patient details					Injury details						Referring ITU			
Patient No.	Patient identifier	Date of birth	Sex	Patient's PCT	GP Postcode	Date of injury	Level of injury	Bony/ neurological	Complete/ incomplete	Motor/ sensory	Associated injuries	Date admitted to ITU	ITU/ Hospital admitted to	Date ventilated	Reason for ventilator support

Referral/transfer					If patient transferred			
Date of referral request	Transfer agreed	Reason for refusal	Was patient also referred to another unit?	Name of Centre/ Hospital	Date of actual transfer	Pressure sore	Grade	Other complications

Discharges and Outcomes

Spinal Cord Injury Centre:

	Patient details					Injury details					
Patient No.	Patient identifier	Date of birth	Sex	Patient's PCT	GP Postcode	Date of injury	Level of injury	Bony/ neurological	Complete/ incomplete	Motor/ sensory	Associated injuries

Referring ITU				Referral/transfer				
Date admitted to ITU	ITU/ Hospital admitted to	Date ventilated	Reason for ventilator support	Date of referral request	Date of actual transfer	Pressure sore	Grade	Other complications

Outcomes										
Patient weaned	Date weaned	Patient started rehab	Date started rehab	Patient transferred to other centre	Date of transfer	Patient discharged to community	Date of discharge	Patient died	Date of death	Other outcome

Final Snapshot of ventilator dependent spinal cord injured patients

Name of Centre: ……

Please use this form to record all ventilator dependent spinal cord injured patients who are either in-patient at your centre or on your waiting list as of **31st March 2010**.

Patient Identifier	Date of birth	Sex	PCT/ GP postcode	Status (in patient or on waiting list)	Date of Injury	Level of injury	Date ventilated	Date of referral	Referring hospital	Date of transfer if inpatient	Length of time on waiting list

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