

THE SPINAL CORD INJURY PRIORITY SETTING PARTNERSHIP

76 NON-RESEARCH QUESTIONS

Complications		Originator
1.	What are the main contributing factors to development of pressure sores/ulcers?	Healthcare professional
2.	What are the long-term medical complications of spinal cord injuries?	Healthcare professional
3.	Is it possible to access information about Tarlov Cysts through the NHS?	Patient

Treatment Options and Technology		Originator
1.	Are there lighter callipers available than the metal heavier ones?	Patient
2.	What websites are available for renting/purchasing equipment for moving and handling a patient with a spinal cord injury?	Healthcare professional
3.	What interventions are available (other than indwelling catheters and leg bags) that allow unlimited intake of liquids?	Patient
4.	Is there information available on bladder and bowel management for women with tetraplegia who are living independently without caregivers?	Patient
5.	What interventions are prioritised for ambulant people with a spinal cord injury?	Healthcare professional
6.	How can patients keep up-to-date with the latest technology and personal care techniques?	Patient
7.	Is there information available on saddle anaesthesia for patients with a spinal cord injury?	Patient
8.	What methods can be used to maintain independence of transfers or pushing?	Patient
9.	Is there information available for the use of cannabis in the treatment of transverse myelitis?	Patient

Physical Activity		Originator
1.	What exercises can be used for patients with high level tetraplegia?	Patient
2.	What sporting facilities are available for patients undergoing rehabilitation with a spinal cord injury?	Healthcare professional
3.	What proportion of patients feels that they received adequate physiotherapy and occupational therapy?	Healthcare professional

Healthcare Provision in a Hospital Setting		Originator
1.	Is there proper coordination between health care professionals to ensure that throughout the UK best practice treatment is available in the major centres for patients with a spinal cord injury?	Other
2.	What proportion of patients has access to a clinical psychologist and/or mental health nurse?	Healthcare professional
3.	Should all spinal centres have a spinal education programme for their patients and should all patients complete it?	Patient
4.	Due to the increasing numbers of those living with a spinal cord injury and being admitted to spinal centres, should the number of hospital beds also increase to match this and are there plans to do this?	Patient
5.	Could Speech and Language Therapy services be made available in spinal cord injury centres?	Healthcare professional
6.	Do patients have the option of transferring to a spinal unit which is closer if they move to a different area?	Patient
7.	What do newly injured patients undertaking initial rehabilitation most want from healthcare providers?	Spouse/partner
8.	What key issues are most important to newly injured individuals at the time of their discharge from a spinal cord injury centre?	Spouse/partner
9.	What proportion of patients feel that they were adequately prepared for discharge from hospital and to return to the community?	Healthcare professional
10.	What is the current practise for screening for dysphagia?	Healthcare professional

Healthcare Provision in a Community Setting		Originator
1.	Is the provision of care and support packages different for patients receiving Independent Living Fund (ILF) and those who do not?	Patient
2.	What support do long standing spinal cord injury individuals living within the community want from healthcare providers?	Spouse/partner
3.	Is there information available for patients to find healthcare professionals who they can talk to in their area?	Patient
4.	How does a patient access physiotherapy and counselling treatment once they have returned to a community setting without going private?	Patient

Funding		Originator
1.	Can spinal cord injury research receive more funding from the government/NHS?	Patient
2.	Is it possible to get a grant to buy a functional electrical stimulation machine, walking aids and other therapies to use at home?	Patient

3.	How can we guarantee non-means-tested care funding for tetraplegics?	Patient
4.	What can be done to improve the availability of Disabled Facilities Grants?	Patient
5.	Is there a central database of charities available which can be used by patients who wish to apply for financial assistance (e.g. hardship funds and funding of equipment)?	Healthcare professional and Patient
6.	What determines the amount of government funding provided for management and treatment of spinal cord injuries in different counties?	Patient

Social care and Support from Local Authorities		Originator
1.	Are there differences in the average size of care and support packages supplied via local authorities to spinal cord injury patients discharged in the last 5 years?	Patient
2.	Is there anything that can be done to increase the number of suitably adapted houses for patients with spinal cord injuries in Britain?	Patient
3.	Would there be a benefit to having a wheelchair award scheme (e.g. grades 1 to 5) for public buildings and rights of way to indicate how accessible they are?	Patient
4.	Is there information available about wheelchair accessible toilets in pubs?	Patient
5.	What proportion of patients feels they receive enough health and social care to maintain independency and fitness?	Patient

Support Groups		Originator
1.	Are there information/support services available that can help partners of patients to prepare for their ageing with a spinal cord injury and the associated complications that go with this?	Spouse/partner
2.	Is there support for carers in order to reduce the burden of caring for spinal cord injury patients?	Healthcare professional
3.	Is there information/support for adults with spinal cord injury in looking after a baby or children?	Patient
4.	Is there an imbalance in the amount of support offered to those with a spinal cord injury compared to those with cauda equina syndrome and transverse myelitis?	Patient
5.	Is there enough information/support for patients discussing sexual function and how this can be improved?	Patient
6.	Are there support groups available for spinal cord injured patients who are not in a wheelchair?	Patient
7.	How can support given to a person with a spinal cord injury, their families and friends be improved?	Patient

8.	What follow up and support services are provided for patients with spinal cord injuries regarding bowel and bladder continence management once they have left a secondary care environment?	Individual with interest in SCI
9.	How can information about prevention of pressure ulcers be provided more effectively to patients and the public?	Healthcare professional
10.	Is there information available on coping with pain, how carers cope with relatives in pain and how to claim benefits when you are unable to work due to ill health?	Patient
11.	What methods can be used to engage more males in seeking psychological help?	Other
12.	What proportion of patients knows their own ASIA score?	Healthcare professional
13.	What proportion of patients feels they clearly understand their injury and its implications?	Healthcare professional

Healthcare Professionals and Researchers		Originator
1.	Is the advice and support given by clinicians sufficient to make an informed decision on method of bladder and bowel management to choose?	Individual with interest in SCI
2.	Should GPs and A&E clinicians be better trained in understanding transverse myelitis, cauda equina syndrome and spinal cord injury and how to diagnose this?	Patient and Spouse/partner
3.	Should GPs explain cauda equina syndrome and its red flags as routine to back pain patients?	Patient
4.	Should district nurses have more training in changing indwelling catheters?	Spouse/partner
5.	Could staff looking after patients who require 24 hour assistance be better educated in wheelchair positioning, dressing someone that has no movement or understanding the emotional state of the patient?	Patient
6.	Should staff in general hospitals improve their knowledge of spinal cord injury and pressure sores?	Patient
7.	How can spinal centres and GPs be helped to provide better support for patients who are ageing with a spinal injury?	Patient
8.	Is further collaboration and communication between centres and researchers needed in order to improve and 'speed up' research?	Spouse/partner
9.	Should patients be encouraged to accept the prognosis of their injury or should they be given hope that they may improve more than is expected?	Patient
10.	What proportion of spinal cord injured patients and their family members feel that their spinal cord injury was explained to them adequately by a surgeon or other care givers and that follow up appointments were arranged within an adequate timeframe?	Patient
11.	What proportion of patients feels they receive enough support from nursing staff?	Healthcare professional
12.	Can information provided by healthcare professionals to SCI patients be uniform across all UK units?	Individual with interest in SCI

13.	Should care givers be better trained to explain SCI to patients?	Patient
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Interest and Involvement in Research		Originator
1.	What is the proportion of acute compared to chronic patients involved in curative research?	Patient
2.	How do patients who wish to take part in trials find information on which trials are being carried out in the UK and how they can volunteer?	Patient
3.	How can spinal cord injured patients influence the design of aids such as crutches, wheelchairs, callipers etc?	Patient
4.	How can patients have better access to updated research news on developments of cures? This may encourage fundraising etc.	Spouse/partner

Media		Originator
1.	What language is used in the media when referring to wheelchair users?	Patient
2.	How can we educate the general public to better understand spinal cord injuries, including cauda equina syndrome and transverse myelitis?	Patient
3.	What percentage of people with spinal cord injury is portrayed in advertisements compared with those in the general population?	Patient
4.	How positive are images in the media of people living with spinal cord injury and can this be addressed?	Patient
5.	How can we challenge negative stereotypes of spinal cord injury sufferers seeking employment or claiming disability benefits?	Patient
6.	Is there a campaign to raise awareness of transverse myelitis (and multiple sclerosis)?	Patient