

Top ten research priorities for spinal cord injury

In the Edwin Smith papyrus—the oldest known surviving text about management of traumatic injuries—injuries to the spinal cord were considered to be “a medical condition that cannot be healed.”¹ Although more than 3000 years later a cure for spinal cord injury has not yet been identified, research into the diagnosis, prognosis, and treatment of spinal cord injury, and its wide range of secondary sequelae has intensified in the past few decades. Nonetheless, to our knowledge, no systematic appraisal of patients’, carers’ and health-care professionals’ preferred research questions into spinal cord has been done to date.

In collaboration with the James Lind Alliance, a UK National Institute for Health Research-supported organisation that aims to identify gaps in scientific, medical, and psychosocial knowledge that matter most to patients, carers, and health

professionals, we completed a multi-disciplinary priority setting partnership that has defined a British research agenda for spinal cord injury for the next 5–10 years. There are as yet, no plans to monitor progress.

Our priority setting process involved four key stages:² (1) collecting research questions, (2) checking of existing research evidence through systematic searches of the literature by the project data manager, (3) interim prioritisation, and (4) a final consensus meeting to reach agreement about the top ten research priorities. We invited individuals with spinal cord dysfunction due to trauma and non-traumatic causes, including transverse myelitis and those with cauda equina syndrome (henceforth grouped and referred to as individuals with spinal cord injury), to participate in this priority setting partnership. Additionally, we encouraged caregivers and health-care professionals with an interest in spinal cord injury to participate. In view of the highly specialist nature of spinal cord injury in children, no

questions addressing paediatric injury were considered.

We obtained 784 questions from 403 survey respondents (290 individuals with spinal cord injury) which, after merging of duplicate questions and checking of systematic reviews for evidence, were reduced to 109 unique unanswered research questions. A total of 293 people (211 individuals with spinal cord injury) participated in the interim prioritisation process, leading to the identification of 25 shared top priorities. At a final consensus meeting, a group of individuals with spinal cord injury, carers, and health professionals agreed their top ten priorities for future research (panel).

Whilst the call for stem-cell research into spinal cord injury resonated with the people involved in this partnership, nine other research priorities show that spinal cord injury research should involve much more than presently meets the public eye. This research agenda for spinal cord injury has been defined by people to whom it matters most, and should now inform the scope and future activities of funders and researchers alike.

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- 1 van Middendorp JJ, Sanchez GM, Burrirdge AL. The Edwin Smith papyrus: a clinical reappraisal of the oldest known document on spinal injuries. *Eur Spine J* 2010; **19**: 1815–23.
- 2 The James Lind Alliance Guidebook. 2014. <http://www.jlaguidebook.org/> (accessed July 12, 2014).

Panel: Top ten research priorities for spinal cord injury

- 1 Does activity based rehabilitation, including functional electrical stimulation coupled with physical activity and hydrotherapy, improve outcomes such as muscle function and neuroplasticity?
- 2 Does stem-cell therapy result in improved outcomes and is this dependent on the type of injury (eg, acute or chronic; complete or incomplete)?
- 3 Does the provision of care packages in the community, including physiotherapy, after discharge from hospital improve health and wellbeing?
- 4 What bladder management strategy is most effective in reducing the number of urinary-tract infections and secondary complications?
- 5 Does early mobilisation or a period of 4–6 weeks of physically active bed rest (ie, physiotherapy exercises whilst lying in bed) result in improved patient outcomes after surgical spinal column stabilisation?
- 6 Does discharge from a hospital to a physically enabling environment improve quality of life?
- 7 Does the provision of specialist rehabilitation services, which includes multidisciplinary team planning, improve health and wellbeing?
- 8 Do interventions such as controlled fibre and fluid intake improve bowel function and quality of life?
- 9 Which are the effects of ageing on the development of complications, such as spasticity and bladder and bowel incontinence, and need for home-based support?
- 10 Does early diagnosis and treatment lead to improved outcomes for people with (a) cauda equina syndrome and (b) transverse myelitis (including relapses)?