



# A System Under Pressure: Experiences of rehabilitation from people with SCI, support partners and clinicians

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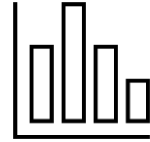
# Project Background



## Project 1

Systematic Review of  
length of stay (LOS),  
intensity, predictors  
and outcomes

Northwestern  
University Team,  
Chicago



## Project 2

Data LOS and  
therapy provision

Australasian Data  
US Data  
NHS England  
Data

## Project 3

Experiences  
and outcomes of  
people living  
with SCI  
(PwSCI)



# Literature

Worldwide, an estimated 21 million people live with SCI who could benefit from rehabilitation. However, there are significant variations in expected rehabilitation outcomes, including quality of life (QOL) and inpatient length of stay (LOS) across nations

Longer LOS may lead to greater neurological recovery and increased functional gains and provide increased opportunities to learn and master self-care skills and regain mobility

However, longer LOS may have diminishing returns on community transition and reintegration - previous studies have reported that prolonged LOS can be associated with negative characteristics such as institutionalisation and reduced opportunities to return to work or community activities.

A study by Wilkinson (2022) looking at LOS in the United States showed that as average length of stay has shortened over time, there has been a decrease in patients' bowel management skills on discharge.



# Partners for Recruitment Thank You

- Participants were recruited through the MASCIP newsletter, Aspire, Back Up, and SIA mailing lists/newsletters, discipline mailing lists eg Spinal Cord Injury Psychologists Advisory Group, and social media
- All 8 of the NHS England commissioned SCICs are patient identification centres and displayed posters and signposted to patients via their outpatient services



# Methods

PwSCI, support partners and healthcare professionals (HCP's), had two groups each which lasted approximately 90 minutes

Focus groups with PwSCI and their support partners covered each stage of the rehabilitation progress from initial goal setting to returning to the community, managing care provisions and personal relationships

HCP's questions related to the goal setting process, pros and cons of different LOS and how this is determined and involvement of families in education and delays to discharge

PwSCI, support partners and HCP's from the eight English SCIC were included in this study.



# Recruitment and Demographics

	People with SCI N=8	Support Partners N = 6
Gender	Male = 4 Female = 4	Female = 4 Male = 2
Average Age (Range)	62.25 (49-76)	58.5 (39-76)
Ethnicity	White Caucasian = 8	White Caucasian = 5 Black, Black British, Caribbean or African = 1
Average time since injury	14.4 years	13 years
Para/tetra	Paraplegia = 5 Tetraplegia = 3	Paraplegia = 2 Tetraplegia = 4
Completeness	Incomplete = 7 Complete = 1	Incomplete = 4 Complete = 2
SCI Centre Representation	5 Centres represented	4 Centres represented

	Healthcare Professionals N=6
Gender	Male = 4 Female = 2
Average Age (years)	44.8
Ethnicity	White Caucasian = 6
Disciplines	5 Disciplines represented: Physiotherapy Occupational Therapy Nursing Advanced Clinical Practitioner Psychology
Average years of experience	17.7 years (9-22)
SCI Centre Representation	5 Centres represented



# People with SCI

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- Mixed experiences of goal setting for all participants
- Timing and readiness to hear information - importance of the 'stage' of rehabilitation that information is given
- Most participants returned to homes which were not suitable for their needs and had negative experiences of this
- Community health teams had a lack of knowledge of SCI and this often led to avoidable SCI complications
- SCIC staff could be quite desensitised to care processes which were new, invasive and often scary for PwSCI

*“They sort of, my experience was the first I knew about suppositories was when someone rolled me over and put one in me bottom without explaining what was happening to me”*

# Support Partners

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- Experienced strain during rehabilitation in juggling partner support while maintaining family, work and administrative roles
- Frequently experienced a need to advocate for their partner in both SCIC's and the community
- Would have benefited from more peer support targeted at support partners as well as those with SCI
- Commented on notable change in relationship dynamics however this was often described as a stronger, deeper and more varied relationship following SCI
- Much of the education was presented to the PwSCI, support partners felt that they would have benefited from this education themselves

*“We didn't get much support at all. I didn't get any support at all. [SCIC's] educate the patient. [SCIC's] don't educate the families.”*

# Healthcare Professionals

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- Increasing pressures on ward teams has reduced the consistency of goal planning and person-centred care overtime
- Having an appointed 'keyworker' for patients was seen as advantageous in the goal planning process as this allows someone to get to know the patient in a more in-depth way and can help predict some challenges that may be faced in the discharge process
- Setting discharge dates can be a challenging part of the goal-planning process, as it may sometimes feel more focused on set timelines than on the individual's rehabilitation goals and outcomes

*"If we're talking about dates and that can become quite negative, which kind of is, is not how we want our goal planning meetings to, experience to be for patients, and it becomes very focused on like an ejection date from the system."*

- Professionals from all disciplines reported feeling pressure within the system and this effects the quality of care that is being provided

*"When we get stretched, we tend to be firefighting a bit with what we can achieve and what we can deliver."*

# Emerging results and overlapping themes

- All three groups discussed the effect staff resource and attitudes had on the level and quality of care received both in a positive and negative way

*“There was a couple [of healthcare assistants] when they got you up in the morning you felt like you could take on the world”*

*“It can have that much impact on your well-being, good care”*

- Both support partners and PwSCI reported feeling unprepared for the inaccessibility in the community they would face once they had returned home
- All groups noted challenges with balancing the goals and expectations of the PwSCI and the goals and expectations of HCPs
- Gaps in social care, community care and inaccessible housing were challenges reported by each group

*“We had his hospital bed in the lounge, he had no access to a toilet, no access to showering facilities, uhm, he was having bowels on bed by nurses”*

- Support provided by charities made a significant impact in the rehabilitation and community reintegration process

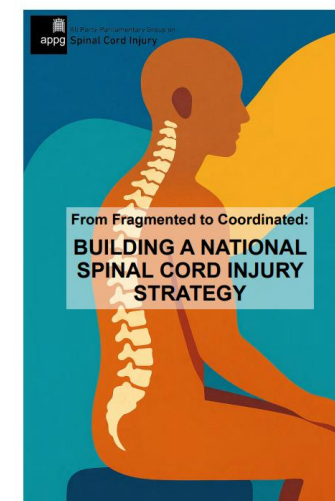
# International differences

- Similarly to the UK, the Netherlands note a large barrier with admissions to SCICs due to shortage of beds and a lack of rehabilitation staff resource
- Discharge delays due to inaccessible housing, equipment provision and care package funding are a frequent barrier to discharge in other nations
- Nations such as the US have a different funding model for healthcare so rehabilitation length is often decided by insurers
- PwSCI across the nations expressed a gratitude to be afforded the opportunity to attend a specialised rehabilitation centre

*“It was like winning the lottery for me. I honestly ended up in the best place in the world I could’ve been. I couldn’t have been helped any better” –  
PwSCI from the Netherlands*

# Story so far...

- Need for greater family involvement in rehabilitation and education – Family and Friend Days
- Focus group experience supports APPG report re housing, ‘cliff edge’
- Study limitations:
  - only includes English SCIC’s (Wales and Scotland were approached but due to time constraints for the grant application were unable to join).
  - Minority of people with a spinal cord injury in the UK receive SCIC based rehabilitation, others tertiary services or district general hospitals
- Study Strengths:
  - First international comparison re LOS, ‘ingredients’ associated with outcome (only includes developed nations for control but could identify what needs to be core and support WHO Package of Interventions for Rehabilitation 2030)
  - Will aid comparison with other nations re quality and LOS and evidence for future
  - Project 2 therapy time and outcome



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# Next Steps and Contacting Us

Currently, analysis is being completed to create shared themes across 5 nations

Following this, a survey will be piloted (phase 2) created

Phase 3: The UK research team need to recruit 500 PwSCI with the support of charitable partners and the eight English SCIC's. To do this, the survey will need to go out to around 1,500 to 2,000 people.

We look forward to sharing the results of this with the rehabilitation community

If you are interested and would like to be contacted about phase 3 of the study, please scan the below QR code or send us an email on [bht.nsicresearchpsychology@nht.net](mailto:bht.nsicresearchpsychology@nht.net)





# Dissemination

## Blog:

[From My Perspective: Blog Posts From Around the World About Rehabilitation for Spinal Cord Injury](#)

## Podcasts:

May 2024 - [Center for Rehabilitation Outcomes Research – YouTube](#)

Oct 2023 - [A conversation with Allen Heinemann, Jane Duff, Marcel Post, and Ashley Craig about a new research project on the length of stay for rehabilitation \(buzzsprout.com\)](#)

