



THE GOTHENBURG  
COMPETENCE CENTRE  
FOR SPINAL CORD INJURY

PERSONSKADE  
FÖRBUNDET RTP



# Setting the agenda for research and knowledge translation – A priority setting partnership

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# Gothenburg Competence Centre for SCI

- Consumer-led competence centre with focus on integrated knowledge translation
- We work with
  - dissemination of existing knowledge in the SCI area
  - development and dissemination of new knowledge in the SCI area
- We cooperates with all individuals and organisations involved in SCI, including persons with lived experience of SCI, to maximise the effect of implementation of knowledge.

# Volume of research



Spinal cord injury



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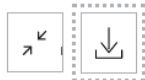
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RESULTS BY YEAR

85,521 results

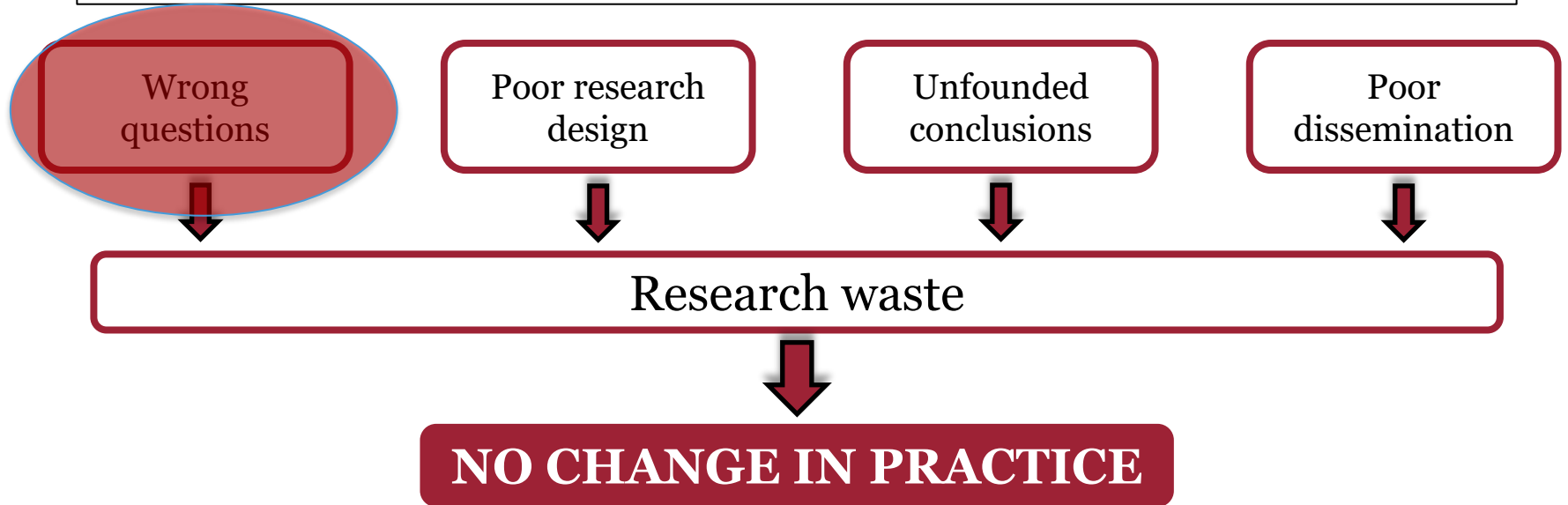
Page 1 of 8,553



# Research waste

**85 % of research is wasted**, usually because it asks the wrong questions, ... or does not change practice.

*Chalmers I, Glasziou P. Avoidable waste in the production and reporting of research evidence. Lancet. 2009 Jul 4;374(9683):86-9.*



# What is a Priority setting partnership?

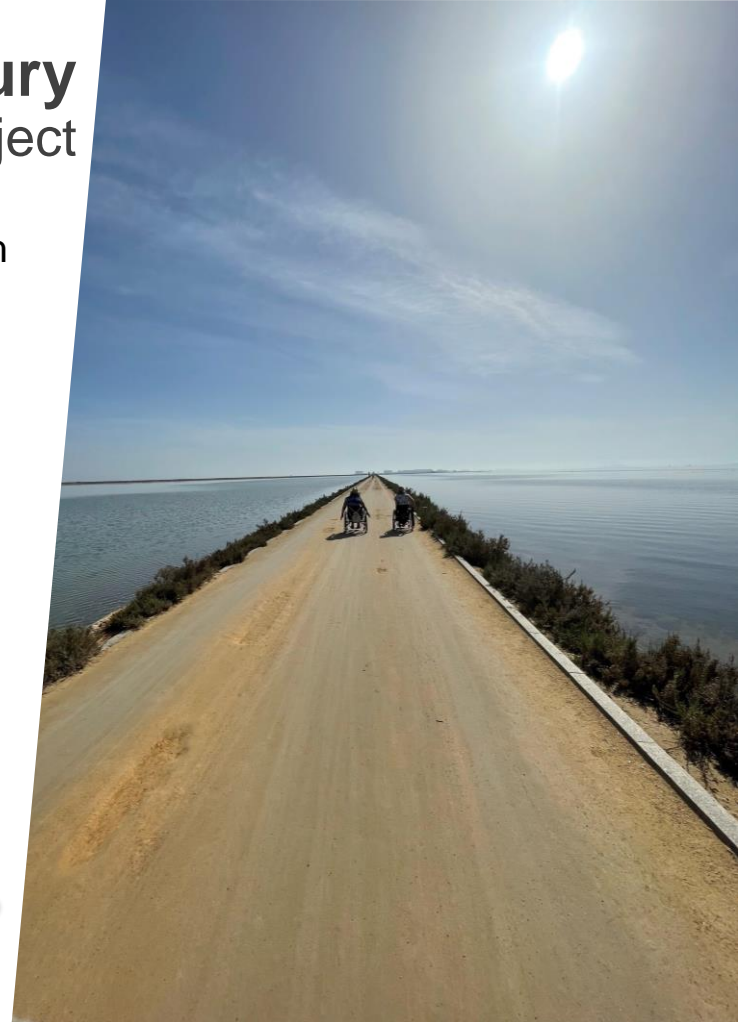
- James Lind Alliance,  
<https://www.jla.nihr.ac.uk/>
- Priority Setting Partnership (PSP) consisting of all stakeholders (knowledge users)
- Characterized by an equal voice and transparency



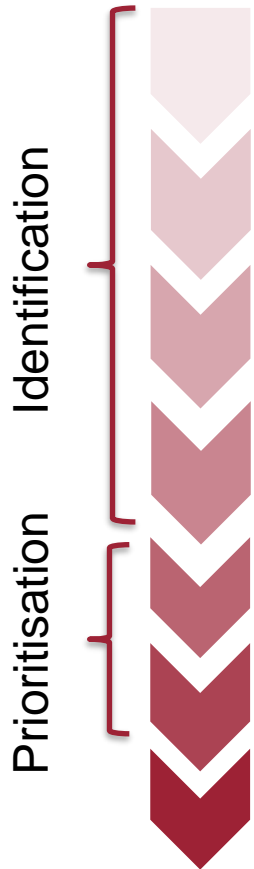
# The Swedish PSP for Spinal Cord Injury

– a mixed-method consensus development project

- Identify needs and what is important to people living with SCI, identify and prioritize uncertainties and knowledge translation gaps
- Project organisation:
  - Expert/steering group
  - Core team
  - JLA Adviser
- The project covers three parts:
  - A. Needs and important areas that must be fulfilled
  - B. Unanswered questions (uncertainties)
  - C. Knowledge translation gaps



# Method



**Online workshops** with the different stakeholders to identify needs and important area

**Online survey** to identify needs, uncertainties and knowledge translation gaps

**Analysis and summary** of workshops and survey together with the expert group

**Literature review** to determine whether every input was answered or unanswered by the current literature (B)

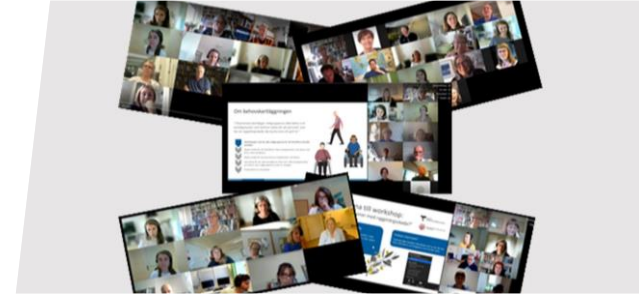
**Interim prioritisation online survey** of uncertainties (B)

**Hybrid workshop** to compile a list of Top-10 knowledge gaps that the stakeholders think are most important (B)

**Presentation and implementation** of results

# Participants

- Online workshops:
  - two for people living with SCI
  - one for relatives to people living with SCI
  - two for health professionals
  - in total 37 individuals participated
- Online surveys:
  - 243 individuals in the initial survey
  - 272 individuals in the interim prioritisation survey
- Final workshop
  - 23 individuals (14 in person and nine online)



What is important for a good life?



A thing?



A situation?



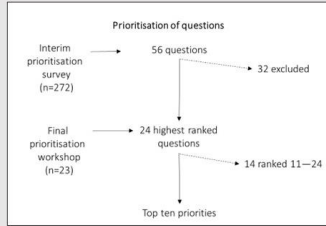
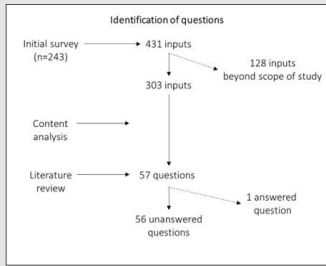
A feeling?



An ability?







# Results

## A. Needs that must be fulfilled

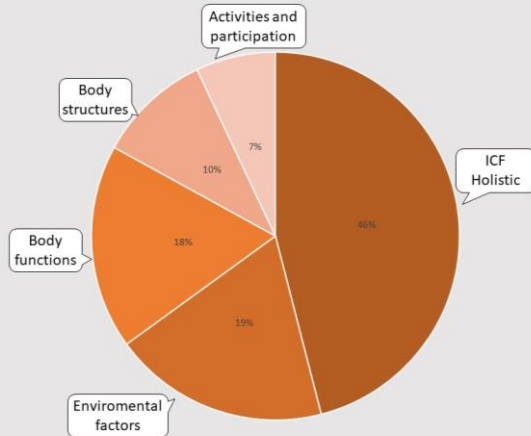
- Needs in all five components of the social-ecological model, i.e., individual, interpersonal, institutional, community and public policy.

## B. Unanswered questions (uncertainties)

- 58 unanswered questions
- 24 unanswered questions was prioritised

## C. Transfer of available knowledge

- 464 knowledge translation gaps with two dominating gaps: general knowledge about SCI in non-specialised SCI care and decision-makers understanding of challenges living with SCI



# Top-10 research questions

1. What kinds of **specialist care**, from the emergency stage to rehabilitation and lifelong follow-up, should be available?
2. What kinds of support and treatment are effective in preventing, relieving and managing **pain**?
3. What kinds of support and treatment are effective in preventing, treating and managing **gastrointestinal problems**?
4. How can the **care services lacking specialist expertise in SCI** best respond to people with these injuries and meet their needs?
5. What kinds of help and treatment are effective in helping people to **cope with their new life situation**, and to find ways of enjoying life, after SCI?
6. What kinds of help and treatment are effective in **preventing and remedying complications**?
7. What kinds of help and treatment are effective in preventing and remedying **breathing problems**?
8. What kinds of support do **close relatives** of people with SCI need?
9. The Swedish Act concerning **personal assistance** applies to the under-65s. What are the implications of this restriction when they turn 65, and for those who get SCI in old age?
10. What kinds of treatment are effective in improving the healing (**regeneration**) ability of damaged nerves?



# Conclusions

## B. Unanswered questions (uncertainties)

- The results call for action to SCI researchers, urging them to design appropriate studies in cooperation with the consumers for achieving optimal scientific progress in the issues that matter most to people with SCI.

## C. Unanswered questions (uncertainties)

- The results send a plea for more knowledge about living life with SCI, specifically a holistic and comprehensive aspect of living with a SCI.

This project encourages research groups to address methods for translating research evidence into practice.

It also encourages consumer organisations to take more actions in knowledge translation of the lived experience.



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# Thank you for your attention!

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Scientific publication: <https://osf.io/73apw/>

JLA website: <https://www.jla.nihr.ac.uk/priority-setting-partnerships/spinal-cord-injury-sweden/top-10-priorities.htm>

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