



What is important for people with SCI, their relatives, and the profession around them?

A Swedish need assessment and Priority Setting Partnership according to James Lind Alliance

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Introduction

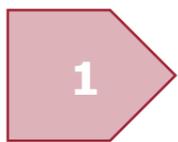
It is important that research and innovation are based in the needs and challenges of everyday life of people with lived experience (PLEx).

James Lind Alliance has developed and used a method to make sure this is made possible: the priority setting partnership (PSP).

The aim of this PSP is to identify and prioritise uncertainties, needs and what is important to people living with SCI according to themselves, their relatives, and the profession in Sweden.

Research questions

- What is important for PLEx to live a good life?
- Are there areas of life that are not as good as they could be, or that create problems for you in your everyday life?
- What areas of your environment would need to change (e.g. rehabilitation, society) for you to live a good life?
- What questions and concerns are difficult to get answered?



Initial workshops

Qualitative collection of needs and important areas in all target groups



Initial survey

Quantitative collection of needs and important areas in all target groups



Analysis and evidence checking

Summary and expert group validation of data; literature search to separate certainties from uncertainties



Prioritisation workshop

Quantitative prioritisation of identified needs, areas and uncertainties in all target groups



Prioritisation survey

Quantitative prioritisation of identified needs, areas and uncertainties in all target groups



Presentation of results

Publishing of top ten list(s) for everyone with an interest in SCI care, research, or innovation to use.

Project flow

Method

The PSP engages all target group in workshops and surveys to identify and prioritise needs, important areas, and uncertainties. It is supported by an advisory board of experts from all target groups.

Unlike other PSPs, it takes into consideration both uncertainties and certainties, in other words: research questions or knowledge translation gaps.

The standard PSP produces one list of the top ten uncertainties, but the tweaked method of this PSP allows for several lists.

Results this far

The PSP plan has been approved by the expert group, JLA and the Swedish Ethical Review Authority. The initial workshops have been analysed and have guided the development of the first survey, which will launch in November 2021. The prioritisation survey and workshop are planned for the first half of 2022.

Expected outcome

List(s) of identified and prioritised knowledge gaps and knowledge translation gaps available for anyone to use. The list(s) will be published on the JLA website and in scientific papers.

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