

# The development of a tailored health-related outcomes set in patients with sacroiliac joint (SIJ) instability

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## Background

Lower back pain (LBP) is one of the most common health problems worldwide and its burden to society has enormous impact on global health and economy. Sacroiliac joint (SIJ) pathology has proven to be the primary pain generator in 15% to 30% of patients with chronic axial LBP. In patients with SIJ instability, still little is known about the outcomes, success and safety of the operative treatment by SIJ fusion. The outcome measures available, so far, are mostly determined by healthcare professionals. Following a new concept in healthcare, the focus these days is to determine outcome parameters that matter most to the patient. These parameters and Patient-Reported Outcomes Measures (PROMs) are developed to make it possible to obtain best value of care for the patient.

### The aim of this study:

- 1) Investigate which health-related outcome measures matter most to patients with SIJ instability.
- 2) Describe the development and implementation of a tailored health-related outcomes set, including PROMs for SIJ fusion patients.

## Methods

A multidisciplinary working group of SIJ pain health care professionals in collaboration with a cohort of patients, who underwent SIJ fusion (n=217), developed a health-related outcomes set. SIJ fusion patients were asked to fill out a questionnaire in which they could express which factors and outcome measures, in their opinion, were significant in the determination of a successful outcome of their treatment. The questionnaire contained a predefined query of multiple-choice questions and was designed by the working group, taking into account the ICHOM outcome sets for low back pain and hip and knee osteoarthritis. Patients were also given the opportunity to suggest additional important patient specific factors/measures. The results of our questionnaire were used to develop a tailored health-related outcomes set for patients with SIJ-instability. Outcome parameters for this set were categorized in the following domains: patient reported health status (sacroiliac pain (VAS pain score), disability (ODI), physical functioning (SF-36 mobility), health-related quality of life (EQ-5D-3L), psychological evaluation (Zung Depression scale), overall patient satisfaction), disease control (reoperation, re-admission, use of pain medication) and complications (acute complications within 30 days of operation).

## Results

Response rate of the patient questionnaire was 72.8% (n=158). From the predefined query of multiple-choice questions, designed by the working group, patients nominated the most important outcome measures, being pain (29.7%), disability (10.1%) and mobility (6.3%). From the factors the patient group could propose as parameters that determine the success of SIJ fusion operation they scored pain (41.1%), disability (20.3%), mobility (13.9%). Within the domain of mobility outcome measures, SIJ patients expressed walking, standing and sitting to be the most important factors in determining outcome and success.



## Conclusion

Outcome measures should not only reflect the opinion of healthcare professionals but should be focused on a patient's perspective. Nowadays, PROMs are key ingredients for a successful treatment. Pursuing improvement in quality of life for the patient should have priority in the evaluation of medical treatment. SIJ fusion seems a successful treatment for patients with SIJ instability. Proper evaluation is crucial and demands a tailored health-related outcomes set with patient participation. Where most standard outcomes sets and questionnaires bundle outcomes into a combined score, this study pinpointed the most important outcome measures specific to SIJ fusion patients and structured a health-related outcome set based on these findings. By putting emphasis on specific patient reported outcome measures relevant to the SIJ fusion patient (pain, disability and mobility: walking, standing and sitting) this outcome set is unique and elementary in modern day value-based health care.