



# Core outcomes for the evaluation of new healthcare programmes in Sweden

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## Background

Healthcare programmes focusing on participation and shared decision-making, such as person-centred care (PCC), have shown to improve several key outcomes, such as, self-efficacy, empowerment, disease management, physical functioning, and health-related quality of life. However, traditional outcomes are less sensitive to these changes, limiting the availability of information for decision making and prioritisation. To aid decision-makers and researchers when evaluating PCC interventions there requires uniformity and transparency through the consistent use and reporting of core outcomes.

## Aim

The aim of this study is to develop a core outcome set for the evaluation of such programmes, including economic evaluations.

## Method

A Delphi study was conducted with participants representing 4 stakeholder groups; patients/patient representatives, healthcare workers, researchers, and managerial decision-makers. A questionnaire was developed using outcomes from a systematic review on the cost-effectiveness of PCC and a cross-sectional study on outcomes used in PCC interventional studies conducted by The University of Gothenburg's Centre for Person-Centred Care (GPCC). The outcomes were complemented based on suggestions during pilot interviews with 2 representatives from each stakeholder group. The study consisted of 2 rounds where outcomes were scored from 1-9 based on their perceived importance for the decision-making process. Participants could suggest new outcomes during the 1<sup>st</sup> round that were included in round 2. After 2 rounds, an outcome was deemed critical to the core outcome set if scored between 7-9 by at least 70% of the participants with no more than 15% scoring 1-3. A final consensus meeting with patient representatives alongside comments from stakeholder group representatives determined the final core outcome set.

## Study Participation

### Round 1

Patient / Patient  
Representative  
n = 13

Healthcare  
Worker  
n = 16

Researcher  
n = 17

Managerial  
decision-maker  
n = 12

### Round 2

Patient / Patient  
Representative  
n = 9

Healthcare  
Worker  
n = 15

Researcher  
n = 16

Managerial  
decision-maker  
n = 6

Figure 1. Total participants in the first and second scoring rounds

## TAKE HOME MESSAGE

This study identifies outcomes important for all stakeholders involved in decision-making about healthcare programmes focusing on participation and shared decision-making in Sweden. Future studies should expand this core outcome set to an international setting and explore variation in preferences among decision-makers.



Figure 2. PCC outcome distribution model

## Results

Outcomes were grouped into; general health, personal capabilities and support systems, care processes, organisational, ehealth and economics. At the end of round 1, 58 participants (patients/patient representatives n=13; healthcare workers n=16; researchers n=17; managerial decision makers n=12) had scored 51 outcomes and recommended a further 13 for inclusion in round 2. In round 2, 46 participants had re-scored the outcomes (missing n=12), with scores being changed between scoring thresholds on 168 separate occasions. Twenty-nine outcomes reached consensus by meeting the scoring criteria amongst all groups on a single outcome or a total weighted score between groups. A further 7 outcomes that only reached consensus in one group were added after in-depth discussion during the consensus meeting. Twenty-eight outcomes that did not reach consensus were removed. Final outcomes for each category, general health (n=7), personal capabilities and support systems (n=5), care processes (n=13), organisational (n=5), ehealth (n=3) and economics (n=3).

## Conclusion

The 36 outcomes that were included in the final core outcome set highlight stakeholder preferences towards outcomes corresponding to personal capabilities and support systems, as well as process measures related to care implementation that place the patient and carers as central actors in the decision-making process.