



Comparing the effectiveness and cost-effectiveness of self-management interventions in four high priority chronic diseases in Europe

Prioritisation of patient-important outcomes

COS Workshop on 10th and 11th of July in Berlin



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What's a Delphi Consensus Method?

A Delphi Consensus Method is a technique for gathering opinions of different stakeholders with the aim of reaching a consensus. In COMPAR-EU, this method was used to prioritise outcomes that are important to measure the success of self-management interventions (SMIs) in patients living with one of the four chronic conditions: type 2 diabetes, heart failure, COPD or obesity. The COMPAR-EU Delphi Process comprised three rounds:

1. Prioritisation of a range of patient-relevant outcomes on an electronic platform
2. 2nd round of the prioritisation including statistical representation of the group rating
3. Consensus workshop in Berlin to agree on the Core Outcome Set for each disease (COS)

The first two rounds were only addressed to patients, while the aim of the third round was to obtain consensus on the opinions of different stakeholders including patients and patients' representatives, carers and carers' representatives, and health care professionals (clinicians and researchers).

In the first round of the Delphi process, patients were asked to prioritise electronically a range of patient-important outcomes for their respective condition using a Likert scale, ranging from 1 (lowest importance) to 9 (highest importance). The outcomes which were gathered from different literature were split into the following 7 categories: Patient's competences in self-management behaviours, health related, quality of life, care-giver's quality of life and competences, perceptions and satisfactions with care, health care use and costs. Patients and patient representatives could also suggest including new outcomes. In total, approximately 10 patients per disease rated around 80 outcomes.

In the second round, participants went through the same process as in the first round. The same outcomes were presented but this time each participant saw the median and the mean of the collective judgment of the whole group and his/her own ranking. This allows and encourages the participants to reassess their initial vote with the aim of reducing the range of rankings and arriving at something closer to a consensus.

The third and final round was the consensus workshop in Berlin with the goal of determining a so-called Core Outcome Set (COS) per disease. A COS consists of at most 15 outcomes that are considered to be most important to measure the success of self-management interventions.

Purpose and the value of the COS consensus workshop

After the first two rounds of COMPAR-EU's Delphi survey in May and June 2018, a consensus workshop took place on the 10th and 11th of July in Berlin, Germany. In the consensus workshop, 20 patients, carers and their representatives were brought together with 20 health care professionals (clinicians and researchers) from a diverse range of European institutions and organisations. Four panels (one for each condition: COPD, heart failure, type 2 diabetes, and obesity) were created to discuss and achieve consensus on the final COS to be



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included in the project. The discussions were accompanied by one COMPAR-EU moderator, two note takers and technical supporters as well as one observer per panel. The purpose of this face-to-face meeting in Berlin was to reach consensus between the perspectives of patients and those of researchers or clinicians, and to address the challenges that these different perspectives pose for COS development.

Patient and public involvement is important as they should have a right to have a say in research that affects them. Involving concerned stakeholders to reveal different views, experiences, and beliefs is vital to ensure that research is of relevance. As COMPAR-EU's objective is to develop decision aids for the adoption of the most suitable SMI, it is important to ensure that those SMIs have an impact on patient-relevant outcomes. Therefore, people who know what it is like to live with the disease should have the opportunity to express their preferences.

Process of the COS consensus workshop

Four tables with the main results of the first two rounds of Delphi surveys were prepared in order to discuss the different outcomes for the four chronic diseases.

Infographics

Infographics were developed for presenting information on patients' values and preferences on outcomes and health states relevant to each condition (figure 1-4). We distributed these infographics at the beginning of the discussions that took place among the panels for each chronic condition. These infographics served as supporting material that could be used in the discussions to clarify concepts or to provide guidance on patients' perspectives as reported in the literature. Infographics were used at the discretion of participants or moderators.

We performed an overview of systematic reviews with the aim of determining what outcomes have a bigger impact on patients' daily life, how it is living with their condition, patients' views regarding self-management, and barriers or facilitators for self-management interventions.

We selected systematic reviews of studies designed to obtain utilities, which are measures of how much value a person derives from an outcome. Relevant qualitative reviews that explore patients' views and attitudes were also included.

We searched MEDLINE, CINAHL, Psycinfo and identified 27 systematic reviews for COPD (including over 800 individual studies), 35 systematic reviews for heart failure (including over 1000 individual studies), 15 systematic reviews for obesity (including over 250 individual studies), and 34 systematic reviews for type 2 diabetes (including over 1000 studies). The main findings of these overviews were summarised in user-friendly infographics written in plain language. Below we present samples of the infographics that were developed for each condition.



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Figure 1: Extract from the COPD infographic



Figure 2: Extract from the heart failure infographic




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Figure 3: Extract from the type 2 diabetes infographic

Self-management competences 1

Patient activation



Based on the self-monitoring values, patients understand how food, exercise, and other living habits influence their blood glucose levels, and learn to judge what they can do as opposed to the foods and actions that are prohibited.

Patients can evaluate the effects of their daily life, and connect their lifestyle with their blood glucose levels.

Knowledge

Individuals report that knowledge about disease processes, the role of medications and their treatment plan, is critical to their ability to successfully self-manage their chronic conditions.

However, knowledge does not necessarily lead to risk-reducing behaviour: people may engage in unhealthy behaviours despite awareness of related risks.



Self-efficacy

If self-management practices are perceived as experiences of improvement of health, then positive effects on current patient's health beliefs and behaviours will be achieved.

In contrast, if they experience adverse effects or threats of further harm, patients will be less willing to continue with self-management.



Health literacy

There are blood sugar numbers that must be understood, medication regimes, and not everyone has the same capacity to understand.

It can be difficult for physicians and nurses to explain things at the appropriate level. Patients benefit from having gaps in their knowledge addressed at their own pace.

Participation and decision-making


Patients express a preference for healthcare professionals' recommendations to be individually tailored. Patients value being heard by healthcare professionals, and appreciate when they are enquired about their personal circumstances.

Figure 4: Extract from the obesity infographic

Self-management / Self-care behaviours 02

Adherence to program

Patients able to achieve their weight loss goals are more likely to maintain their weight loss.




Physical activity

Feeling too overweight is frequently reported by patients as a barrier to physical activity.

Patients are aware that increasing their physical activity is essential for weight control, health and wellbeing; yet the very weight they wish to lose makes it difficult for them to pursue this healthy behaviour.

Eating management


Rather than eating to satisfy hunger, some patients eat to relieve emotional discomfort or stress. Eating when there is no physical need leads to weight regain.



<https://www.weightlosssolutionstips.com/light-drink-to-avoid-binge-eating.html>


Dietary planning

Dietary engagement has several external barriers including lack of time, lack of knowledge, adverse weather, and family and work demands.



Addictive behaviours

Some studies found that alcohol is a particular problem for men, which support a perceived causal link between alcohol consumption and increased appetite.




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COS elicitation process

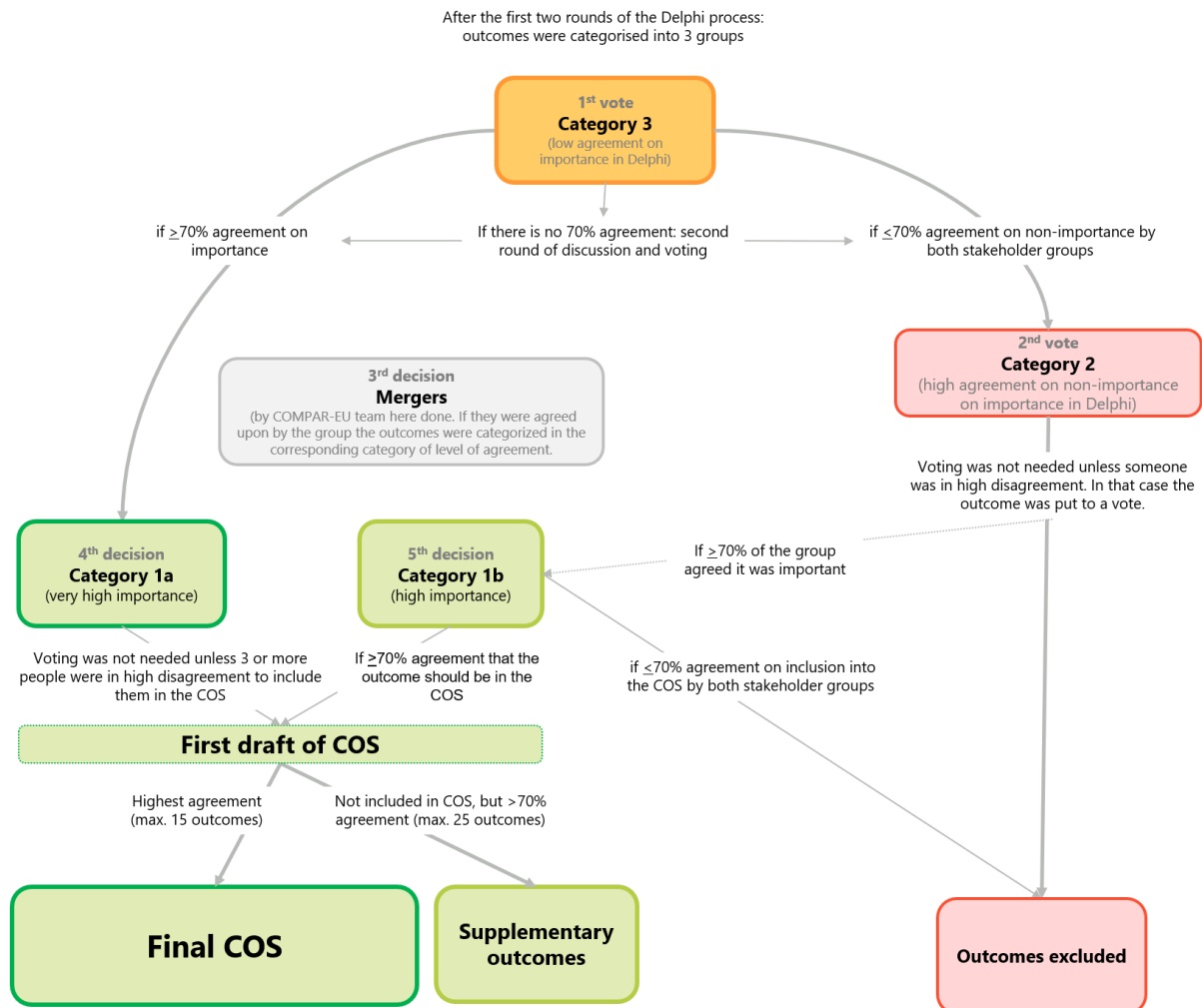
After the first two rounds of the Delphi process, the outcomes have been categorised into three groups for each disease:

1. Outcomes with a high level of consensus on the importance to measure the impact of SMIs:
 - a) Very high importance: At least 70% of Delphi participants have rated a score of **eight or higher** on the nine-point Likert scale, a maximum of 15% have rated a score of three or lower.
 - b) High importance: At least 70% of Delphi participants have rated a score of **seven or higher** on the nine-point Likert scale, a maximum of 15% have rated a score of three or lower.
2. Outcomes with a high level of consensus on the non-importance to measure the impact of SMIs: At least 70% of Delphi participants have rated a score of six or lower on the nine-point Likert scale.
3. Outcomes with a mixed level of consensus on the importance to measure the impact of SMIs.

Figure 2 visualises the COS elicitation process carried out in the consensus workshop in Berlin.



Figure 2: COS elicitation process



At the first day of the two-day COS consensus workshop, the outcomes in the third category (low consensus) were discussed before the participants voted either for inclusion or exclusion from the COS. Every participant received a voting paper for every single outcome to ensure anonymous voting. Consensus was achieved by having at least 70% of support either for inclusion in the first or in the second category. If there was no 70% consensus, a second round of discussion and voting was carried out. If one of the stakeholder groups (patients or professionals) agreed on the importance of inclusion or exclusion (at least 70% agreement), the outcome was in-/excluded, even if the overall group didn't agree. Participants had the chance to suggest new outcomes to be considered in the discussion.

At the second day, a list of outcomes categorised into the second group was presented (those moved from the third category and those coming from the first two rounds of the Delphi process). The aim was to validate



that those outcomes should not be included in the final COS. Voting was not needed unless someone was in high disagreement.

After the first day, the project team decided to merge some related outcomes in each disease in order to reduce the number of outcomes to be voted. These mergers were discussed in each panel. If they agreed on the mergers, the participants voted either for inclusion or exclusion. If someone didn't agree on the mergers, the individual outcomes were voted (unless the outcomes that were originally in category 3 and have been voted the day before).

Afterwards, the outcomes included in the 1a) category were presented. Voting was not needed unless 3 or more people were in high disagreement to include them in the final COS.

In the next round, a list of the outcomes included in the 1b) category was presented. After the discussion, the outcomes were voted on the list handed out to each participant (unless the outcomes that were originally in category 3 and have been voted the day before).

The last step was the discussion of the ranking of the outcomes in the 1b) category based on the level of agreement. Those with the highest agreement were included in the final COS up to a maximum of 15 outcomes. Outcomes that were not included in the final COS but had an agreement of 70% or higher were considered as supplementary outcomes. The number of supplementary outcomes must not exceed a number of 25. If there were more outcomes with a level of agreement of 70%, the panel had to discuss and reduce the number of supplementary outcomes.

Core Outcome Set - Achievements

Each panel ended up with a Core Outcome Set for their respective disease and agreed on some supplementary outcomes to measure the success of self-management interventions.

The following table presents the final results for each disease panel.

Table 1: Number of outcomes included in the final COS and supplementary outcomes for each disease

	COPD	Obesity	Heart Failure	Type 2 Diabetes
COS	16	15	16	13
Supplementary	1	5	9	4



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