

CONFERENCE ABSTRACT

Researching what matters to people: Developing Core Outcome Sets for Self-Management Interventions in Chronic Diseases

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Introduction

Patient involvement has substantially increased among different areas of care in the last decades. However, patient involvement in research is still weak. One of the areas in which patient involvement would be more important is the selection of outcomes to measure effectiveness of interventions. This links to the recent advancement of core outcome sets (COS) - minimum set of outcomes agreed across researchers in one specific topic. We need to make sure that COS properly reflect patients' preferences, a basic step to ensure that research advances are aligned with what matters most to patients.

Within the Horizon 2020 COMPAR-EU project we have developed COS for measuring the efficacy of self-management among adults living with COPD, heart failure (HF) type 2 diabetes (T2DM) or obesity, based on patient preferences and including the views of healthcare professionals and researchers.

Methods

Initially, a long list of outcomes focused on each condition was developed. The resulting extensive lists were refined and translated into plain language for patients.

This list was integrated into an online survey platform for patients and patient representatives to vote for using a modified Delphi Technique in two rounds. Participants were asked to rate the importance of the outcomes for measuring the success of self-management interventions (1-9 scale). Simultaneously, a scoping review of systematic reviews on patients' values and preferences regarding self-management was conducted. Once both were completed, the outcomes were discussed and agreed upon in a two-day face-to-face consensus meeting with patients, patient representatives, healthcare professionals and researchers.

Results

39 patients and patient representatives participated (9 COPD, 9 HF, 11 T2DM and 10 Obesity) in round I and 38 (9 COPD, 9 HF, 11 T2DM and 9 Obesity) in round II of the online Delphi Surveys.

These results were combined with those of the values and preferences overview. During the Consensus meeting, 19 patients and patient representatives together with 20 healthcare professionals and researchers reached an agreement on four COS, including 16 outcomes for COPD, 16 for HF, 13 for T2DM and 15 for Obesity.

Discussion

Often, research measures effectiveness with outcomes guided by research interest and feasibility. However, this doesn't always match the preferences of patients. This could involve that despite advances in research we don't advance in the areas that matter to patients.

Conclusions

Participatory processes involving patients can help to develop COS that are relevant not only for research but also for those living with the condition, moving us closer to patient centered care.

Lessons learned

COS can help inform better clinical decisions and understand patients' priorities. It could also guide policy decision-makers since the outcome measures show what is of crucial importance to realise patient centred care.

Limitations

As in any participatory process, there could be a bias in the sample of patients and other stakeholders that participated. This was mitigated by complementing it with an overview on patient preferences.

Suggestions for future research

The development of COMPAR-EU COS for COPD, HF, T2DM and Obesity could help increase the value of self-management research for patients.