



## What matters to patients with Chronic Obstructive Pulmonary Disease (COPD) when it comes to self-management outcomes

### Introduction

Most people over 65 years live with one or more chronic health conditions. Management of these conditions accounts for a significant portion of healthcare costs today: somewhere between 70% and 80%\*.

Patients living with chronic conditions mostly manage their condition themselves, at home and in the community, often helped by family or other informal carers. Providing patients with the right support for self-management and living well with a condition is an essential part of good chronic disease care and prolongs life expectancy.

Studies suggest that the right kind of self-management support can improve patients' health outcomes as well as bring value for society. However, today healthcare professionals and policymakers lack information about what self-management support activities (referred to as "self-management interventions", or SMIs further below) work best for different patients in different contexts.

**COMPARE-EU** is a project partly funded by the European Commission under its research framework programme "Horizon 2020". It started in January 2018 and will end in December 2022. The project aims to identify, compare, and rank the most effective and cost-effective SMIs for adults in Europe living with one of four chronic conditions: T2DM, Chronic Obstructive Pulmonary Disease (COPD), obesity and heart failure. **The project has developed 4 Core Outcome Set (COS) to guide self-management interventions in these diseases and will go on to develop an online decision-making tool for policymakers, researchers, patients, and the healthcare industry.**

What is a Core Outcome Set: a list of outcomes which patients and healthcare professionals have recommended that researchers should measure and report if they are undertaking a research study in a particular area. Prior to the selection of the COS, extensive literature search and analyses were undertaken by COMPARE-EU representatives.

### What new knowledge does this research bring?

A key strength of our COS is that it is strongly **based on patients' preferences** while also reflecting the perspectives of healthcare professionals and researchers. This means the COS should be quite **reliable and could be used in many different settings**. As a next step, the COS will be used to design an online tool to support decision-making by policymakers, healthcare professionals, developers of chronic disease management guidelines, patients, and their families on what are the most suitable SMIs in different contexts.

How was the COS developed?

First, COMPAR-EU researchers analysed the scientific literature and found a long list of different outcomes. We, the COMPAR-EU project consortium, then selected the most important of those outcomes in a two-round Delphi process. A Delphi process is a technique to find agreement between experts through a series of structured questionnaires and roundtable discussions.


This group voted **16 outcomes** to be a part of the final COS. Within these **16 outcomes**, **six** are considered particularly important by all participants, meaning very high support – **70% (or more)** of the participants’ approval. On ten outcomes, there were more mixed opinions in the group, however they are also part of the COS.

What are the outcomes patients consider most important?

The **six outcomes most important** to patients in self-management of COPD were:

- # Patient activation # Self-efficacy # Participation and decision-making
- # Self-monitoring # Smoking cessation & #COPD symptoms (short-term)

**The full core outcome set for COPD**

|  |   |
|--|---|
| <u>Preferred Self-Management Outcome</u>   | <u>Explanation</u>  |
| Patient activation   | The knowledge, skills, and confidence a patient has on managing his own health and healthcare, including a feeling of being responsible for taking care of his own health and feeling empowered to act when needed. Education is an empowering process for many patients, enabling them to take charge of their own health. |
| Self-efficacy  | A person's belief or judgement that they are capable of doing something, often related to a specific goal in self-managing their condition, feeling of confidence and of being in control of their own condition and life.  |
| Participation and decision-making  | Feeling able to participate actively in one’s own care (as much as the patient wishes). When a patient ‘takes ownership’ of their condition, they are more likely to sustain active participation in the long term.   |
| Self-monitoring  | The extent to which patients regularly monitor themselves as agreed with their healthcare professional, for example concerning their symptoms or physical activities or other disease related parameters.   |
| Smoking cessation  | Stopping or at least reducing smoking is pre-requisite and an important part of management of COPD.   |

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| <b>COPD symptoms (short-term)</b>          | <b>Relief of symptoms, including cough and breathlessness, in the short-term. COPD requires frequent monitoring – morning and evening – if the patient is to gain control over their condition.</b>  |
| <b>Adherence</b>                           | The extent to which a patient follows the recommended or prescribed treatment upon a shared agreement with a healthcare professional, such as taking medication, following life-style advice, and attending scheduled visits to healthcare providers.  |
| <b>Sleep quality</b>                       | Sleep quality includes interrupted sleep, sleep problems, and sleepiness. Sleep monitoring is a critical part of how well the patient is handling stress in adjusting their lifestyle while living with chronic illness., stress hormones if not getting enough sleep are releasing in the blood stream.   |
| <b>Exacerbation</b>                        | Worsening of symptoms, such as increased breathlessness, mucus, sputum production, change in colour of sputum, feeling out of breath. It is important to be vigilant about any worsening of symptoms and having a plan that one can follow if this happens.  |
| <b>Physical activity - Muscle strength</b> | Referral and/or participation in a Pulmonary Rehabilitation Programme, physical activity & exercise capacity. Exercise, diet and stress-free lifestyle are crucial to managing a chronic illness.  |
| <b>Coping with the disease</b>             | How well a person feels able to cope with stress or other difficulties caused by the disease, including depression and anxiety.  |
| <b>Activities of daily living</b>          | Being able to do usual activities, such as personal hygiene, housework, sex life, managing finances and work.  |
| <b>Caregiver knowledge and competence</b>  | It is critically important that the (family/informal) caregiver has the right knowledge and skills on the disease and its management.  |
| <b>Caregiver quality of life</b>           | Caregiver’s quality of life, including the burden that they feel from the caregiver tasks.   |
| <b>Emergency room visits</b>               | Number of visits to emergency department visits and unplanned hospital admissions. Fewer emergency visits show the condition is well under control.  |
| <b>Cost effectiveness</b>                  | Includes value for money of the self-management intervention and the good use of health system resources.  |
| <b>SUPPLEMENTARY OUTCOMES*</b>             |  |
| <b>Knowledge</b>                           | Having a good understanding of the health condition, its treatment, and other aspects, such as lifestyle and healthy choices. The first step on the road to identifying the right self-care and self-management support for each individual patient is a full history and a complete set of medical tests to create a baseline from which the self-care patient’s plan will be designed and monitored. It matters because everyone “self-manages” – With or Without Support. |



\*Supplementary outcomes are outcomes which were viewed as secondary in terms of importance to patients, researchers and healthcare professionals.

**Background:** Chronic conditions affect over **80% of people above 65 years**. Also, between **70% and 80%** of healthcare costs arise from chronic disease management. The literature suggests that an **appropriate selection** of SMI outcomes is **essential** if research is to guide decision-making and inform policy. SMIs can improve clinical and societal outcomes in chronic conditions as well.

**What is a self-management/self-care:** self-management is defined as `what individuals, families and communities do with the intention to promote, maintain, or restore health and to cope with illness and disability with or without the support of healthcare professionals. It includes but is not limited to *self-prevention, self-diagnosis, self-medication* and *self-management* of illness and disability.

The project partners are the [European Patients' Forum](#); [Avedis Donabedian Research Institute](#) from Spain; [Institute for Medical Technology Assessment](#) from the Netherlands; [Netherlands institute for health services research](#); [OptiMedis AG](#) from Germany; [University of Ioannina](#) from Greece & [Sant Pau Research Institute](#) from Spain.

**What is a Lay Summary:** A lay summary is a brief summary of a research project that is used to explain complex ideas and technical and scientific terms to people who do not have prior knowledge about the subject. They are important not only for patients but also for lay persons and non-specialist medical professionals.

**What is a Delphi Process:** A technique which seeks to obtain compromise and agreement on the opinions of experts on a temporary panel, through a series of structured questionnaires and roundtable consultations.

**Who chose the COPD COS:** Outcomes were prioritised in a two-round Delphi Process by patients and patient organisation representatives, researchers, and healthcare professionals from around Europe in Berlin in 2018.

**What new knowledge did this research bring:** A key strength of COMPAR-EU COS is that they are strongly based on patient preferences while also reflecting the perspectives of clinicians, researchers and civil society representatives. We are confident that the COS and the supplementary outcomes reflect the preferences of all key stakeholders. Therefore, the resulting COS might be applicable with context adaptation to wide type of settings across Europe, and even worldwide.

### More information needed?

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# COMPAR-EU

## Coordinator of the project



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