

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

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

### What is **self-management**?

Self-management is defined as what individuals, families and communities do 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.

## What are the outcomes people with COPD consider most important?



#### **Activation**

The knowledge, skills, and confidence a patient has in managing their own health and healthcare when needed. This calls for a feeling of responsibility and empowerment, with education being a useful process for many patients.



#### 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 person wishes). When people 'take ownership' of their condition, they are more likely to sustain active participation in the long term.



#### **Self-monitoring**

The extent to which people with COPD or carers regularly monitor themselves as agreed with their healthcare professional, for example concerning 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.



# COPD symptoms (short-term)

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.

COMPAR-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 self-management interventions for adults in Europe living with one of four chronic conditions: Type 2 Diabetes Mellitus (T2DM), Chronic Obstructive Pulmonary Disease (COPD), obesity and heart failure. The project has developed 4 Core Outcome Sets (COS) to guide self-management interventions in these diseases and developed an online decision-making tool for policymakers, researchers, patients, and the healthcare industry.

Self-management Interventions (SMIs) are supportive interventions that healthcare staff, peers, or laypersons systematically provide to increase people' skills and confidence in their ability to manage a long-term disease.

## 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 is quite reliable and could be used in many different settings.

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.

This group voted 16 outcomes to be a part of the final COPD COS. Within these 16 outcomes, six are considered particularly important by all participants, meaning very high support – 70% (or more) of the participants' approval.

https://self-management.eu/

#### More information needed?

projects@eu-patient.eu | + 32 2 274 08 67

Full list of outcomes and explanation:



Relevant article: Camus-García E, González-González AI, Heijmans M, Niño de Guzmán E, Valli C, Beltran J, Pardo-Hernández H, Ninov L, Strammiello V, Immonen K, Mavridis D, Ballester M, Suñol R, Orrego C. <u>"Self-management interventions for adults living with Chronic Obstructive Pulmonary Disease (COPD): The development of a Core Outcome Set for COMPAR-EU project." PLoS One. 2021 Mar 1;16(3):e0247522. doi: 10.1371/journal.pone.0247522. PMID: 33647039; PMCID: PMC7920347.</u>

#### Project coordinator



#### Project partners













