



Obesity and what matters to patients the most 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.

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 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 COMPAREU 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, COMPAREU researchers analysed the scientific literature and found a long list of different outcomes. We, the COMPAREU 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.

The group voted 15 outcomes to be a part of the final COS. Of these **15 outcomes, 5 are considered particularly important** by all participants, meaning very **high support – 70% (or more)** of the participants' approval. The remaining ten outcomes received mixed opinions in the group, however they are also part of the COS.

What are the outcomes patients consider most important?

The **five outcomes most important** to patients in self-management of Obesity were:




**#Self-efficacy #Participation and Decisions Making #Adherence to programme
#Social interactions & #Patient-healthcare provider relationship**

You will find the full COS at the end of this document.

More information needed?

Please contact Mr. Lyudmil Ninov, EPF Senior Programme Officer by email: lyudmil.ninov@eu-patient.eu or by telephone: + 32 2 274 08 67. You can also visit the project website: <https://self-management.eu/>

The full core outcome set for obesity

	
Obesity Core Outcome Set	
Preferred Self-Management Outcome	Explanation
Self-efficacy	A person's judgement that s/he is capable of doing something, often related to a specific goal s/he wants to achieve, feeling of confidence, and of being in control. Health

	literacy ¹ is a factor that can contribute to self-efficacy.
Participation and decision-making	Feeling able to participate actively in her/his own care and treatment decisions (as much as s/he wishes), feeling motivated and able to participate.
Social interactions	Relationships with friends; having the confidence / energy / motivation to participate in social activities; relationships with family and/or ability to care for children.
Patient-healthcare provider-team relationship	Confidence and trust in the healthcare professional; how good the communication is between patient and healthcare professional(s); having enough time for consultation; how satisfied the patient is generally with her/his care; patient feels s/he has enough information.
Adherence to (treatment) programme	The extent to which the patient follows the agreed treatment programme, such as diet, exercise plan, life-style advice, etc. as a whole; taking prescribed medication.

¹ Having the cognitive and social skills that determine a person's ability to find health-related information, understand the information, judge its trustworthiness, and to take appropriate action in everyday life (for example regarding lifestyle choices, self-care and so on)

<p>Self-monitoring (including self-recording)</p>	<p>The extent to which a patient (regularly) monitors herself/himself as agreed with her/his healthcare professionals, for example her/his symptoms or her/his weight.</p>
<p>Quality of life – Physical and psychological functioning</p>	<p>1) Usual Activities: Being able to do usual activities, such as personal hygiene, housework, managing finances. 2) Normality: Feeling able to live a 'normal' life. 3) Mobility: Being able to for example walk, climb stairs, bend, cross legs, get up from chairs). 4) Work: Being able to do work tasks, or to take up work/paid employment. 5) Physical Activities: Being able to participate in and enjoy physical activities. 6) Depression: Feeling depressed. 7) Anxiety: Feeling anxious. 8) Stress: Feeling stressed.</p>
<p>Coping with the disease</p>	<p>How well a person feels able to cope with stress or other difficulties caused by the disease; Mental attitude toward the condition.</p>
<p>Patient activation</p>	<p>The knowledge, skills, and confidence a person has in managing their own health and healthcare, including a feeling of being responsible for taking care of their own health.</p>

<p>Integration at work</p>	<p>Being able to do work tasks, or to take up work/paid employment or to be able to be a part and feel included in a team, work environment, etc.</p>
<p>Physical Activity</p>	<p>Physical activity /Exercise as advised (Adherence to the exercise plan).</p>
<p>Weight management</p>	<p>1) Weight loss: Reduction in weight. 2) Stable weight: Being able to keep a stable weight. 3) Waist size: Measure of waist circumference.</p>
<p>Co-morbidities management</p>	<p>1) Blood pressure control: Lowering of blood pressure or needing to use less blood pressure medication. 2) Reduce the chance of developing other chronic conditions: such a heart disease, diabetes, coronary artery disease, metabolic syndrome. (Obesity is a risk factor for developing other chronic conditions.)</p>
<p>Cost-effectiveness for the health system – value-based outcomes</p>	<p>1) Costs for the healthcare system; cost savings for the healthcare system as a result of the self-management intervention; value for money of the self-management intervention (cost-effectiveness).</p>

SUPPLEMENTARY OUTCOMES*	
Addictive behaviours	E.g. alcohol, drugs, gambling, shopping... Limiting/Eliminating, if not excluding addictive behaviours, especially alcohol, is important.
Sleep quality	1) Breathing problems during sleep: Being able to breathe easily when sleeping/ not needing the sleep mask as much as before (obstructive sleep apnea). 2) Overall quality of sleep.
Medication-adverse events	Problems or injuries related with the treatment, such as medication side effects or side-effects of surgeries.
Pain	Feeling pain or discomfort.
Sex Life	Being able to have a satisfactory sex life.

*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 T2DM 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.

COMPAR-EU

Coordinator of the project:



Partners of the project:

