



## Heart Failure 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 COMPAR-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.

The group voted **16 outcomes** to be a part of the final COS. Within these 16 outcomes, **4 are considered particularly important** by all participants, meaning they have received very high support – **70% (or more) of the participants’ approval**. On twelve 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 **4 outcomes most important** to patients in self-management of Heart Failure were:

**# Quality of life, #Knowledge, #Self-efficacy & #Patient activation**

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

### The full core outcome set for Heart Failure

	
<u>Preferred Self-Management Outcome:</u>	<u>Explanation:</u>
<b>Patient activation</b>	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. This is measured using a dedicated measuring scale, the so-called degree of patient activation.
<b>Self-efficacy</b>	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.
<b>Knowledge</b>	Having understanding of the health condition and diagnosis, treatment options, and other aspects (risk factors included), such as lifestyle and healthy choices.
<b>Quality of life (including sex life, normality, depression, positive attitude, social activities and friends, being able to do usual activities and QALY)</b>	Being able to do everyday activities, such as: practicing personal hygiene, household work, sex, managing personal finances, social contacts, and job tasks. As QALY (Quality-Adjusted Life Year) incorporates both quantity and quality of life, it therefore provides a reasonable estimate of the amount of quality time (i.e., health benefit) an individual may experience as a result of a particular intervention.

<b>Health literacy</b>	Having the cognitive and social skills needed to find health-related information, understand the information, judge its trustworthiness, and take appropriate action in everyday life.
<b>Participation and decisions making</b>	Feeling capable to participate actively in her/his own care and treatment decisions (as much as s/he wishes).
<b>Taking medication or other treatment as agreed (adherence)</b>	The extent to which a patient follows the prescribed treatment, such as taking medication as agreed and following lifestyle advice and recommendations.
<b>Self-monitoring</b>	The extent to which a patient regularly monitors themselves as agreed with her/his healthcare professionals, for example her/his symptoms or her/his weight.
<b>Body Weight Management</b>	1) Weight loss: reduction in weight. 2) Stable weight: being able to keep a stable weight. 3) waist size: reduction in waist circumference.
<b>Breathlessness (difficult or laboured breathing)</b>	Getting fewer moments of breathlessness and being able to do more activities.
<b>Mortality</b>	Reducing deaths from all possible causes.
<b>Effort test/Exercise capacity</b>	The maximum amount of physical exertion that a patient can sustain.
<b>Physical Activities</b>	Being able to participate in and enjoy physical activities. Physical activity refers to activities agreed with a health care provider as part of disease-management.
<b>Perception of health care professional team relationship and communication</b>	Patient's confidence (trust) in the healthcare provider and how well the communication is perceived.
<b>Number of hospital admissions</b>	A decrease in the number of unplanned hospital admissions.
<b>Value for money of the self-management intervention</b>	Cost-effective use of resources.
<b>SUPPLEMENTARY OUTCOMES*</b>	
<b>Adherence to diet as agreed (including salt and water)</b>	Keeping diet recommendations as agreed with her/his healthcare professionals, including diet advice related to water intake (drinking the appropriate amount of water (or other liquids), and salt intake (not eating too much salt).
<b>Smoking (cessation)</b>	Smoking habits / how much the patient smokes (if at all).
<b>Alcohol (control)</b>	Alcohol drinking habits. As people with heart failure suffer from heart rhythm problems (arrhythmia), decreased or limited alcohol consumption is recommended.
<b>Swelling (including leg and abdominal oedema)</b>	Fast weight gain of more than 2 kilos (3 pounds) in three days or swelling of the legs or ankles or increasing swelling or pain in the stomach area.
<b>Tiredness (Fatigue)</b>	Being physically tired or lacking in energy.

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<b>Caregiver quality of life (including burden)</b>	Caregiver quality of life and the burden that he/she feels from the caregiver tasks.
<b>Caregiver self-efficacy</b>	A (family) caregiver's belief/judgment that s/he is capable of doing something, often related to a specific goal s/he wants to achieve, feeling of confidence and being in control.
<b>Number of outpatient visits</b>	Number of medical visits, including emergency visits.
<b>(Number of) re-hospitalizations</b>	Unexpected return to hospital, for example for unplanned procedures or problems (re-admission rates).

\*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 HF 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 COMPARE-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?**

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

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## Coordinator of the project



## Partners of the project



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