

COMPAR-EU

COMPAR-EU News #2

Comparing the effectiveness and cost-effectiveness of self-management interventions in 4 high priority chronic diseases in Europe

Dear readers and friends,

COMPAR-EU's first year was very busy, successful, challenging, and above all – inspirational! We developed and externally validated a [COMPAR-EU self-management interventions taxonomy](#) to increase clarity in defining and hence, comparing self-management interventions (SMIs). A special highlight was the workshop in Berlin with patients, researchers, and healthcare professionals. In a face-to-face meeting, [the most important patient-relevant outcomes were discussed](#). The so-called Core Outcome Sets (COS) were developed for each of the conditions studied (Type 2 Diabetes, Obesity, COPD, and Heart Failure) and will be prioritised in comparing different SMIs. Currently, we are at a crucial moment! A lot of effort is invested in the data extraction process of 3,500 relevant SMI studies. By analysing the data, we'll be able to answer questions such as: What are the most effective SMIs in improving any specific outcome that a patients prioritizes? Which SMIs are most cost-effective for the health system? Stay tuned and keep updated on the data extraction progress!

Your COMPAR-EU team



COMPAR-EU analysis plan meeting in Barcelona, Spain

In this newsletter, learn more about:

- [How self-management can succeed from a patient's perspective](#)
- [Short update on our work packages](#)
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How self-management can succeed from a patient's perspective

We first met Jacqueline Bowman-Busato at the [COS workshop](#) in Berlin last year. She represented the patient's perspective in the panel of obesity and explained what matters most to her in management of her chronic condition. In her newly published contribution for COMPAR-EU, she shared her experiences on the challenges she had to face on her way to successful self-management. For the past 23 years, she had been living with complex chronic, relapsing diseases. She has only begun to feel in control of her two diseases in a meaningful way over the past 18 months. "Self-management has empowered me to better know and understand myself on so many levels." [Read](#) the whole success story of Jacqueline and learn how she finally succeeded to fully understand and embrace responsible self-management.

Update on our work packages



'This year, together with other partners, EPF is adapting some of the main project deliverables into lay language together with other partners, and making sure they are understandable and relevant to the patient community. Furthermore, through various interactive activities meaningful patient participation will be embedded into the processes and outcomes of the COMPAR-EU project!'
Lyudmil Ninov, EPF



'It's great to see that we were able to reach an expert consensus on the SMIs taxonomy. We are now ready to tackle the challenging analysis ahead of us.'
Carola Orrego, FAD

Click [here](#) to get an overview of all Work Packages (WP) and to see the timeline of our Milestones and Deliverables.

How to incorporate patients in COMPAR-EU (WP3)

At this stage of the project, aside from “translating” key project deliverables into lay language summaries, a second main priority for EPF will be to make sure representatives of the patient community are meaningfully involved in the project via several interactive and reflective activities, such as:

1. Online webinars involving the EPF membership (72 patient organisations);
2. Small working groups composed of interested patient representatives and/or patients who attended the Berlin COS workshop last year;
3. The members of the EPF Youth Group – a group of 11 young patients coming from different European countries with different chronic conditions.

A central role for EPF in the COMPAR-EU project is to ensure active, meaningful and strong patient presence from the very beginning until the end, which would significantly contribute to the validation of the project outcomes and achievements.

Finalising the last details of the analysis plan (WP4)

To determine how to deal with complex interventions in network meta-analysis (NMA) and how to best balance the trade-off between describing interventions in detail and ensuring that our NMA has enough statistical power, two two-day meetings were set. [Nivel](#), [IR-HSCSP](#), [UOI](#), [Opti-medix](#) and [FAD](#) discussed the last details of the COMPAR-EU analysis plan with the goal of adding value to the knowledge on self-management of patients, professionals, industry, researchers and decision makers. Great to see how all COMPAR-EU partners are pulling in the same direction and collaborate in such an enthusiastic way!

Data collection progress (WP4)

After four months of screening almost 30,000 abstracts of relevant studies on self-management, [Nivel](#), [FAD](#) and [IR-HSCSP](#) started the extraction process via a dedicated software. [Nivel](#), the WP leader, emphasizes: *‘It is a very intensive process in which we have to extract data from 3,500 studies that we selected from the title and abstract screening. This month we started with the full data-extraction for diabetes and the total data extraction for the four diseases will run until April 2020. We are working with a team of 16 reviewers of NIVEL, FAD and IR-HSCSP. We all collaborate closely together, NIVEL coordinating the process together with FAD who developed the data-extraction form. Finally, our work will result in very comprehensive databases on SMI for the four diseases separately.’*

To ensure inter-researcher reliability, all data extractors participated in an internal [training session](#).

Set up of a Self-management Blog (WP9)

How to best communicate about COMPAR-EU-related topics? We have set up a [Self-management Blog](#) and integrated it into our website www.self-management.eu to inform you about developments in research, policy, and practice. We will publish reports on patient's experiences with self-management, conduct interviews with experts, and explore implementation strategies for decision aids. Furthermore, we will recommend several interesting scientific articles to read on a monthly basis. Besides our partners' contributions, our [Advisory Board members](#) will share their insights into the importance of self-management and the need for shared decision-making. Look forward to receive worthwhile publications!

Wish to read more about a specific topic or have an idea for a new blogpost? Write us to contact@self-management.eu.

COMPAR-EU meets the Advisory Board for the first time

A very interactive and stimulating discussion arose at the first meeting with the [members of the Advisory Board](#), led by Sandra Hoyer (Philips GmbH). Communication and methodological issues were commented and the exploitation of the project's (expected) results was thoroughly discussed. All the different experiences in the healthcare system bring a much-needed perspective to our work on self-management.



'What a great collaboration! We are convinced that the Advisory Board helps us to further push self-management into practice.'
Nina Adrion, OptiMedis AG



From left to right: Dr Monique Heijmans (Nivel, COMPAR-EU), Prof Dr Rosa Suñol (FAD, COMPAR-EU), Dr Bert Boer (Erasmus School of Health Policy and Management, Advisory Board), Sandra Hoyer (Philips GmbH, Advisory Board), Dr Saskia de Groot (IMTA, COMPAR-EU), Dr Oliver Groene (OptiMedis AG, COMPAR-EU), Jacqueline Bowman-Busato (Third-I, Advisory Board), Nina Adrion (OptiMedis AG, COMPAR-EU), Dr Angela Coulter (University of Oxford, Advisory Board), Dr Francisco Camarrelles (Spanish Society of Family and Community Medicine, Advisory Board), Dr Shirlene Oh (Imperial College Health Partners and Advisory Board).

COMPAR-EU poster presentations

A great effort by the entire COMPAR-EU team to disseminate the work carried out! The first two COMPAR-EU posters have already been presented, with six more abstracts accepted.

Towards optimal self-management support for chronically ill with low health literacy levels

Maclein van der Griend MSc, Monique Heijmans PhD, Prof. Jeroen Raaijmakers PhD

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Department of Family Medicine, Care and Public Health Research Institute (CAPHRI), Maastricht University, The Netherlands

Health literacy and self-management
Low health literacy is negatively related to the self-management of the chronically ill. Internationally, many self-management interventions are developed and implemented, but few of them are tailored to the level of health literacy skills of patients. Moreover, it is possible that patients with low health literacy skills differ in their self-management priorities and their preferences for self-management support. At the moment, self-management support does not take account of the needs and preferences of chronically ill patients with low health literacy levels, whereas low health literacy is one of the most important barriers for successful self-management.

Research question
How can patients with low health literacy skills be optimally supported in the self-management of their chronic disease?

Expected results
This study gives insight into the most important outcomes for self-management from the perspective of patients with low health literacy, and into the most effective and cost-effective interventions for patients with low health literacy to improve these outcomes. Findings will be built into an online platform for support patients, professionals and policy makers to choose the most optimal self-management interventions for people with low health literacy that fit to their needs and preferences.

Methods
Literature review
Focus groups
Network Meta-Analysis

COMPAR-EU
This study is part of a larger research project named COMPAR-EU (2018-2022), funded by the European Commission, which aims to identify, compare, and rate the most effective and cost-effective SMI for adults in Europe living with a high priority chronic disease (asthma, obesity, heart failure or COPD).

Maclein van der Griend: m.vandergriend@nivel.nl
Information about COMPAR-EU: www.self-management.eu

NIVEL
Research for better care

Nivel presented a poster on optimal self-management support for chronically ill with low health literacy levels at the [4th European Health Literacy Conference](#) in Dublin (14/15 March 2019).

At a [regional symposium of a national network of health services researchers](#), OptiMedis presented the development of the Core Outcome Sets (6 May 2019).



At both conferences, delegates were particularly interested in the process of patient involvement in COMPAR-EU.

Let's meet in Cape Town, Santiago and Adelaide for our next presentations. Check out the dates:

Advancing patient-centred care: development and external validation of comprehensive taxonomy of self-management interventions in chronic conditions

20th – 23rd of October 2019 short oral presentation ISQua 36th International Conference, Cape Town, South Africa

Are we researching in the areas that matter for patients? Developing core outcome sets for self-management interventions in chronic diseases

20th – 23rd of October 2019 long oral presentation ISQua 36th International Conference, Cape Town, South Africa

The perspective of patients living with chronic heart failure on self-management interventions: A mixed-method overview for the COMPAR-EU project

22nd – 25th of October 2019 short oral presentation 26th Cochrane Colloquium, Santiago, Chile

The perspective of patients living with obesity on self-management interventions: A mixed-method overview for the COMPAR-EU project

22nd – 25th of October 2019 short oral presentation 26th Cochrane Colloquium, Santiago, Chile

The perspective of patients living with type 2 diabetes mellitus on self-management interventions: A mixed-method overview for the COMPAR-EU project

22nd – 25th of October 2019	long oral presentations	26th Cochrane Colloquium, Santiago, Chile
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What do patients and their caregivers value on self-management interventions for chronic conditions? A scoping review of systematic reviews for the COMPAR-EU project

22nd – 25th of October 2019	long oral presentation	26th Cochrane Colloquium, Santiago, Chile
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How to compare the (cost-)effectiveness of self-management interventions: using network meta-analysis to include both direct and indirect assessments of multiple treatment options

30th of October – 02nd of November 2019	short oral presentation	G-I-N & JBI Conference 2019, Adelaide, Australia
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Development and external validation of a comprehensive Taxonomy of Self-Management Interventions in chronic conditions: the COMPAR-EU taxonomy

30th of October – 02nd of November 2019	short oral presentation	G-I-N & JBI Conference 2019, Adelaide, Australia
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Incorporating patients' preferences in the development of core outcome sets for four chronic conditions: COMPAR-EU project

30th of October – 02nd of November 2019	long oral presentation	G-I-N & JBI Conference 2019, Adelaide, Australia
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International Shared Decision-Making Society

After many years of collaboration, the [International Shared Decision Making Society \(ISDM\)](#) has been founded in November 2018 in Hamburg, Germany. Its purpose is to foster the science and practice of shared decision making and person-centred care among researchers, clinicians, patients, health policy makers and others. This includes the promotion of education, and training of scientific and practical work in shared decision making and patient-centered health care as well as the support of institutions that deal with these topics. Prof Martin Härter from the Department of Medical Psychology at the University Medical Center Hamburg-Eppendorf, current president of the ISDM, is grateful about the development: *'It is an exciting moment that we have now a professional organisation that will help us to foster shared decision making and patient-centred care world-wide. I am very grateful to all the colleagues that helped to change this dream into reality'*. Since March 2019, it is possible to become a [personal member](#) of the society. In just the first weeks, the society received more than 120 applications coming from 20 countries of all five continents.

The first general assembly will take place during the 10th ISDM conference in Québec, Canada (7th to 10th July 2019).

Upcoming Events

26 - 29 June 19	24 th WONCA Europe Conference	Bratislava, Slovenia
07 - 10 July 19	10 th International Shared Decision Making Conference	Quebec City, Canada
30 Sep - 01 Oct 19	2 nd COMPAR-EU consortium meeting	Ioannina, Greece
20 - 23 October 19	ISQua 36 th International Conference	Cape Town, South Africa
22 - 25 October 19	26 th Cochrane Colloquium	Santiago, Chile
30 Oct - 02 Nov 19	G-I-N & JBI Conference 2019	Adelaide, Australia
12 - 14 Nov 19	EPF Congress on patient involvement	Brussels, Belgium
20 - 23 Nov 19	12 th European Public Health Conference (EU-PHA)	Marseille, France

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