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
In this newsletter, learn more about:

- How self-management can succeed from a patient’s perspective
- Short update on our work packages
- The first Advisory Board meeting in Paris
- COMPAR-EU poster presentations
- Foundation of the International Shared Decision-Making Society
- Upcoming events

Click here to read this newsletter on our website in PDF.

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, Optimed 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 article 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
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.

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, Opti-Medis 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:

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<thead>
<tr>
<th>Event</th>
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<th>Type</th>
<th>Conference</th>
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<tr>
<td>Advancing patient-centred care: development and external validation of comprehensive taxonomy of self-management interventions in chronic conditions</td>
<td>20th – 23rd of October 2019</td>
<td>short oral presentation</td>
<td>ISQua 36th International Conference, Cape Town, South Africa</td>
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<td>Are we researching in the areas that matter for patients? Developing core outcome sets for self-management interventions in chronic diseases</td>
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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

26th Cochrane Colloquium, Santiago, Chile

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

26th Cochrane Colloquium, Santiago, Chile

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

G-I-N & JBI Conference 2019, Adelaide, Australia

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

G-I-N & JBI Conference 2019, Adelaide, Australia

Incorporating patients’ preferences in the development of core outcome sets for four chronic conditions: COMPAR-EU project

30th of October – 02nd of November 2019

G-I-N & JBI Conference 2019, Adelaide, Australia

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

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<td>26 - 29 June 19</td>
<td>24th WONCA Europe Conference</td>
<td>Bratislava, Slovenia</td>
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<td>07 - 10 July 19</td>
<td>10th International Shared Decision Making Conference</td>
<td>Quebec City, Canada</td>
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<td>30 Sep - 01 Oct 19</td>
<td>2nd COMPAR-EU consortium meeting</td>
<td>Ioannina, Greece</td>
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<td>EPF Congress on patient involvement</td>
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<td>20 - 23 Nov 19</td>
<td>12th European Public Health Conference (EU-PHA)</td>
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Get involved

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