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COMPAR-EU

Dear readers and friends,

another six months have passed and we are delighted that the COVID-19 situation in many European countries is easing. Hopefully, project meetings and conferences in the field of self-management can be held again in person very soon. Despite the challenges that the COVID-19 pandemic brought for all of us, both personally and professionally, we have been able to advance our workplan and are looking forward to sharing the progress of our work with you. In this newsletter you can read updates about our work: how we have involved patients in taking important decisions, how we analysed the available evidence on the effectiveness and cost-effectiveness of self-management interventions, which contextual factors affect self-management interventions, and how we \are planning to synthesize all our research evidence and outputs. The development of a comprehensive platform is a key part of these plans and we are excited to report on the progress of this task.

Please enjoy reading our newsletter and learn more about the COMPAR-EU project progress. We wish you an enjoyable summer!

Your COMPAR-EU team

COMPAR-EU Video

Why is the COMPAR-EU project relevant? What does the platform look like? How does the patient benefit? These are questions that Carola Orrego Villagrán, Pablo Alonso Coello and Oliver Gröne answer in the new video.

Get an interesting insight into the work on the project!

Click here to watch the video with English subtitles. A Spanish subtitled version is available here.

Update on Work Packages

Presenting some preliminary results of our research at the 21st international conference on integrated care

Fundación Avedis Donabedian (FAD): At the conference we presented some highlights on the use of PREMs (Patient Reported Experience Measures) and PROMs (Patient Reported Outcome Measures) in studies of effectiveness of self-management. We found that many studies addressed PROMs, but very few studied PREMs. Although PROMs were more reported in the litera-ture, there remain many outcomes that are important to patients which are not commonly measured. For example, patients in our four diseases (Type 2 Diabetes, Obesity, Heart Failure and COPD) had highlighted participation and decision making as a key outcome to include in our core outcome sets : less than 1% of studies that we found in the literature measured this.

Some outcomes are more commonly reported, but are still not covered by all studies. Patients' quality of life, for example, was measured in 26% of RCTs on diabetes, 21% in obesity, 57% for heart failure and 66% for COPD. This highlights the fact that we still have work to do to better take patient preferences into consideration before conducting research. If as researchers we want to improve patients' lives, we have to do so in the areas that are important to patients themselves.

We hope that our COMPAR-EU core outcome sets for Type 2 Diabetes, Obesity, Heart Failure and COPD, developed with patients, can help better align future research with patient preferences.

Do you want to know more about FAD's work on the project? [Click here](#) to read more about Work Package 2, which FAD is leading.

What's new with the EPF team and the Patient Panel?

European Patients´ Forum (EPF): During the first half of 2021, the European Patients' Forum (EPF) has been focusing its efforts on the key aspects of our work in patient involvement, co-design and engagement. Together with the Patient Panel (PP), we held four webinars to coordinate PP's input into COMPAR-EU activities, and contributed to the work of the IT Platform Task Force. Working together with the Patient Panel gives us the chance to take their perspective into account. Here we would like to share some statements with you:

- *We expect the COMPAR-EU platform to select those self-management interventions that are available and financially covered by our health system."*
- *"The platform needs to be accessible for people with visual/hearing disabilities."*
- *"Since the COMPAR-EU platform addresses different stakeholders, this should be taken into ac-count when presenting its results."*

Get to know the Patient Panel members on our [website](#).

Our efforts have also been focused on kicking off the translation of the project lay summaries into eight European languages, and preparing these in an attractive and accessible design.

This year, we also welcomed a new [EPF team member](#), Juan Fernandez, Policy Assistant. Juan will be supporting EPF in our policy work in the framework of the COMPAR-EU project, in particular the upcoming work on regulatory frameworks and standards, as well as various events and lay materials.

Do you want to know more about EPF's work on the project? [Click here](#) to read more about Work Package 3, which EPF is leading.

What do self-management interventions look like?

Netherlands Institute for Health Services Research (Nivel): Over the past two years, we have collected data on self-management interventions for people with Type 2 diabetes, heart failure, obesity and COPD from more than 2000 Randomized Controlled Trials (RCT). These data are systematically stored in a database, forming the basis for the Network Meta-Analyses (WP5) and cost-effectiveness analyses (WP6).

In the coming months we will start writing four papers, one per disease, in which we will describe and summarize the findings for each disease in relation to type and number of interventions, outcomes, patient characteristics, self-management components and profiles of patients.

In addition, we are writing a descriptive paper on those self-management interventions in the databases that are (also) given to people with limited levels of health literacy (HL), as they constitute a large and important group that necessitates particular attention in self-management support. By learning from existing interventions directed to people with limited HL, this paper will help professionals to better tailor their self-

management interventions to the needs and capabilities of this group of patients.

An important product of WP4 is an overview of questionnaires and other measuring tools used in the RCT's to measure the effects of self-management interventions with respect to different outcomes such as quality of life, adherence, HbA1c and dyspnea. These questionnaires, with detailed information about form, content, quality and application possibilities, will be made available to researchers and professionals via the platform.

Do you want to know more about Nivel's work on the project? <u>Click here</u> to read more about Work Package 4, which Nivel is leading.

Finalizing analyses for estimating effectiveness of self-management interventions

University of Ioannina (UOI): Following our main analysis on the effectiveness of the self-management interventions (SMIs), we are now working on updating all the analyses, using the final corrected datasets, to achieve a clearer insight about the effectiveness of the various SMIs for the outcomes of interest. We are employing both standard network meta-analysis and the additive component network meta-analysis, focusing on exploring and interpreting the results. We are also working on the development of graphical tools for attractive and comprehensible presentation of the effectiveness of the SMIs.

For example, we are developing new visualization graphs, plots and tables that will allow us to illustrate the relevant effectiveness or the ranking of either the interventions or the components of each SMI, and will aid presentation of results to different stakeholders. For the next few months, we will keep working on the presentation and interpretation of results, contributing to the integration of results into the decision-making tools and the COMPAR-EU platform.

Do you want to know more about UOI's work on the project? <u>Click here</u> to read more about Work Package 5, which UOI is leading.

How do we capture the potential impact of self-management interventions on the costs of informal care?

Institute for Medical Technology Assessment (iMTA): We are currently finalizing the four different cost-effectiveness models, and will start the cost-effectiveness analyses of self-management interventions (SMIs) in the coming months. The cost-effectiveness analyses that we conduct adopts a societal perspective; this means that all relevant social costs and benefits, regardless of who bears them, are included in the analyses. In addition to costs within the health care sector - including costs of the SMIs - we therefore include other costs, such as those of informal care.

Because data regarding the impact of SMIs on informal care use is limited, we aim to predict informal care use based on age and proximity to death. By using proximity to death to predict informal care use we capture the postponement of informal care driven by the potential postponement of complications due to the SMI (which could have an impact on life expectancy).

We use data from a longitudinal dataset which contains information on health and informal care use of respondents from different European countries. Preliminary findings showed that there is indeed a relationship between age, proximity to death, and informal care use. When we have the final estimates, these can be included in our health economic models on the four chronic conditions that we study within the COMPAR-EU project.

Do you want to know more about iMTA's work on the project? [Click here](#) to read more about Work Package 6, which iMTA is leading.

Which contextual factors influence the successful implementation of self-management interventions?

Netherlands Institute for Health Services Research (Nivel): Now that we're steadily advancing our analysis of which self-management interventions (SMIs) are most effective in general, an important next step in the process is to find out which contextual factors influence the successful implementation of the most effective SMIs. This is the goal of WP7. Such contextual factors may for instance include demographic characteristics of patients, training and motivation of intervention providers, or higher-level factors such as the country of implementation.

To create a comprehensive overview of which contextual factors are most influential - and should therefore be taken into account when implementing the most effective SMIs - we undertake three analyses in WP7. Firstly, in the past few months our team has worked hard to conduct a systematic review into which context factors have been reported in previous reviews. Secondly, we are currently in the process of letting experts prioritize these context factors in a Delphi study. Finally, in the coming months we'll also look at the specific contextual factors reported in the source articles of the network meta-analysis (WP5). Overall this means that there are a lot of exciting results coming up!

Do you want to know more about Nivel's work on the project? Click here to read more about Work Package 7, which Nivel is leading.

Important progress with the platform and decision-making tools

Fundació Privada Institut de Recerca de l´Hospital de la Santa Creu i Sant Pau (IR-HSCSP): COMPAR-EU will put together four panels (Type 2 Diabetes, Obesity, COPD, Heat Failure) that will formulate recommendations on the most promising self-management interventions. The T2DM panel is the most advanced, and our next activity will be a webinar on how to formulate recommendations with the GRADE approach.

In our Work Package, we are also developing decision aid tools that will provide support for patients and healthcare professionals to make informed decisions on the adoption of the most suitable self-management interventions. Decision aids will include information on the most important outcomes, the certainty we can place on the research results, as well as practical considerations about the self-management interventions being considered (e.g., burden). These tools will be designed for use in face-to-face clinical encounters or to be self-administered by patients before clinical encounters.

At the moment, we are working with patients and with our IT company to have an optimal version ready to pilot in the Autumn. The online platform for COMPAR-EU is also moving along: this will include all the products and resources developed during the project, including recommendations, decision aids, and synthesis of the research.

Do you want to know more about IR-HSCSP's work on the project? Click here to read more about Work Package 8, which IR-HSCSP is leading.
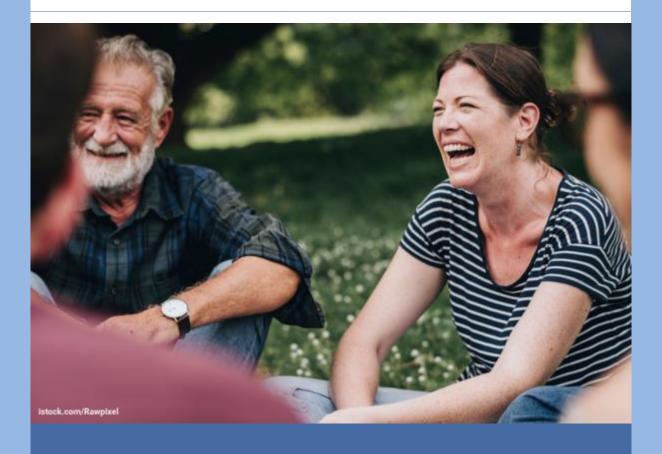
Mapping the determinants and enablers of the use of decision tools in practice

OptiMedis: A critical measure of the success of COMPAR-EU will be whether the outputs result in meaningful changes for patients. Many well evidenced and exhaustively developed tools and interventions do not deliver their potential impact because their use requires changes in ways of working, and there is insufficient support for these changes.

Accordingly, the development of business plans for decision tools is a COMPAR-EU deliverable. These business plans will provide information about the key enablers and barriers in making use of the decision tools, which can directly change ways of working with patients. To develop the business plans, we will hold interviews and focus groups with managers and healthcare professionals in COMPAR-EU countries, using their insights to build and refine plans for the various provider and health system contexts. We are planning to demonstrate the tools and then gather interviewees' perspectives about barriers and enablers, using a common theoretical framework. This information will be important to the sustainability of the overall platform, and will help inform the business canvas templates.

Together with EPF, we have also kicked off work on a scoping review of European regulatory frameworks and standards on self-management interventions and patient decision aids, which we will carry out throughout the summer. With this analysis we can better understand how the macro-level factors (e.g. national strategies, policy and regulations, mandates, and guidelines) will influence implementation of the COMPAR-EU platform.

Do you want to know more about OptiMedis' work on the project? [Click here] to read more about Work Package 9, which OptiMedis is leading.

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Latest Blog Articles

Online self-management enhancing interventions; lessons learned to bear in mind

Even before we were confronted with the current pandemic, numerous online interventions to improve self-management were developed, evaluated and in some cases successfully implemented. In this article, I review some self-management enhancing PhD-projects and show how the actual use (uptake) and implementation of our carefully developed interventions turned out there.

Read full article here.

COMPAR-EU Patient Panel Activities – 2021 Mid-Term Review

European Patients' Forum (EPF) is a COMPAR-EU project partner, tasked with ensuring that patient centricity remains at the heart of the project's activities, objectives, and future endeavours. In this edition, EPF shares what has been achieved so far in 2021 and highlights immediate next steps, mainly in connection to the work carried out by members of the Patient Panel.

Read full article here.

Patient Decision Aids for Self-Management Interventions

Patient decision aids (PDAs) have been developed to enable people to be more involved in decisions and plans about their care. We briefly explore some of the key drivers and barriers to their adoption.

Read full article here.

Prolonging lives with self-management

COMPAR-EU aims to rank the most (cost-)effective interventions for self-management and provide relevant research supporting this aim. In two recently published papers we provide standardized methods for the inclusion of future costs in cost effectiveness analyses, in the Netherlands and England and Wales respectively.

Read full article here.

A new year for patient empowerment and self-management: 2021 plans and opportunities!

The European Patients´ Forum (EPF) is a COMPAR-EU consortium partner, tasked with ensuring that patient

centricity remains at the heart of the project's objectives. In this blog, EPF shares its 2021 plans to continue eliciting patient priorities and preferences, mainly through its work with the Patient Panel, among many other engaging activities that lie ahead.

Read full article [here](#).

Helping decision makers making informed judgments: COMPAR-EU decision-making tools

After estimating the relative merit of self-management interventions, COMPAR-EU is developing different interactive tools to facilitate decision-making for different stakeholders and scenarios. We briefly outline three key interactive tools that will be available in a web-based platform in early 2022.

Read full article [here](#).

Upcoming Events

08-11 July 2021
ISQua International Conference [read more](#)

12-15 July 2021
iHEA Congress [read more](#)

05-08 Sep 2021
European Respiratory Society International Congress 2021 [read more](#)

04-07 Oct 2021
1st North American Conference on Integrated Care [read more](#)

26-29 Oct 2021
EPF Congress 2021 [read more](#)

Publications

Niño de Guzmán Quispe E, Martínez García L, Orrego Villagrán C, Heijmans M, Sunol R, Fraile-Navarro D, Pérez-Bracchiglione J, Ninov L, Salas-Gama K, Viteri García A, Alonso-Coello P (2021)

The Perspectives of Patients with Chronic Diseases and Their Caregivers on Self-Management Interven-tions: A Scoping Review of Reviews.

Read full article [here](#).

Camus-Garcia E, Gonzalez-Gonzalez AI, Heijmans M, Niño de Guzman E, Valli C, Beltran J, et al. (2021)

Self-management interventions for adults living with Chronic Obstructive Pulmonary Disease (COPD): The development of a Core Outcome Set for COMPAR-EU project.

Read full article here.

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