COMPAR-EU

Dear readers and friends,

since the summer holiday period, when we were all able to enjoy the sunshine and re-charge our batteries, we have made a lot of new advances in our work packages. This year, we could also meet and discuss the progress and challenges in person at the consortium meeting in Hamburg. In this newsletter you can find updates about our work: how we have involved patients in the co-design of the COMPAR-EU platform, how we are working on interpreting the effectiveness of self-management interventions and how we estimated the costs of these interventions. In terms of platform development, we are starting to integrate a part of generated evidence and work on design of other key sections synthesizing research outcomes. The platform will also include decision-making tools tailored for different end users and relevant stakeholders, and we are excited to report on the progress in developing these tools.

Furthermore, we would like to put a spotlight on the new initiative, called "Self-Management Europe" that published already two "Alerts" about practical recommendations to enhance self-management and patient empowerment in practice. The initiative could complement the work done in COMPAR-EU beyond the project.

Please enjoy reading our newsletter and learn more about the COMPAR-EU project progress. We wish you a healthy, fun-filled and stress-free holiday season in advance.

Your COMPAR-EU team

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

Consortium meeting in Hamburg

This year, we were finally able to meet in person again. Our consortium meeting took place in October 2021 in Hamburg and was hosted by OptiMedis. We focussed on the results of the network meta-analysis, the COMPAR-EU platform and much more.

COMPAR-EU project update

Patient involvement in COMPAR-EU

The European Patients' Forum (EPF) has been working hard over the last three months to advance mainly on the work around the project lay summaries and plan for 2022. In this time, we have selected a company to support us in further translating the lay summaries into six additional languages and will soon launch a call for tender to develop these lay summaries into attractive and interesting leaflets and videos in order to boost dissemination and uptake.

Our Patient Panel has been actively involved across various project activities. Members of the Panel have been on the receiving end by been regularly updated on project's progress, but most importantly they have been co-designing the final end product – the IT platform and contributing to the transformation of key deliverable and milestones into plain language, just so the patient community can benefit of COMPAR-EU.

EPF's Policy Team worked to identify and collect a series of policy and regulatory frameworks/standards that are relevant to the introduction of self-management decision-making tools across European settings. For this endeavour, both scientific and grey literature was reviewed. As an example, some of the collected frameworks were first published by national European medical societies, patient organisations, and/or indexed publications (amongst others). These frameworks will be extend-ed and updated later during the project's life span.

Get to know the panels we work with here and for more information on the lay summaries click here.

Develop, test and evolve: What's new on the COMPAR-EU platform?

We are advancing in the development of our COMPAR-EU platform, which will include all our key final results. We are currently working on the integration of repositories of tools to measure PROMs and PREMs, and one describing all the interventions found in the literature. Additionally, we are working with the rest of the partners in the design of the specific sections to show detailed results on Network Meta-Analyses (NMA) for each of the analysed outcomes, contextual factors, and cost-effectiveness analysis.

In terms of panel work, we have assembled four panels, one for each condition, with an average of ten panellists per panel and a wide diversity of backgrounds. We have held a total of nine meetings (six training and three recommendations meetings), and we have surveyed panels about the importance of the out-comes and the magnitude of effects thresholds for the outcomes of interest. The Diabetes Panel and Obesity Panels are in the process of making judgements and recommendations using the GRADE ap-proach for the first intervention and will soon be addressing the rest of the selected in-terventions. The COPD Panel has already held two briefing and training meetings to formulate recommendations, and we expect to hold the first meetings with the Heart Failure Panel by the first week of December.

As part of IR-HSCSP's Work Package, we developed – through an iterative approach – a first prototype of the decision aid web-based tools. These tools will provide support for patients and healthcare professionals to make informed decisions on the adoption of the most suitable self-management interventions. The prototype was reviewed by a Task Force, which is a multidisciplinary stakeholder group including patients, clinicians, methodologists, and other relevant stakeholders, and by an external group of patients who have been involved in previous steps of the COMPAR-EU project. With the Task force group, we held regular meetings in which we presented the tools and their pro-gress, whereas with the external group of patients, we conducted a workshop in which we presented the prototype, and finally we conducted semi-structured interviews with some patients. At the moment, we are working with our IT company to make all the necessary changes in the decision aid web-based tools and have an optimal version ready to conduct a user-testing with patients and health professionals by the end of 2021.

Click here to read more about the COMPAR-EU platform.

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Testing patient decision aids with patients and health care providers

In close collaboration between OptiMedis and IR-HSCSP we developed a protocol for the user-testing of the interactive patient decision aids, covering the processes of recruitment, data collection (incl. interview guideline), transcription, data analysis and data reporting.

We will collect feedback on the patient decision aids from patients and health care providers via semi-structured face-to-face interviews, either online or offline, depending on the preferences of those involved. Interviews will be conducted in three languages (English, German, Spanish) and will be audio- or video-recorded. An interview guide will be used to ensure that all relevant areas are covered across all interviews, while at the same time leaving space to explore unintended directions. Themes covered by the interview guide refer to aspects such as understandability, usability, findability, usefulness, credibility or identification as well as implementation aspects of the tool (general impression, applicability for personal use, for preparation of a consultation, for use during a consultation, factors supporting/hindering use). Participants will be walked through a clickable mock-up of the patient decision aid and will be encouraged to verbalize their thoughts and impressions while exploring the tool (think aloud technique).

We aim to interview five patients and five health care providers per language, with the option for further interviews until thematic saturation is reached. The interviews will be transcribed and analyzed in the respective languages using content analysis. OptiMedis will translate all results into English and summarize the results in a final report. This report will serve as a basis for potential further changes to the interactive patient decision aid.

Click here to read more about the work packages.

Exploring methods to present and interpret the effectiveness of self-management interventions - Progress and challenges

Having almost completed the updates on all the analyses on the effectiveness of the self-management interventions (SMIs), we are now working on a more in-depth exploration and interpretation of the Net-work Meta-Analyses (NMA) results. To this end, we have contributed to the presentation of results to the members of the four panels that are working on the formulation of recommendations on the most promising SMIs.

In the meantime, we have made significant progress on the development of graphical tools presenting the effectiveness of the SMIs in a comprehensive and straightforward way.

Standard NMA has two main problems in sparse networks with multicomponent interventions, such as the ones we are working with in COMPAR-EU. The first problem is that intervention effectiveness is confounded with study characteristics. The second one is that there is not a clear pattern on how effectiveness is associated with the presence, or not, of specific components. The new graphs provide a visual mean of understanding which components work and is an important addition to the arsenal of methods for assessing multicomponent interventions.

Our scientific research on methodological aspects of NMA and component NMA (CNMA) have been also advanced through our involvement on the COMPAR-EU project and a new scientific paper from our team have been published as a book chapter. We have also published empirical research exploring how the main statistical assumption of NMA (that of consistency) is associated with network characteristics. In the upcoming 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.

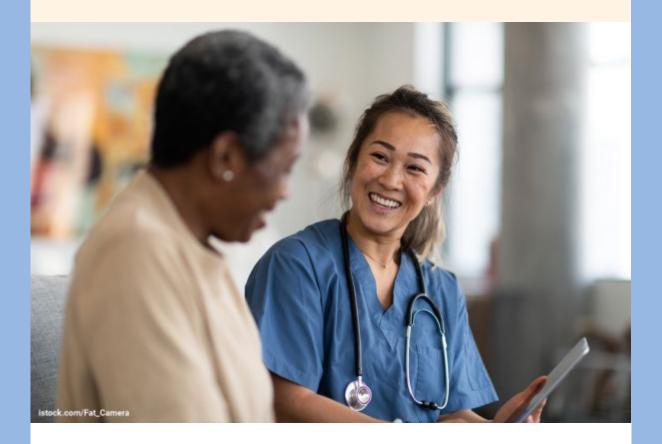**Click here to read more about all collaborating partners.**

Future costs manuscript submitted for review

Alongside the development of cost-effectiveness models for self-management interventions, the work package on cost-effectiveness is estimated future medical and non-medical costs in Germany, Spain, and Greece. These costs were developed for inclusion in the cost-effectiveness models, as there were no appropriate estimates publicly available in these countries. Our methodology builds on previous estimations for standardised future costs in the Netherlands and the UK.

In this context, a paper was recently submitted for review, comparing medical and non-medical cost estimates between the Netherlands, the UK, Germany, Spain, and Greece. As countries differ in the availability of data, our work illustrates how both individual and aggregate level data sources can be used to construct standardized estimates of future costs. The medical and nonmedical cost results show a large variation in the cost levels between countries. Greek costs were particularly low compared to the other country's costs. The impact of including the future costs in an incremental cost-effectiveness ratio (ICER) analysis showed varied greatly between countries, ranging

from €1,000 to €35,000 per quality-of-life-year gained. The variation between countries in impact on the ICER is largest when considering medical costs, and indicate differences in both structure and level of healthcare financing in these countries. These country specific differences were discussed further in a paper recently submitted by iMTA.

Click here to see all publications.

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Self-Management Europe has great ambitions!

Around one year ago, we started the design and development of the European Research and Innovation Centre on patient empowerment and self-management: Self-Management Europe (SME). Our ambition is to become a central place for health care professionals, policymakers and patients to look for knowledge and evidence on self-management interventions and empowerment and to share information and experiences on these topics.

In this way we want to create a network of researchers, health care professionals, developers, industry and other stakeholders whose common goal is to improve patient self-management and empowerment of patients with chronic diseases in Europe. SME is a spin-off of COMPAR-EU and initiated by four COMPAR-EU partners that all have a broad experience on self-management, patient empowerment and personalized health care: FAD, Nivel, OptiMedis and EPF.

SME aims to raise public, professional and political awareness of the critical role patients play in living with chronic disease by providing the most updated and innovative multidisciplinary knowledge about self-management interventions and empowerment and how to address these topics in Europe in policy and practice; SME wants to

provide practical tools to encourage and support health care professionals to adopt SMI in their real life contexts; work with organizations and industry to develop approaches to incorporate SMI in practice; will organize training courses on implementing approaches which support patients' self-management and empowerment, and make the expertise of experienced programs and interventions available to others.

During the last year we worked on a website and on a mission paper on SME (in progress). While we are looking for some structural funding to carry out the ambitious activities outlined above, we are giving small steps on some areas that, in our opinion, complement the work done in COMPAR-EU. The first dissemination activity of SME were two "ALERTS" for healthcare professionals, managers and other stakeholders looking for practical recommendations to implement practices that enhance self-management and patient empowerment. The first alert was on empowerment of patient to take an active role in health care, the second alert on health literacy.

Click here to read more about Self-Management Europe.

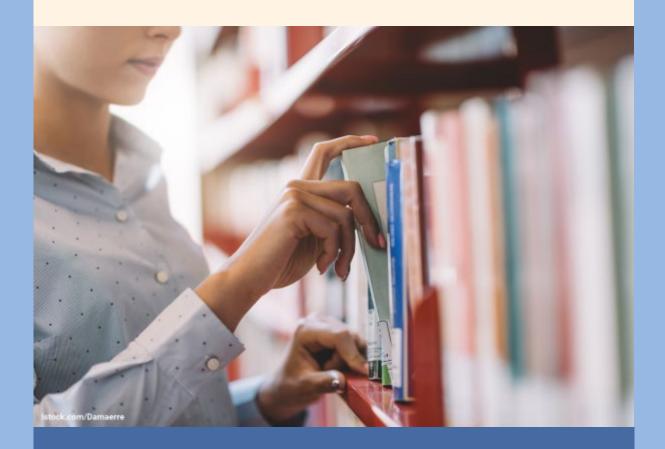# Publications and scientific spread in COMPAR-EU in 2021

During this year, from COMPAR-EU we have been working intensively on the development of the platform, and the decision-making tools to integrate in the platform. This has not prevented us from making progress in the publication and scientific dissemination.

We have published four papers in peer review journals, including the paper on our taxonomy, two papers explaining the development and prioritization of core outcome sets for obesity and COPD, and a scoping review based on the perspectives of Patients with chronic diseases and their caregivers on Self-Management.

We have had the opportunity to present some of the outputs of COMPAR-EU in different scientific conferences including ISQua's 37th International Conference, in the 21st

International Conference on Integrated Care and, we also had the opportunity to organize a 90-minutes session about "Supporting the implementation of patient-centred care in clinical settings" and where we presented some of the COMPAR-EU results.

If you want to access the entire online session, you can access click here. It is available until the 12th of December 2021.

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Latest Blog Articles

Development and user-testing of a web-based patient decision aid for self-management interventions

Decision aids are tools that can be used by clinicians and patients to support shared decision-making about health care options. COMPAR-EU decision-aids are interactive web-based tools and are available in several languages.

Read full article here.

Managing my Type 2 Diabetes: personal patient story of a successful journey

''So far, I have shed 18 kgs and reduced insulin by 89%,'' shares Nora Macelli. Read more to learn about how Nora was motivated to make a change through self-management, and why she is involved in the COMPAR-EU Patient Panel.

Read full article here.

Applying incentives to adopting shared decision-making with patient decision tools

Individuals and organizations can participate in shared decision-making with patient decision aids if there are sustainable incentives that motivate them to use them in routine clinical care.

Read full article here.

Longevity gains and postponed informal care with self-management interventions?

The burden posed by a disease not only affects the sufferers, but also their relatives. Therefore, it is important to adopt a societal viewpoint when deciding which kind of costs and health benefits to include in an economic evaluation.

Read full article here.

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 usage (uptake) and implementation of our carefully developed interventions turned out there.

Read full article here.

Publications

Valli C, Sunol R, Orrego C, Niño de Guzmán E, Strammiello V, Adrion N, Immonen K, Ninov L, Gaag M, Ballester M, Alonso-Coello P.

The development of a core outcomes set for self-management interventions for patients living with obesity.

Read full article here.

Orrego C, Ballester M, Heymans M, Camus E, Groene O, Nino de Guzman E, Pardo-Hernandez H, Sunol R, COMPAR-EU Group (2021)

Talking the same language on patient empowerment: Development and content validation of a taxonomy of self-management interventions for chronic conditions.

Read full article here.

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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