













### Perceptions of healthcare professionals about the implementation of Shared Decision Making in primary care: a qualitative study from a Virtual Community of Practice

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### BACKGROUND

The incorporation of **shared decision-making** (SDM) represents a central aspect of empowerment processes. It facilitates greater activation on the part of patients, increasing the likelihood of gaining control over their healthcare and developing skills to solve their health problems. Despite these benefits, there are difficulties in the implementation of the SDM among healthcare professionals due to internal and external factors related to the context and health systems.

Table 1. Characteristics of the participants

Characteristics	Frequency
Age (years), mean (SD)	47.03 (8.55)
Sex, n (%)	
Male	31 (21.2%)
Female	115 (78.8%)
Profession, n (%)	
Physicians	80 (54.8%)
Nurses	66 (45.2%)
Residents tutor	
No	112 (76.7%)
Yes	34 (23.3%)
Years of experience, mean (SD)	21.77 (8.08)
Years in primary care, mean (SD)	18.0 (8.28)
Years in the health centre, mean (SD)	8.16 (7.70)

SD= Standard deviation.

### Screenshots of the Virtual Community of Practice



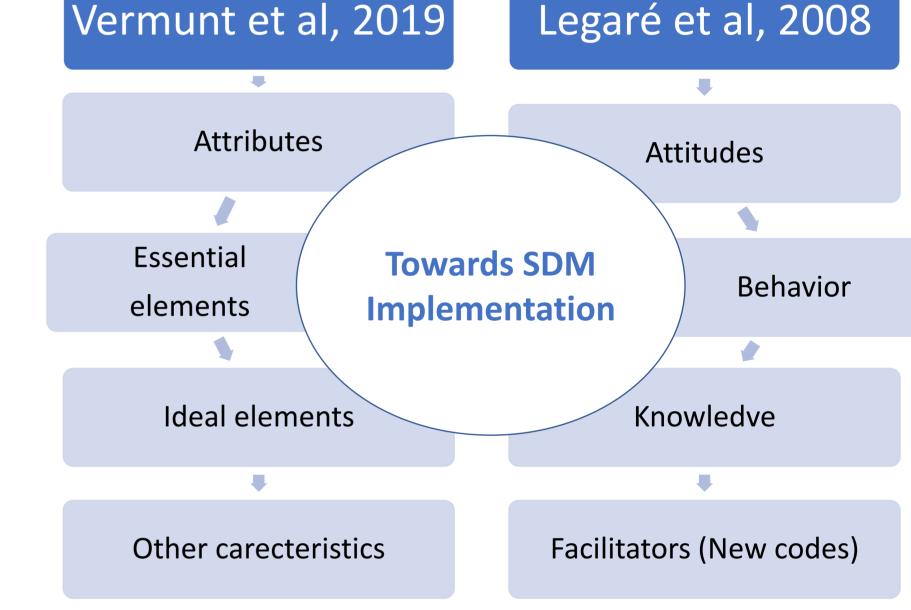
### AIM

To explore primary care professionals' perceptions of the SDM model, based on their preconceptions and experience in clinical practice.

### **METHODS**

A qualitative design based on framework analysis was proposed, then a secondary content analysis of the contributions and comments made by healthcare professionals in the Virtual communities of practice (VCoP) forums was conducted, within a cluster-randomised clinical trial developed in the e-MPODERA project. The comments were analyzed with Nvivo12 program.

Table 2. Themes of the framework used for data analysis. Extracted of Framework on the implementation of SDM in primary care developed for the analysis of the interventions of health professionals in the VCoP.





Video de Victor Montori para el Webinario de Toma de **Decisiones Compartidas** DECISIONES COMPARTIDAS

En este vídeo Victor Montori hace un recorrido por diferentes modelos que se han propuesto para entender la Toma de Decisiones Compartidas. Nos aporta... 10 comentarios

15 comentarios



Herramienta para la toma de decisiones compartidas

DECISIONES COMPARTIDAS, DIABETES. HERRAMIENTAS PARA LA TOMA DE DECISION COMPARTIDA

¿Qué te parece este vídeo? ¿Aplicarías una herramienta así con tus pacientes? Coméntalo en el Debate!





102 respuestas

"Being realistic, SOMETIMES, we empower our patients and most of the time we are paternalistic, imposing, directing because we believe we are in possession of the truth.". P20

### Figure 1. Selection of quotations made by healthcare professionals on the VCoP

**RESULTS** 

Regarding SDM implementation, in the opinion of the healthcare professionals, external aspects can be a challenge in this process, such as the pressure of care, the time available for each patient and the complex profiles of some patients. They also commented that in clinical practice, their own attitudes, behaviors and knowledge can be a barrier or a facilitator for the successful implementation of SDM.

"A good number of patients frequently ask questions related to things that they have not understood, especially in relation to technical terms. I think it is absolutely necessary that doubts are resolved by us in a natural way and remove the fear that we sometimes have to ask. "P 125

"On more occasions than we think, the beliefs or expectations of our patients are not satisfied by our scientific actions. I think we should learn to value a little more these aspects that have to do with the sociocultural - ethnic birth context.".

"You try to motivate the patients to involve them in decision-making to facilitate an objective, and they tell you "that you are the professional, that you tell them what to do and if they have time, they will do it." P106

### CONCLUSIONS

Exploring patients' values and preferences, providing them with up-to-date and evidence-based health information, and validating their understanding, are the most relevant qualities for this group of healthcare professionals. The implementation of the SDM could be helped by specific training to broaden their knowledge and enable them to develop competencies to manage some barriers such as time management and patients who are not interested in a more participative clinical relationship as proposed by the SDM.

Key words: Health professionals' perceptions, Empowerment, Shared-decision making, Virtual community of practice.















Screenshot of e-mpodera2 vCoP

DONABEDIAN

empodera-2 (ECA)

e-mpodera

¡Bienvenid@s al grupo de empodera-2!





e-pract

n Inicio

Admin8

Cerrar sesion Mis puntos: 212

Editar mi perfil de usuario Mis alertas por email

Avanzado - Admin

### Implementation of e-mpodera2: A virtual Community of Practice for people with ischemic heart disease

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#### **BACKGROUND**

Virtual Communities of Practice (VCoPs) have become a strategic approach for transferring knowledge among people with similar circumstances. VCoPs allow informal learning through information exchange, social support and skills acquisition to cope with the disease.

### **METHOD**

A gamified co-designed VCoP (e-mpodera2) is the intervention of a pragmatic randomised controlled trial that is currently being conducted in Catalonia, Madrid and Canary Islands, Spain. Its effectiveness and cost-effectiveness for the empowerment of people with ischemic heart disease (IHD) will be evaluated.

The **implementation process** included:

- 1) A Co-creation Phase: A Patient Journey Map created by people with a long IHD background that helped to co-produce a VCoP content framework. Contents and resources were piloted.
- 2) A tailored VCoP based on the content framework was designed following three stages: a) on-boarding, b) deep empowerment, c) maintenance and consolidation of skills and behaviors.

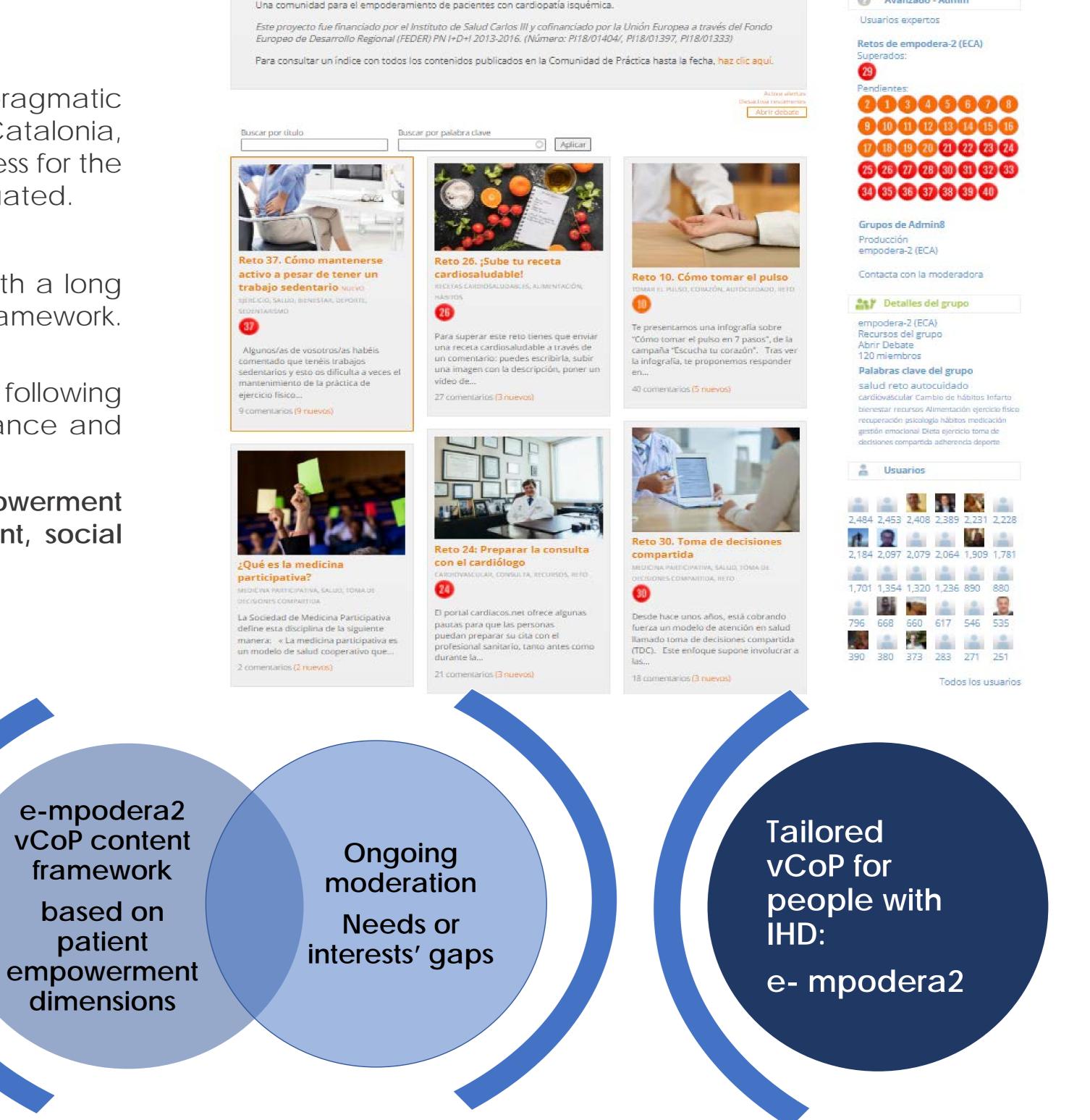
A workflow for contents' building was created regarding empowerment dimensions: health literacy, shared decision-making, self-management, social and family support.

**Patient** 

Journey

Map

Figure 1. The implementation process



### 1) Co-creation Phase

**Empower-**

ment

priorities

Contents

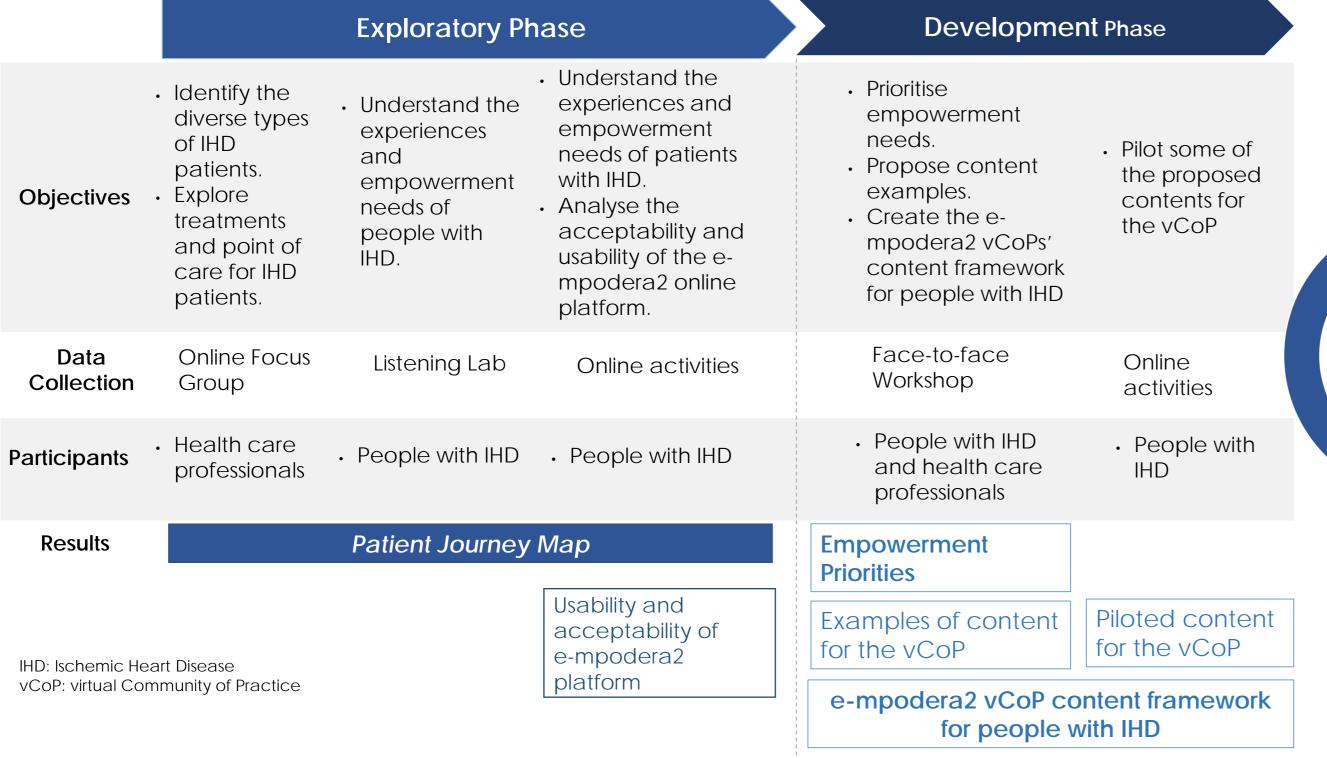
examples

and

piloted

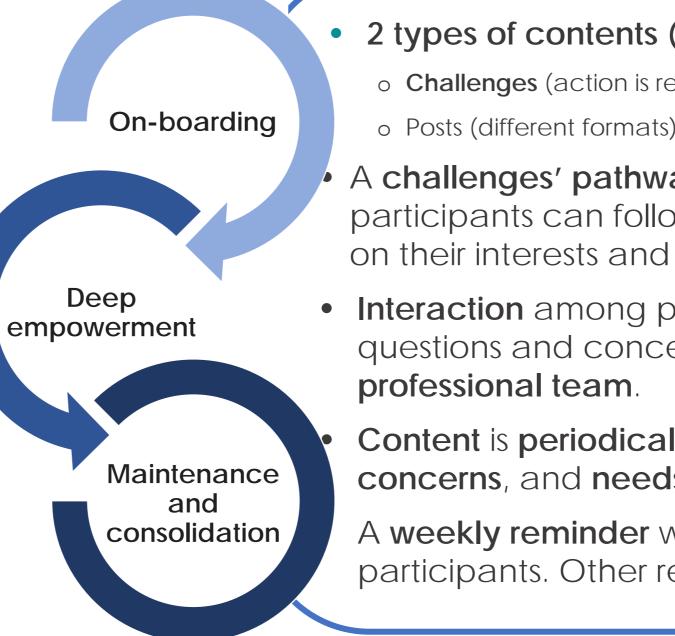
contents

### Figure 2. Co-creation Phase



### 2) Designing a live intervention for RCT

Figure 3. Live intervention in RCT



- 2 types of contents (each week):
- o Challenges (action is required and points and badges are obtained when accomplished)
- o Posts (different formats)
- A challenges' pathway was suggested with related additional content that participants can follow, although they can build their own pathway based on their interests and concerns regarding IHD.
- Interaction among patients is boosted by a moderator who answers questions and concerns as appear, supported by a multidisciplinary

Content is periodically added following user's knowledge gaps, main concerns, and needs identified by the moderator.

A weekly reminder with new content and user's comments is sent to participants. Other reminders to engage participation.

### RESULTS

The main topics of interest were: Healthy eating, sports, ceasing smoking, managing stress and negative emotions, facing habits' change, getting back to normal life. On-boarding, people tend to interact more with content than with other individuals. In the deep empowerment phase, participants asked more specific questions and new topics emerged, feeding the content framework.

### **Table 1. Participation and contents**

130 different contents
51 challenges
56 posts (4 threads opened by users)
61.5% of published content was commented
8 virtual meetings & 2 webinars

29% users did 70% of contributions

### CONCLUSIONS

- An ongoing tailored educational intervention may better approach people's needs and priorities regarding IHD.
- Different strategies were implemented to boost participation: Synchronous and asynchronous.
- The combination of previous co-produced framework content, partnership with professionals, and the ongoing co-creation of the intervention seems to be a key element in engaging and maintaining an active learning context and improving the community experience for different types of users.

















### A virtual Community of Practice to improve self-management for people with ischemic heart disease

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### BACKGROUND

Virtual Communities of Practice (VCoP) offer ubiquitous access to knowledge for people in similar situations, especially valuable for the self-management of patients with chronic diseases. Main benefits include information exchange, social support, and skills improvement to cope with the disease.

This project aims to evaluate the effectiveness and costeffectiveness of a VCoP regarding activation improvement and other empowerment measures in patients with ischemic heart disease (IHD).

### METHOD

A pragmatic randomized controlled trial is taking place in Catalonia, Madrid and Canary Islands, Spain.

Three hundred patients with a recent diagnosis of IHD are being recruited to participate in the intervention/control (usual care) group.

The intervention group is being offered participation in a codesigned gamified VCoP for 12 month, which proposes content based on the dimensions of empowerment.

- **Primary outcome**: Patient Activation Measure (PAM) questionnaire at baseline, 6, 12 and 18 months.
- **Secondary outcomes** include: clinical variables; self-efficacy on managing the disease (Self-management of Chronic Disease Scale, SMCDS), quality of life (EuroQoL questionnaire, EQ-5D-5L), anxiety and depression (Hospital Anxiety and Depression Scale, HADS-A & HADS-D), adherence to Mediterranean diet (MEDAS), and health resources use.

Data is collected from self-reported questionnaires and electronic medical records.

Table 1. Characteristics of patients

	Intervention group (n = 137)	Control group (n = 133)
Age, M (SD)	57.60 (8.83)	58.99 (8.79)
Age range	32-77	40-86
Gender, n (%)		
- Women	26 (19.0)	19 (14.3)
– Men	109 (79.6)	114 (85.7)
Autonomous Community, n (%)		
<ul><li>Canary Islands</li></ul>	32 (23.4)	44 (33.1)
<ul><li>Catalonia</li></ul>	61 (44.5)	44 (33.1)
<ul><li>Madrid</li></ul>	44 (32.1)	45 (33.8)
Marital status, n (%)		
- Single	14 (10.4)	10 (7.8)
<ul><li>Married</li></ul>	83 (61.5)	81 (62.8)
<ul><li>With partner</li></ul>	14 (10.4)	10 (7.8)
<ul><li>Separated/divorced</li></ul>	20 (14.8)	17 (13.2)
<ul><li>Widowed</li></ul>	2 (1.5)	4 (3.1)
Living alone, n (%)	18 (13.1)	15 (11.3)
Educational level, n (%)		
<ul> <li>Primary education not</li> </ul>	2 (1 5)	7 (
completed	2 (1.5)	7 (5.4)
<ul> <li>Primary education</li> </ul>	26 (19.3)	23 (17.8)
<ul> <li>Secondary education</li> </ul>	44 (32.6)	41 (31.8)
<ul> <li>Tertiary education</li> </ul>	59 (43.7)	56 (43.4)
- Other	4 (2.9)	2 (1.6)
Clinical variables	Intervention group (n = 126)	Control group (n = 117)
<ul><li>Obesity, n (%)</li></ul>	23 (18.3)	32 (27.4)
If obese, body mass index, M	22 0 (2 0)	22 4 (2 E)
(SD)	32.8 (3.9)	33.6 (3.5)
<ul><li>Smoking, n (%)</li></ul>	46 (36.5)	40 (34.2)
<ul> <li>Lipid profile</li> </ul>		
HDL-C, M (SD)	43.9 (13.0)	43.8 (22.3)
LDL-C, M (SD)	92.0 (41.0)	89.7 (38.3)
<ul> <li>Number of angina episodes in</li> </ul>	0.3 (1.0)	0.4 (0.8)
the last week, M (SD)	0.3 (1.0)	0.4 (0.0)
<ul> <li>Duration of the ischemic heart disease, in months, M (SD)</li> </ul>	9.7 (13.3)	12.5 (23.7)

### **RESULTS**

- Two hundred seventy participants have been recruited so far. Intervention and control groups did not show significant differences at baseline in any variable (Tables 1 and 2).
- At the time of the analysis, 185 and 117 participants have completed 6- and 12-months questionnaires since recruitment, respectively.
- Among completers, at 6 months the intervention did not show significant effects on any of the assessed measures (Table 3).
- At 12-months, a significant difference was found for patient activation (PAM) and adherence to Mediterranean diet (MEDAS): the change in the trajectory of the two groups over time was significant, favoring the intervention group. A tendency towards significance was also found for self-efficacy on managing the disease (SMDCS) (Table 3).

Table 2. Baseline scores of dependent variables

	N	Intervention	Control	P*				
PAM (0-100)	259	62.49 (16.23)	62.58 (15.46)	0.961				
SMDCS (0-10)	263	6.69 (2.00)	6.74 (1.97)	0.844				
HADS- Depression (0-21)	262	3.76 (4.02)	4.21 (4.26)	0.380				
HADS-Anxiety (0-21)	261	6.11 (4.03)	6.10 (4.31)	0.980				
MEDAS (0-14)	263	9.14 (2.05)	9.64 (2.13)	0.057				
EQoL-5D-5L (0-1)	269	0.85 (0.16)	0.85 (0.17)	0.926				
p-value from Stu	ident'	s t-test for inde	ependent					

Table 3. Effect of the intervention at 6 / 12-month follow-up in study

		6 ו	months		12 months						
		Intervention	Control			Intervention	Control		rm-ANOVA		
	N	Mean (SD)	Mean (SD)	B (p) <sup>1</sup>	N	Mean (SD)	Mean (SD)	B (p) <sup>1</sup>	N	F (p) <sup>2</sup>	
PAM (0-100)	145	64.20 (15.48)	59.11 (19.57)	5.33 (0.068)	76	65.2 (18.9)	59.01 (20.56)	7.18 (0.112)	75	3.11 <b>(0.048)</b>	
SMDCS (0-10)	147	6.98 (2.05)	7.00 (2.16)	0.22 (0.386)	77	7.28 (1.89)	6.58 (2.54)	0.93 <b>(0.036)</b>	76	2.90 <b>(0.063)</b>	
HADS-Depression (0-21)	146	3.15 (3.47)	3-90 (4.35)	-0.32 (0.440)	72	3.24 (3.66)	3.63 (3.42)	0.35 (0.586)	71	0.48 (0.620)	
HADS-Anxiety (0-21)	146	5.32 (3.92)	5.74 (3.92)	-0.13 (0.785)	71	4.70 (3.21)	5.34 (4.29)	-0.24 (0.744)	70	0.11 (0.878)	
MEDAS (0-14)	147	9.35 (2.13)	9.64 (2.23)	-0.19 (0.459)	75	10.24 (1.89)	9.39 (3.45)	1.23 <b>(0.002)</b>	74	7.14 <b>(0.001)</b>	
EQoL-5D-5L	145	0.89 (0.15)	0.86 (0.15)	0.02 (0.307)	71	0.91 (0.11)	0.86 (0.17)	0.02 (0.393)	70	0.49 (0.548)	

<sup>1</sup> Unstandardized beta (p-value) from linear regression models with group as independent variable, adjusting for the baseline scores of the corresponding dependent variable. <sup>2</sup> Within-subject effects for the interaction between time (baseline, 6, 12 months) and group.

### CONCLUSIONS

samples

- Recruiting was a major challenge due to Covid-19 situation that affected primary and specialized care.
- The preliminary analysis of this study is showing positive results in some outcomes in patients with a recent diagnosis of IHD by using a VCoP, which could be extended to other chronic patients/settings.





### Patient Participation:

A form of emancipation or a way to strenghen providers' power?

**Anja Minheere Wim Lambrechts** 



### Introduction

Patient and Public Involvement (PPI) in health research and projects adds different perspectives to researchers' knowledge because patients possess experiential knowledge (Castro et al.,2016).

In addition, PPI is also necessary for moral reasonsbased on the principle that people whose lives are most affected by research should have the opportunity to provide their input.

### Research question:

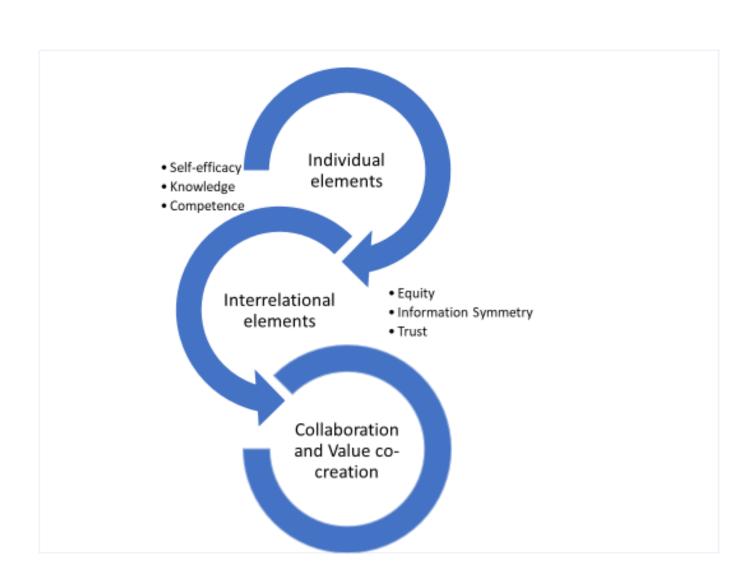
Poorly designed PPI can negatively impact those involved, as power inequities can lead to frustration about the limited opportunities to contribute to the research direction (Russell et al.,2020).

To avoid PPI being tokenistic and insignificant, we need to explore what is required to establish valuable collaboration from both the patient and the researcher's perspectives.

Therefore, this research will explore the influence and power of patient participants in Regional Health Improvement Collaboratives (RHICs).

### Methods

The literature shows that valuable collaboration in a world of power inequities is complex. We found that self-efficacy, knowledge, and competence are vital elements of individual empowerment, and that information symmetry, mutual trust, and equity are essential elements of interrelationships. In this study, we will explore these elements in more depth, their interaction, and their influence on collaboration and value co-creation



### Figure 1 conceptual model

A qualitative research design is developed. Data are collected through stakeholder observation of three cases and semi-structured interviews with the patient participants. Each case is an RHIC designed to achieve healthcare innovation with improved healthcare outcomes.

### **Main conclusions**

In this study, we found that:

- A patient participant needs to be individually empowered to collaborate with other stakeholders and achieve cocreation.
- The patient participant must be capable, representable, and qualified to accomplish this individual empowerment.
- Adequate funding, interaction time, and trust with patient participants can help negotiate roles, balance power, and lead to meaningful patient collaboration.

### Further:

- We highlighted the importance of trust to develop meaningful collaboration and value co-creation.
- We observed that when interpersonal dynamics, such as trust and equity, are suboptimal, the patient participants are not supported within the RHICs even if they are individually empowered.

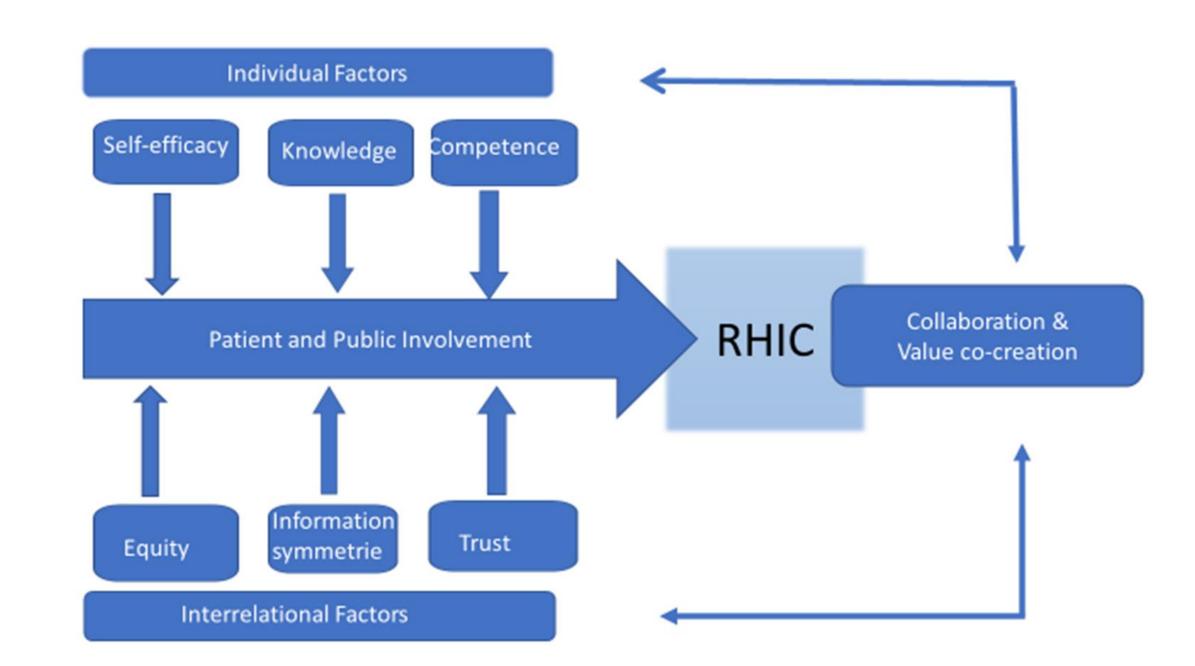


Figure 2 Factors influencing PPI

### To summarize,

- Stakeholders must be willing to build sustainable relationships, have the intention to be genuinely engaged, and are open to mutual and reciprocal learning to avoid tokenistic patient participation.
- This study shows that successful value creation in RHICs, with meaningful patient participation, is challenging.
- To examine how patient engagement is enacted and positioned within healthcare supply chains in general and more specifically in RHICs, more dialogue and inquiry are needed.



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## Exploring efficacy of self-management interventions on Body Mass Index (BMI) on type II diabetes

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University of Ioannina<sup>1</sup>, University of Toronto<sup>2</sup>, Paris Descartes University<sup>3</sup>



### Introduction

**Background**: Self-management support may improve BMI but there is uncertainty about which type of support is the most effective to manage type II diabetes.

**Aim**: Compare the relative effectiveness of self management interventions (SMIs) in the BMI of patients with type II diabetes and explore how SMIs' components influence the improvement of this disease.

**Method**: We conducted a systematic review of randomized controlled trials (RCTs) with network meta-analysis (NMA). We included components such as the type of support, the recipient, delivery method, and type of provider. We identified published RCTs from 2000 up to 2018. We performed pairwise and network meta-analysis (standard and component NMA) to estimate the relative effectiveness of any pair of interventions. This review is part of a wider study (COMPAR-EU project).

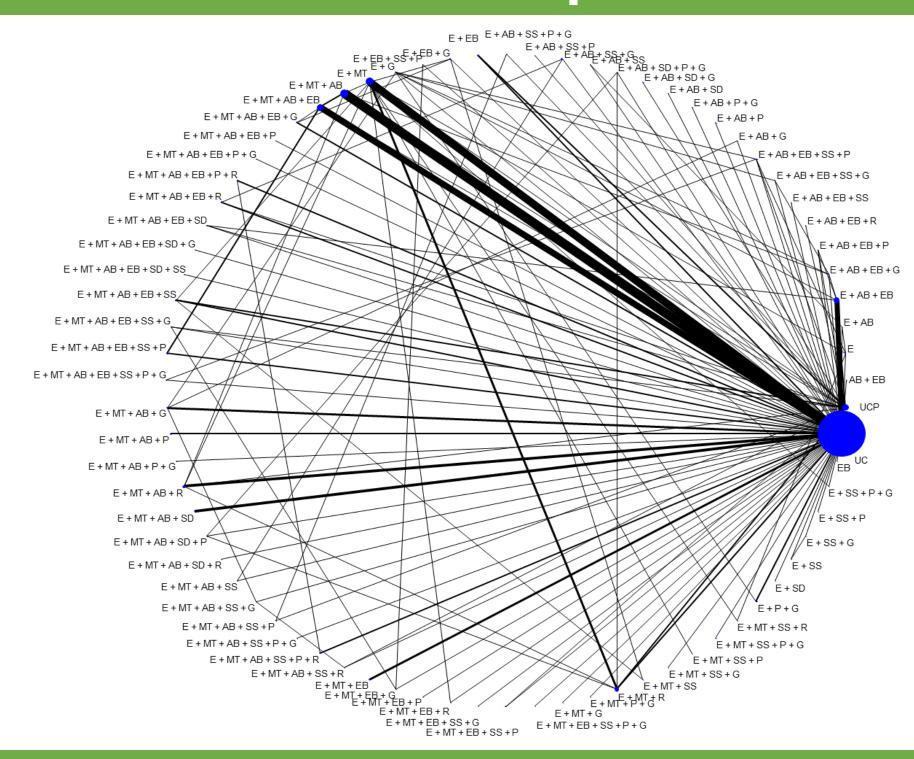
### Study characteristics

- A total of 204 studies involving 33574 participants met the criteria for inclusion in our component and standard network meta-analysis for type II diabetes.
- The effect size used was mean difference.
- The effect size for the comparison SMI vs. UCP was not statistically significant under the random-effects model. Egger's test (p-value=0.03) suggested that there is evidence for small-study effects.
- Between-study variance (heterogeneity) was moderate in the network,  $\tau^2 = 0.22$ , and quantified as  $I^2 = 61.1\%$  [Q-statistic, p-value < 0.0001].

### **Abbreviations**

	Abbreviation	Component			
1	AB	Action - based behavioural change techniques			
2	E	Education			
3	EB	Emotional - based behavioural change techniques			
4	G	Group			
5	MT	Monitoring techniques			
6	Р	Peers and lay persons			
7	R	Remote			
8	SD	Shared decision making			
9	SS	Social support			
10	UC	Usual Care			
11	UCP	Usual Care Plus			

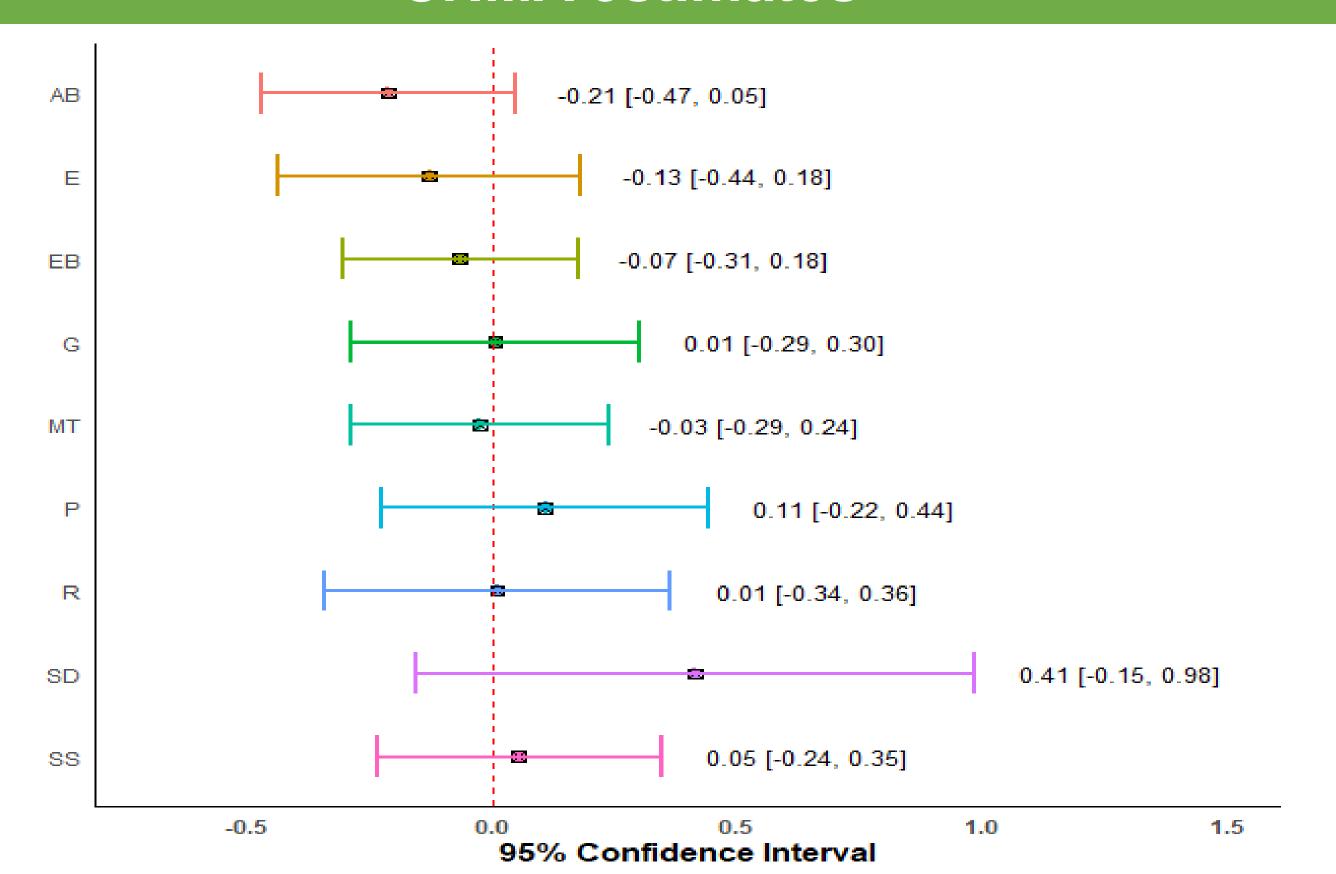
### Network plot



### NMA estimates

Node	NMA estimate	<b>Prediction Interval</b>	P-Score
E + AB + EB + SS	-1.88 [-2.89 , -0.88]	[-3.26 , -0.51]	0.93
E + MT + P + G	-1.70 [-3.03 , -0.37]	[-3.33 , -0.07]	0.90
E + MT + EB + SS + G	-2.40 [-5.34 , 0.54]	[-5.50, 0.70]	0.89
E + MT + AB + EB + R	-1.28 [-1.88 , -0.68]	[-2.39 , -0.16]	0.87
E + SD	-2.10 [-4.90, 0.70]	[-5.07, 0.87]	0.86
E + MT + AB + SD + P	-1.83 [-4.40 , 0.74]	[-4.58, 0.92]	0.84
E + SS + G	-1.08 [-1.94 , -0.22]	[-2.35, 0.19]	0.82
AB + EB	-2.80 [-8.43 , 2.83]	[-8.54 , 2.94]	0.80

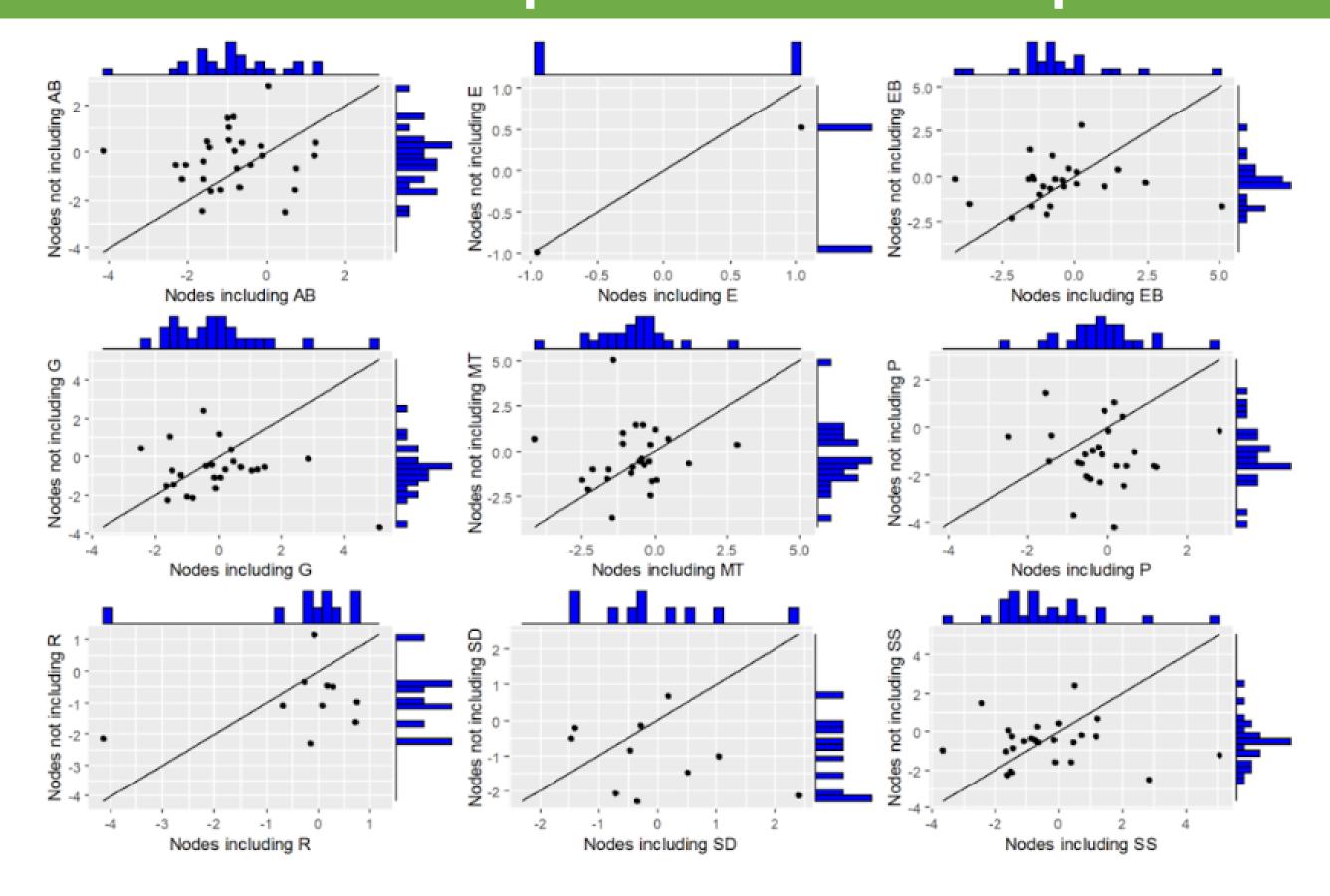
### **CNMA** estimates



### Heat plot of components



### Leave-one-component-out scatter plots



### Discussion

Most NMA intervention effects were associated with much uncertainty and CNMA showed that none of the components show statistically significant results. Most of the trials had medium or high risk of bias. The network plot is very well informed from direct and indirect evidence.

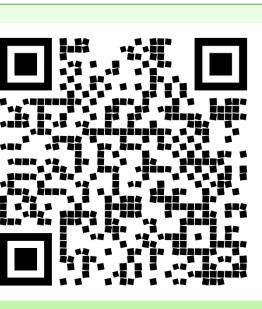


This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 754936.

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### Development and user-testing of decision aids for patients for the self-management of four chronic conditions

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#### Introduction

Decision aids (DA) are tools that enable patients to compare several treatment options and make informed choices. These tools include information on the available treatment options, evidence about their benefits and risks with related certainty, as well as practical considerations about the interventions being considered.

#### **Methods**

We followed a systematic iterative mixed methods process including:

- 1) Scoping and design,
- 2) Development of a mock-up and prototype,
- 3) User-testing with patients and clinicians.

The first two steps were overseen by a multidisciplinary research team including patients, clinicians, methodologists, and other relevant stakeholders. For the user-testing, we recruited a purposive sample of patients and health professionals until data saturation and conducted semi-structured interviews. We performed content analysis of the interviews and used participants feedback to improve the DA tools.

#### **Objective**

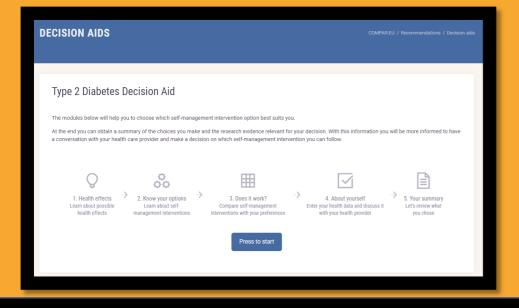
To develop an interactive web-based DA for patients with one of four chronic conditions (type 2 diabetes mellitus, obesity, heart failure and chronic obstructive pulmonary disease) making decisions about self-management interventions.

#### **Preliminary results**

The DA includes a menu of five modules:

- 1) Health effects,
- 2) Know your options,
- 3) Does it work?,
- 4) About yourself,
- 5) Your Summary.

The first four modules provide important information on the health condition to guide patients and/or health professionals through the process of choosing the best self-management intervention option. The fifth section provides an overview of the choices made and the relevant research evidence about the effects that can be saved or printed by the users. **Twenty-six** participants (type 2 diabetes patients and health care professional) from Germany, Greece, Spain, Malta, Romania and Ireland provided important feedback categorized as: **Positive feedback**, **specific suggestions** (e.g., change the order of the modules), **cosmetic** suggestions (e.g., improve the visual of the tables), **big** problems (e.g., understanding the content) and **stoppers** (e.g., navigation difficulties).



#### **Discussion**

Overall, participants were satisfied with the DA and found it useful. These web-based DA can help patients and clinicians to discuss the pros and cons of SMI and facilitate decision-making at the point of care.

### The Perspectives of Patients with Chronic Diseases and Their Caregivers on Self-Management Interventions: A Scoping Review of Reviews

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### Background

The increasing burden of chronic diseases on healthcare and society has become a significant concern. A response to this challenge include selfpatient-centred management interventions (SMIs).

In COMPAR-EU, patients' and caregivers' (informal healthcare professionals) caregivers perspectives on SM are key component. SM was conceived as a dynamic, interactive, and daily process in which individuals managed chronic diseases. Perspectives are the result of preferences and experiences with SM. Preferences represent the relative desirability of alternatives among outcomes, and experiences explain the nature and impact of chronic diseases and how a specific intervention affects patients' health and quality of life.

### Objectives

- 1) to summarise the preferences and experiences of patients, informal caregivers, and healthcare professionals with SM in four chronic diseases, and
- to identify and describe the relevant outcomes for SMIs from these perspectives.

### Methods

A mixed-methods scoping review of reviews (Arksey and O'Malley's ). Reporting using the PRISMA-ScR checklist.

We searched in MEDLINE (through PubMed), CINAHL, and PsycINFO from inception to December 2020. We included SRs of any design published in English including (1) adult patients (aged ≥ 18y) with one of the four selected chronic diseases (T2DM, obesity, COPD, or HF), without restrictions on severity (2) informal caregivers, mostly family members; or (3) healthcare professionals.; focused on (1) patients' preferences, (2) caregivers' preferences, (3) health states related to the disease or (4) experiences with SM; including studies from any country or setting except those limited to inpatient care.

Selection of studies and data collection were conducted by 4 to 5 authors working in pairs.

Quantitative data were narratively synthesized, while qualitative data, applying a descriptive thematic synthesis.

We also categorised the identified descriptive themes and subthemes into three categories: SMIs outcomes, modifiable factors of SMIs, or both.

### Results

Searches resulted in 11,785 unique references; 448 records were selected for full-text screening, and 148 reviews were included

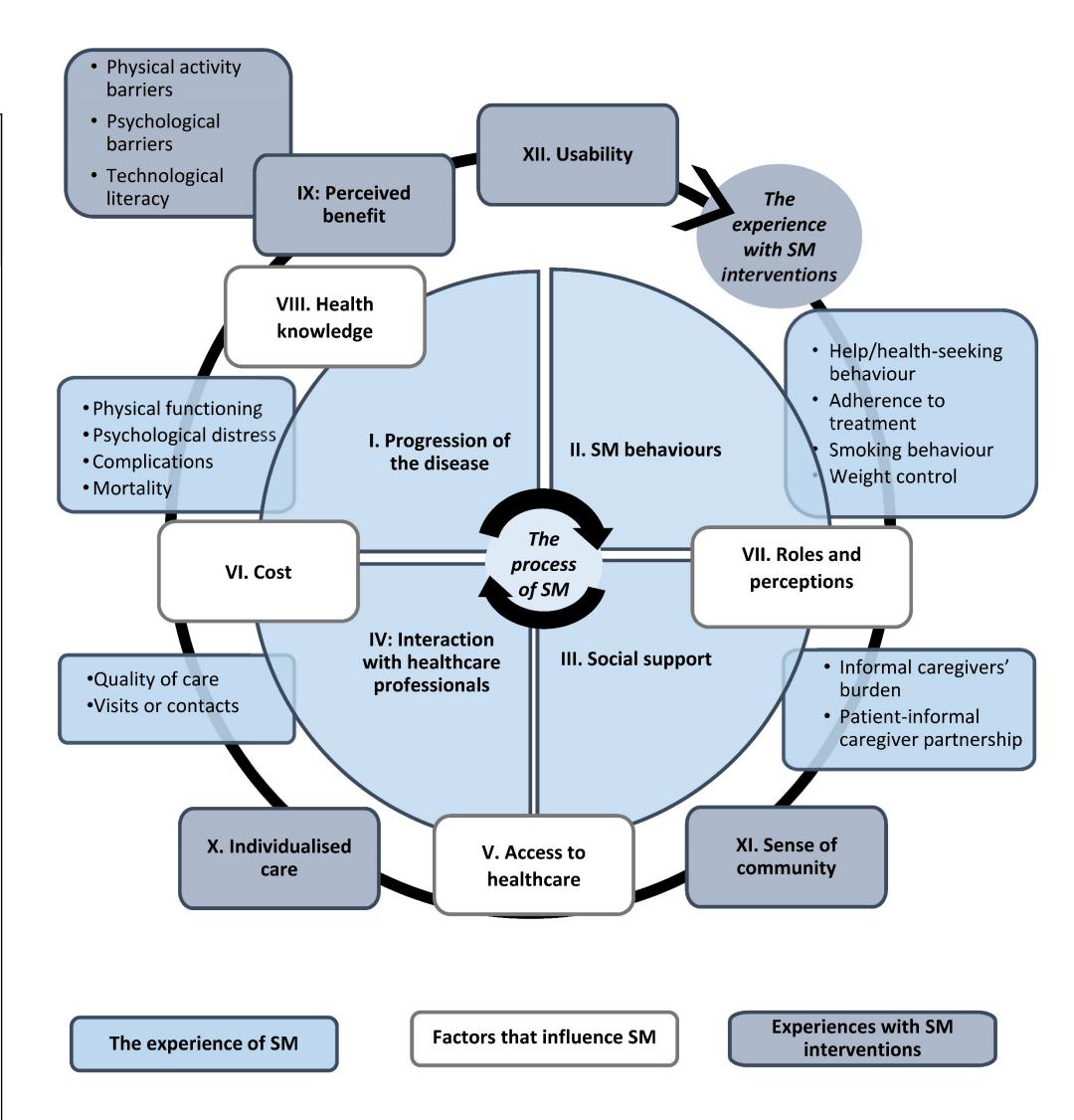
**Table 1. Characteristics of included reviews** 

		T2DM n (%)	Obesity n (%)	COPD n (%)	HF n (%)	More than one n (%)	Overall n (%)
Reviews		53 (35.8)	20 (13.5)	32 (21.6)	38 (25.7)	5 (3.4)	148 (100.0)
Pı	ublication year	33 (33.0)	20 (13.3)	<i>32</i> (21.0)	33 (23.7)	3 (3.1)	(100.0)
	2002 to 2015	26 (33.3)	11 (14.1)	15 (19.2)	25 (32.1)	1 (1.3)	78 (100.0)
	2016 to 2020	_		17 (24.3)			70 (100.0)
Τ\	pe of reviews	_, (55.5)	o (==.o)	_, ()	(,	. (0., )	, (200.0)
	Quantitative SRs	14 (45.2)	4 (12.9)	7 (22.6)	6 (19.4)		31 (100.0)
	QES	25 (32.1)	•	20 (25.6)	•	3 (3.8)	
	MMRS	11 (35.5)	2 (6.5)	-	12 (38.7)	,	31 (100.0)
	Other	3 (37.5)	,	1 (12.5)		, ,	8 (100.0)
In	cluded studies	, ,	, ,	, ,	, ,		,
	2 to 20	27 (33.3)	13 (16.0)	21 (25.9)	17 (21.0)	3 (3.7)	81 (100.0)
	21 to 40	19 (44.2)		5 (11.6)		1 (2.3)	43 (100.0)
	41 to 213	6 (28.6)		6 (28.6)			21 (100.0)
	Non-reported	1 (33.3)			2 (66.7)		3 (100.0)
Po	opulation						
	Patients	42 (37.2)	15 (13.3)	25 (22.1)	27 (23.9)	4 (3.5)	113 (100)
	Inf. caregivers	_		3 (30.0)	6 (60.0)	1 (10.0)	10 (100.0)
	HCP	1 (50.0)	1 (50.0)				2 (100.0)
	More than one	10 (43.5)	4 (17.4)	4 (17.4)	5 (21.7)		23 (100.0)
Pł	nenomena of inter Preferences on	rest					
	health states	10 (52.6)	1 (5.3)	5 (26.3)	3 (15.8)		19 (100.0)
	Experiences with SM process	36 (35.3)	15 (14.7)	19 (18.6)	29 (28.4)	3 (2.9)	102(100)
	Experiences with SMIs	11 (27.5)	6 (15.0)	12 (30.0)	9 (22.5)	2 (5.0)	40 (100.0)

We identified twelve main themes (Fig 1). Eight described the process of SM (progression of the disease, SM behaviours, social support, interaction with healthcare professionals, access to healthcare, the cost for patients, culturally defined roles and perceptions, and health knowledge), and four, the experiences with SM interventions (the perceived benefit of the intervention, individualised care, sense of community with peers, and usability of equipment). Most themes and subthemes were categorised as outcomes of SM interventions.

The process of SM shaped patients and their caregivers' perspectives on SMIs. Their perspectives were influenced by the perceived benefit of the intervention, the sense of community, the intervention's usability, and the level of individualised care.

Fig. 1 The process of self-management and the experience with SMIs



Most themes were consistently identified across the four diseases, only a few disease-specific themes, The three perspectives were recognised for five themes only. On the other hand, the perspective of informal caregivers was not identified in obesity (Fig.2).

Fig. 2. Identified themes by disease and perspective

Main	themes / subthemes	T2DM	Obesity	COPD	HF
	I. Progression of the disease	Ť	Ť	Ť	#
	<ul> <li>Physical functioning</li> </ul>	ŧ	ŧ	Ť	Ť
	<ul> <li>Psychological distress and</li> </ul>	\$ 4E3	ģ	# LNY	i sw
	stigma	'		∨	∨
	<ul> <li>Fear of complications</li> </ul>	#			
	<ul> <li>Mortality</li> </ul>	† 🖑 🚑		<b>†</b> 30	i Wil
	II. SM behaviours	Ť	Ť	Ť	
_	<ul> <li>Help or health-seeking</li> </ul>		<u> </u>	<b>∳</b> 4€3	ı <b>i</b>
SM	behaviours		11 (==0)	¶ 10 <u>−0</u>	Т
of	<ul> <li>Adherence to treatment</li> </ul>	† 🖑 🕰	Å	ŧ	<b>†</b> 🖑
ce	<ul> <li>Adverse events</li> </ul>	ŧ		ŧ	
experience	Treatment burden	ŧ		<b>†</b> V	#
per	<ul> <li>Smoking behaviours</li> </ul>			Ť	
eX	Weight control	İ	Ŷ		ŧ
The	III. Social Support	ŧ	*	<b>†</b> W	† W
-	<ul> <li>Informal caregivers' burden</li> </ul>			M	S <sub>M</sub>
	<ul> <li>Patient-informal caregiver</li> </ul>			•	• 500
	partnership	Ŧ		Ŧ	# ₩
	IV. Interaction with healthcare			<b>₽</b> 500- <u></u>	• ana
	professionals	₩ 653	<b>₽</b> 6 <b>E</b> 3		
	<ul> <li>Perceived quality of care</li> </ul>	ŧ	#	ŧ	#
	<ul> <li>Visits or contacts with</li> </ul>		±	±	
	healthcare professionals		*	#	
<b>س</b> ح	V. Access to healthcare	ŧ	Å	ŧ	•
ha S	VI. Cost for natients	<b>†</b>	*	İ	†
	VII. Culturally defined roles and perceptions				
Factors nfluenc	perceptions	Ŧ			¥
m 4	VIII. Health knowledge	† Æ	Å		
	IX. Perceived benefit of the	· -		• • • • •	·-
SM	intervention	₽ <b>653</b>	#	† <b>*</b>	† 6G
	<ul> <li>Physical activity barriers</li> </ul>	<b>‡</b>		#	•
wit	A D     '     '   CBA				
nce v intio	uptake	Ť	#	Ť	Ť
experience with interventions	<ul> <li>Technological (digital) literacy</li> </ul>	<b>‡</b>	*	*	į
er ter	X. Individualised care	<b>.</b>	<u>"</u>		*
	XI. Sense of community with		II	a_	ll .
The	peers	#	Ť	Ħ	<b>†</b> 🖑
<b>—</b>	XII. Usability of SM equipment	† 6 <b>1</b> 3	ģ	ģ	•
	An. Osubinty of Sivi equipment	'0-0	ll l	1	II .

Our findings cover aspects of the process of self-management alongside the disease trajectory, the factors that influence this process, and the experiences related with SMIs from the patients' and caregivers' perspectives.

We identified what patients, and their caregivers describe as relevant regarding SM. This set of themes can inform the selection of patient-important outcomes, decision-making processes, including the formulation of recommendations, as well as the design and implementation of SMIs.

### **Funding**

This work was supported by the European Union's Horizon 2020 research and innovation programme [754936]. ENDG was funded by a Rio Hortega contract from the Instituto de Salud Carlos III [CM17/00199].

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https://doi-org.sire.ub.edu/10.1007/s40271-021-00514-2

### How do patients with Type 2 Diabetes Mellitus value the importance of outcomes? An overview of reviews



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### Background

Developing trustworthy recommendations for Type 2 Diabetes Mellitus (T2DM) requires incorporating the patient perspective on the importance of outcomes.

Preferences against interventions implicitly about relative inform importance (or value) people place on the expected or definite outcomes connected to a specific intervention.

Utility represents patients' preference for a particular outcome and is anchored on a scale from zero (dead) to one (perfect health) but can take negative values (worse than death).

Disutility represents the decrement in utility due to a specific symptom or complication and is often expressed as a negative value representing the impact of the symptom or disease.

A broad review of the available evidence for T2DM patients would be a relevant evidence synthesis for the development of clinical recommendations for this population.

### **Objective**

To review and summarise the available evidence on how patients with T2DM value the importance of outcomes.

Utility represents patients' preference for a particular outcome. Disutility represents the decrement in utility

### Methods

Overview of systematic reviews (SRs) (CRD42019117867). We included SRS reporting patients' utilities or disutilities T2DM outcomes. We searched MEDLINE (PubMed), CINAHL and PsycINFO until June 2021. Study selection and data extraction were conducted in pairs. We evaluated the quality with the Joanna Briggs Institute (JBI) Critical Appraisal Checklist and the overlap with the corrected covered area.

We conducted a content analysis to classify the outcomes. We described utility and disutility estimates per outcome. DCEs studies were narratively summarized.

We performed a random-effects model meta-analysis. To examine sources of heterogeneity, we conducted subgroup and sensitivity analysis to evaluate the potential impact of selecting one method in dataset development.

### Results

Table 1. Mean utility and disutility values by T2DM outcomes

Categories and outcomes	Measure	Mean*	[95% CI]	Observations/ participants	l <sup>2</sup>
1. T2DM 1.1 Baseline T2DM (without	Utility	0.788	0.772 to 0.804	46 /56,824	97.8%
complications)	Disutility	-0.038	NR	1/1,257	NA
1.2 Diabetes in general	Utility Disutility	0.748 -0.044	0.736 to 0.759 (SD) 0.04	109/81,273 3/NR	99.0% NA
2. Glycaemic Complications	,		,	•	
2.1 Hypoglycaemia not specified 2.2 Hypoglycaemic symptom severity:	Utility	0.730	0.690 to 0.770	1/136	NA
None	Utility	0.800	0.760 to 0.840	1/78	NA 
2.3 Hypoglycaemic symptom severity: Mild	Utility	0.730	0.690 to 0.770	1/40	NA
2.4 Hypoglycaemic symptom severity:	Utility	0.700	0.660 to 0.740	1/12	NA
Severe  2.5 Hypoglycaemic symptom severity:	•				
Very severe	Utility	0.540	0.500 to 0.580	1/4	NA
2.6 Daytime hypoglycaemia 2.7 Night-time hypoglycaemia	Utility Utility	0.680	0.640 to 0.720 0.560 to 0.640	1/53 1/23	NA NA
2.8 Hyperglycaemia	Utility	0.730	0.690 to 0.770	1/64	NA NA
2.9 Major hypoglycaemia event	Disutility	-0.159 -0.045	(SD) 0.11 (SD) 0.028	3/3,689	NA NA
2.10 Minor hypoglycaemia event  3. Macrovascular Complications	Disutility	-0.043	(30) 0.028	3/3,689	NA
3.1 Heart failure	Utility	0.587	0.325 to 0.848	2/8,584	97.3%
	Disutility Utility	-0.084 0.689	-0.120 to -0.048 0.580 to 0.798	6/16,038 6/8,043	70.9% 99.1%
3.2 Ischemic heart disease	Disutility	-0.070	-0.107 to -0.034	10/20,217	92.9%
3.3 Myocardial infarction	Utility Disutility	0.764 -0.057	0.725 to 0.802 -0.078 to -0.036	6/2,853 19/18,943	84.4% 80.6%
3.4 Peripherical vascular disease	Utility	0.800	NA	1/12,772	NA
r cripitericai vasculai alsease	Disutility	-0.084	-0.124 to -0.045	4/6,637 3/7 500	41.7%
3.5 Cardiovascular disorder	Utility Disutility	0.713 -0.019	0.640 to 0.787 -0.070 to 0.032	3/7,509 1/7,327	88.4% NA
3.6 Stroke	Utility	0.596	0.490 to 0.702	12/18,195	99.1%
	Disutility Utility	-0.150 0.785	-0.182 to -0.118 0.716 to 0.854	24/35,947 2/9,542	95.4% 70.2%
3.7 Transient ischaemic attack (TIA)	Disutility	-0.052	-0.076 to -0.029	3/10,614	47.8%
3.8 Cerebrovascular disorder	Utility	0.597	0.448 to 0.745	3/1,442	94.7%
3.9 Macrovascular complications	Disutility Utility	-0.044 0.717	-0.068 to -0.020 0.686 to 0.747	1/1,257 3/61	NA 0.0%
4. Microvascular Complications	- cincy			·	
4.1 Diabetic retinopathy	Utility	0.698	0.588 to 0.808	6/1,709	98.7%
4.2 Visual acuity mild affection	Disutility Utility	-0.023 0.812	-0.101 to 0.056 0.745 to 0.878	1/933 4/276	NA 87.1%
4.3 Visual acuity moderate affection	Utility	0.725	0.673 to 0.777	8/403	74.9%
	Disutility Utility	-0.110 0.632	-0.188 to -0.032 0.524 to 0.740	2/2,074 4/64	87.0% 52.7%
4.4 Visual acuity severe affection	Disutility	-0.150	-0.228 to -0.072	1/5,266	NA
4.5 Blindness	Utility	0.529	0.393 to 0.665	10/1,703	99.0%
4.6 Cataract	Disutility Disutility	-0.057 -0.016	-0.135 to 0.021 -0.031 to -0.001	1/3,192 1/858	NA NA
4.7 Ophthalmologic complications	Utility	0.722	0.565 to 0.879	2/180	94.3%
4.8 Moderate macular oedema	Disutility	-0.0400	NR	1/577	NA
4.0 Dialogia kida ay diagaa	Utility	0.684	0.624 to 0.743	10/14,136	71.8%
4.9 Diabetic kidney disease	Disutility	-0.029	-0.048 to -0.010	5/9,330	0%
4.10 End-stage renal disease	Utility Disutility	0.552 -0.177	0.487 to 0.617 -0.307 to -0.047	21/10,957 6/10,585	99.8% 99.8%
4.11 Diabetic peripheral neuropathic	Utility	0.468	0.372 to 0.565	10/1,411	98.5%
pain	Utility	0.668	0.561 to 0.774	8/930	98.9%
4.12 Diabetic peripheral neuropathy	Disutility	-0.121	-0.191 to -0.051	4/6,015	63.5%
4.13 Lower extremity disease: Foot	Utility	0.568	0.470 to 0.667	10/1,980	97.9%
ulcers 4.14 Primary healed foot ulcer	Disutility Utility	-0.127 0.600	-0.238 to -0.017 NR	3/5,316 1/176	81.9% NA
4.15 Lower extremity disease:	Disutility	-0.085	-0.171 to 0.001	1/NR	NA
Neuropathy & PV	Utility	0.537	0.453 to 0.621	9/1462	94.5%
4.16 Amputation	Disutility	-0.205	-0.344 to -0.066	3/4,339	77%
4.17 Microvascular complications	Utility	0.723	(SD) 0.035	3/52	NA
<b>5. Comorbidities</b> 5.1 Hypertension	Utility	0.790	0.774 to 0.806	1/631	NA
5.2 Excess BMI per unit above 25	Disutility	-0.006	-0.008 to -0.004	3/5,316	0.0%
5.3 Overweight 5.4 Obesity	Utility	0.777	0.603 to 0.951	3/15,503 3/2 645	98.5%
5.4 Obesity 5.5 Extreme obesity	Utility Utility	0.673 0.400	0.502 to 0.845 0.363 to 0.437	3/2,645 1/74	98.4% NA
5.6. Depression	Disutility	-0.202	NR	1/NR	NA
5.7 Comorbidities  6. Diabetes Management	Utility	0.663	0.539 to 0.787	6/1,460	99.4%
Type of glucose control					
6.1 Glucose control (excellent)	Utility	0.870	0.820 to 0.920	1/NR	NA NA
6.2 Glucose control (good) 6.3 Glucose control (fair)	Utility Utility	0.880 0.860	0.840 to 0.920 0.820 to 0.900	1/NR 1/NR	NA NA
6.4 Glucose control (poor)	Utility	0.850	0.800 to 0.900	1/NR	NA
Modality of care	l l+ili+v	0.765	0 691 +0 0 946	1/2 126	Q2 Q0/
6.5 Diet and exercise 6.6 Intensive blood glucose control	Utility Utility	0.765 0.737	0.684 to 0.846 0.640 to 0.833	4/2,126 3/2,308	93.9% 96.9%
6.7 Less intensive self-monitoring	Utility	0.760	0.757 to 0.763	1/150	NA
6.8 More intensive self-monitoring 6.9 Usual care	Utility Utility	0.730 0.737	0.727 to 0.733 0.677 to 0.798	1/151 6/1,763	NA 99.2%
Type of medication	Othicy	0.737	U.U// 1U U./98	0/ 1,/ 03	JJ. 270
6.10 Oral hypoglycaemic agents	Utility	0.756	0.663 to 0.849	4/259	96.3%
6.11 Insulin only or combined	Disutility Utility	-0.025 0.630	NR 0.595 to 0.665	1/NR 1/NR	NA NA
,	Utility	0.773	0.607 to 0.939	3/269	98.5%
6.12 Only insulin	Disutility	-0.049	NR	1/NR	NA
6.13 Non-insulin injectable treatment	Utility	0.850	0.825 to 0.875	1/228	NA

We included eleven SRs, including a total of 230 studies with a slight overlap. Most SRs (64%) included a population. The frequent method to estimate utility values was the EuroQoL (EQ-5D) (72%). Only two SRs conducted a meta-analysis. Most were highquality SRs. Six SRs assessed the quality of included studies; each one applied different criteria or tools with variable quality result.

We merged 344 different outcomes' labels into 58 outcomes and grouped them into six categories.

Utility values were retrieved for 51 outcomes, while disutilities for 28 outcomes.

Most pooled utilities (n=25/29)86.2%) and half of pooled disutilities (n=7/13, 53.8%) showed high heterogeneity ( $I^2 \ge 75\%$ ). Prediction Intervals were estimated for eleven outcomes; of these, only four had the same sign (diabetes in general, baseline T2DM (without kidney complications), diabetic disease, and end-stage renal disease).

Most pooled values in the subgroup analysis by method presented heterogeneity (n=20/24, high 83.3%), without differences from the overall analysis.

Utility values were lower than diabetes without complications for extreme obesity, diabetic peripheral neuropathic pain, very severe hypoglycaemia, heart failure, and insulin-only or combined.

In contrast, **good and** excellent glucose control and non-insulin injectable treatment obtained values higher than T2DM without complications

The highest disutility values were for amputation, depression, major hypoglycaemia event, stroke, and using only insulin

### Conclusion

- •We provide a set of utility and disutility values for 58 outcomes of Type 2 Diabetes Mellitus (T2DM), reflecting the patient perspective on the importance of T2DM complications, comorbidities, and treatment-related outcomes...
- Utility and disutility values may inform the development of clinical recommendations, as well as the design of decision-support tools, and economic analysis

### **Funding**

This work was supported by the European Union's Horizon 2020 research and innovation programme [754936]. ENDG was funded by a Rio Hortega contract from the Instituto de Salud Carlos

### Contact

III [CM17/00199].

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### Patients' and caregivers' perspectives on outcomes of Self-Management Interventions for Type 2 Diabetes Mellitus: an overview of reviews

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### Background

Self-management interventions (SMIs) for Type 2 Diabetes mellitus (T2DM) are promising strategies. Qualitative research is beneficial when exploring complex scenarios in-depth exploration of participants' lived experiences and perspectives. There are many qualitative and mixed methods (SRs) systematic reviews focused experiences with T2DM, self-management and SMIs; a review integrating these findings would be valuable and informative.

This study is the qualitative branch of a mixed methods overview of reviews. We aimed to review and summarise how patients with T2DM and their caregivers experience and perceive the outcomes of SMIs.

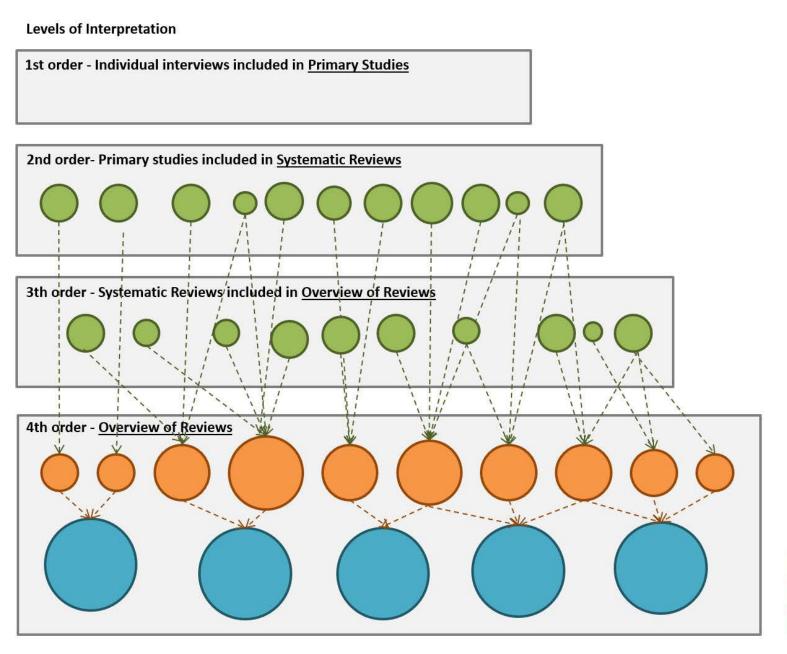
More specifically, our research questions were related to the experiences and perceptions of patients and their caregivers of outcomes' importance when dealing with the disease, selfmanagement, or participating in SMIs.

### Methods

Overview of SRs (CRD42019117867). We included SRS of studies exploring patients' and informal caregivers' experiences with Self-management and SMIs. We searched MEDLINE (PubMed), CINAHL and PsycINFO until June 2021. Study selection and data extraction were conducted in pairs. We evaluated the quality with the Joanna Briggs Institute (JBI) Critical Appraisal Checklist and the overlap with the corrected covered area. We analised and synthesized qualitative data using a thematic synthesis approach using NVivo 12 Pro. The levels of analysis comprised second-order (primary studies) and third-order SRs constructs. We did not specify any a priori theme.

The synthesis followed three stages 1) text coding line-by-line coding of the text of each SR; 2) developing descriptive themes; 3) re-interpretation and synthesis of this newly organised information, to produce analytical themes that go beyond the findings of the SRs authors (overview of SRs) (Figure 1). We conducted a collaborative analysis with three review authors to consider alternative interpretations and ensured that fourth-order constructs remain grounded in the primary studies.

Figure 1. Thematic synthesis stages and levels of interpretation





### Results

We included 54 SRs representing 1,031 studies with a slight overlap. Included reviews involved 26 qualitative evidence syntheses (48.1%), 22 mixed methods research synthesis (40.7%), and six quantitative SRs (11%). Reviews were conducted in 13 countries; being UK (n=14, 25.9%), USA (n=7, 13%) and Australia (n=6, 11%), the most frequent ones. The majority were published between 2016 to 2020 (n=33, 61.1%). The number of included studies ranged from five to 120, with a majority including 20 or fewer (n=30, 55.6%). Most evaluated methodological quality (n=44, 81.5%).

#### 4<sup>th</sup> order themes per outcome

Knowledge: Health education should consider patients' information needs, training preferences, and health beliefs.

### **Supporting sub-themes**

- Insufficient influences Self-Management knowledge (SM)behaviours
- Knowledge can improve well-being but does not necessarily influence SM behaviours
- Information needs and training preferences are variable
- Traditional health beliefs may explain patients' understanding of diabetes

Health literacy: Insufficient numeracy and literacy skills are barriers to accessing healthcare, leading to misunderstandings on how patients manage the disease and on their expectations with the provision of care.

Self-efficacy: SM interventions with adequate support, acknowledging patients' characteristics, diabetes psychological and emotional burden, chronicity, and treatment complexity, can) help patients to gain self-efficacy, which despite being a challenging process, increases more proactive and proper care.

Patients activation: Patients' actions in SM require accepting the diabetic identity managing the tension between disease- and lifecentred approaches, and living in the present and for the future, guided by their perceived barriers and personal models using their resources.

Adherence to a healthy diet: Achieving a healthy diet requires practical knowledge, self-discipline and proactivity, support from family and friends, and a culturally sensitive approach.

Physical activity: Barriers to being physically active can be tackled by increasing patients' perceived support, the expected or experienced benefits of exercise, and self-efficacy.

The journey of diabetes self-management starts

with personal adjustments accepting the diagnosis

and treatment. Health literacy unlocks patients'

healthcare access, and knowledge provision is

better received in a positive patient-provider

relationship within a culturally sensitive approach.

Shared decision-making enables engagement in

self-management interventions, and their

achievement requires building up capabilities,

behavioural skills, and social support. Self-

monitoring facilitates awareness of glycaemic

complications and glucose control importance.

However, fear of hypoglycaemia and weight

which requires training and time to integrate into

everyday life and adjust to their contextual factors.

Adherence to treatment: Fear shapes medication-taking behaviour and treatment progression to insulin

Self-monitoring: Self-monitoring blood glucose with adequate support helps patients who decide to take an active role in their

**SM behaviours** are the result of a development process influenced by context and the type of self-care approach Glycemic control is an attribute of great concern for patients Weight change influences adherence to treatment and can be influenced by social interactions

Competing comorbidities represent barriers to SM The importance of **lipid control** depends on patients' awareness of risk of cardiovascular disease

Long-term complications: Patients identify multiple factors for retinopathy screening and foot self-care with mixed perceptions of cardiovascular risk.

Hyperglycaemia may distress patients, however, some not acknowledge symptoms and complications

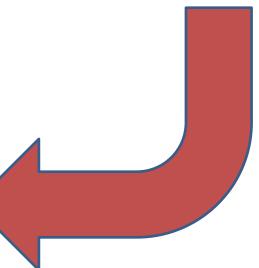
**Hypoglycaemia** is a fearsome threat that impacts patients' life and SM.

**Death** related feelings can influence engagement in SM Quality of life: Diabetes impacts on patients' sense of identity, a myriad of emotions arises with complications or when dealing with treatment or SM, which can lead to stigma. Social support might help to overcome these barriers

The experience of care depends on the individualised care level, the nature and characteristics of the patient-HCP relationship, and cultural appropriateness.

The decision-making process is influenced by the divergent agenda between patients and HCPs, the quality of communication, the cultural context, and the lack of time Scheduled care requires patients to face challenges getting the appointment, and accessing specialised care, while attendance is influenced by cultural background and previous experiences

Value for money of SM Financial constraints can limit SM



We comprehensively analysed the main themes for 23 outcomes and provided summaries with different levels of detail that informed the

### change may hinder treatment adherence. Patients with diabetes do not readily perceive the risk of long-term complications. Moreover, getting healthcare access can be difficult in some contexts, and attendance varies according to previous experiences. Quality of life constraints and physical and psychological barriers can make it challenging to follow self-management. Ultimately, self-management interventions with adequate support enhance patients' self-efficacy,

development of recommendations for SMIs for T2DM.

### Conclusion

Our results can inform health policymakers and main stakeholders of the development of future interventions to support patients with T2DM, addressing the main factors affecting their disease journey.

### Funding

This work was supported by the European Union's Horizon 2020 research and innovation programme [754936]. ENDG was funded by a Rio Hortega contract from the Instituto de Salud Carlos III [CM17/00199].

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# The Body Map Tool: a digital communication aid for young people with a chronic condition and their care providers

Femke van Schelven, Mara van Weele & Hennie Boeije

The Netherlands Institute for Health Services Research

### Background

Young people with a somatic chronic condition receive treatment to reduce symptoms ...

... but treatment can also pose a heavy burden on them and affect their quality of life ...

... still, care providers and young people rarely discuss this so-called treatment burden.

**Objective:** To develop a visual body mapping tool that facilitates communication about treatment burden between young people with a chronic condition and their care providers.

### Methods

### Development of paper prototype

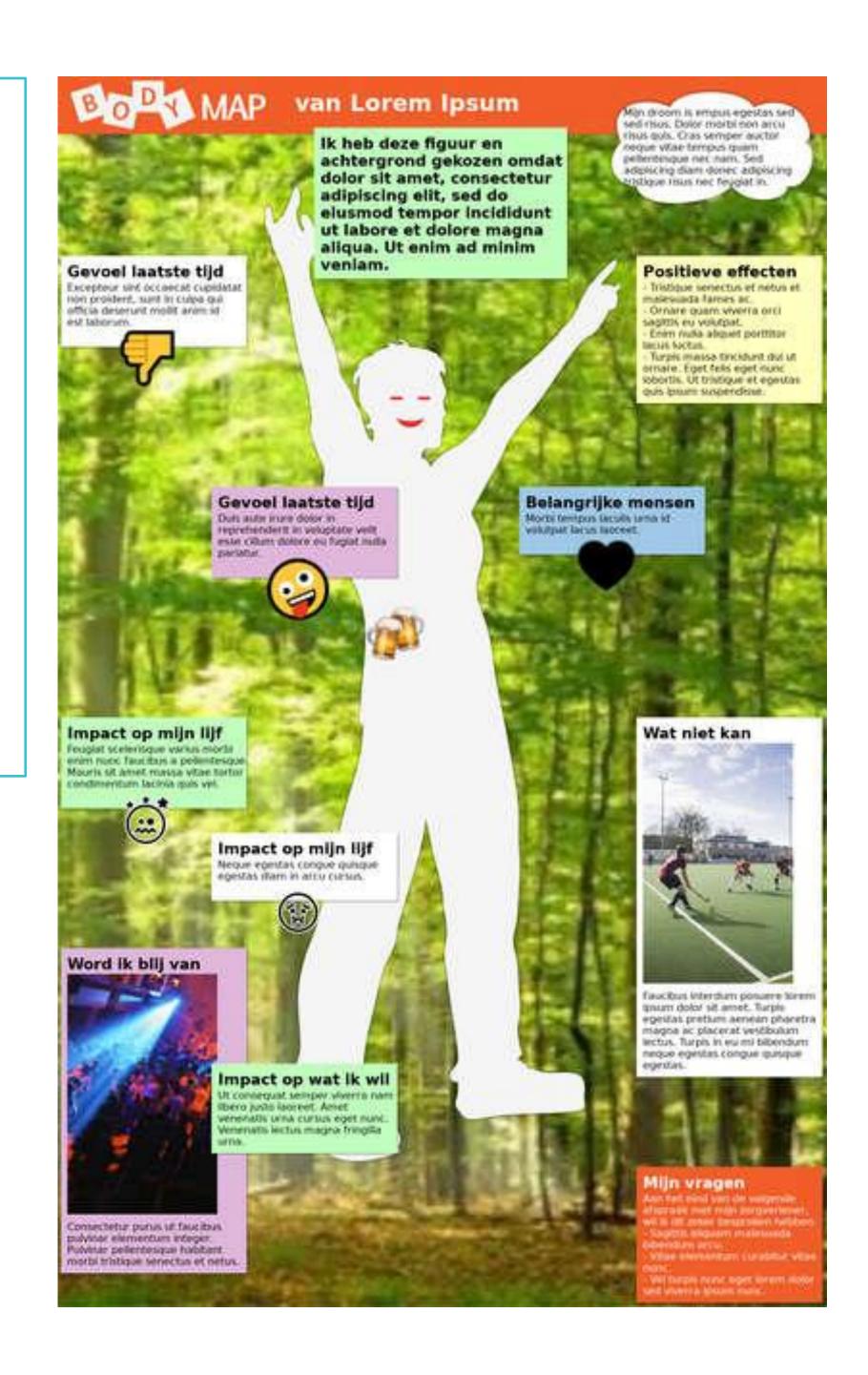
- Literature search on body mapping
- Interview with health care provider
- Co-design session with young people

### Development of digital demo tool

Iterative process
 with a team of
 researchers,
 young people
 with a chronic
 condition and
 care providers

### **Application of tool**

- Six workshops with young people
- Dialogue
   session with
   young people
   and care
   providers



### Results

With the digital Body Map Tool, young people create a 'body map': an image of a body in which they depict treatment burden with photos, icons and text. A 'chat robot' guides this process. Young people can print the body map and discuss it with their care provider.

### What do the users think of the tool?

- A picture is worth a thousand words: The tool helps to discuss topics that are difficult to express in words.
- Taking control: It helps to tell your story and take control in dialogues with care providers.
- Being seen as a person: It helps to draw attention to treatment burden.

### Conclusion

Our digital Body Map Tool helped young people with a chronic condition to tell their stories, as they could visualize and show experiences before discussing them. We are currently developing a similar tool — called UP!—to support communication between young people with a mental chronic condition and care providers. The use of a visual body map tool may also be of interest to adult patient groups, such as people with low health literacy.

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# Self-care and digital health in the 5th Self-Care Week of semFYC.

### **Authors**

María del Campo Gimenez, Elena Muñoz Seco, Francisco Camarelles Guillem. Spanish Society of Family and Community Medicine.

### Background

**Self-care interventions** favor greater health coverage and access, reduce health inequalities, promote equity in health, are related to an improvement in the quality of services, better results are obtained in terms of health, human and social rights, and there is a more efficient use of health services and resources.

For all this, the World Health Organization recommends various self-care interventions, including digital health interventions. Digital health interventions offer opportunities to promote and provide information on self-care interventions.

### Methods

The Spanish Society of Family and Community Medicine (semFYC) celebrates its V Self-Care Week october 2022.

The objectives of the Self-Care Week are to promote self-care in health, inform and sensitize patients about the importance of self-care, raise awareness and motivate health professionals, focusing this year on **digital health**.

In this edition, the main objective is to find out how patients use websites, social networks, forums and mobile applications related to health and self-care.

For this purpose, semFYC has launched an online survey addressed to patients: <u>Autocuidado y salud digital</u>.

### **Findings**

The results will be published during the celebration of the V Self-Care Week on 17-21 October 2022.

### Discussion

The results will allow expanding knowledge about self-care and digital health and developing action plans to improve the self-care of the population.

### Tú puedes hacer mucho por tu salud ¿Usas habitualmente algún dispositivo digital relacionado con tu salud? | ¿Utilizas algún portal digital de salud de tu Servicio de Salud o Centro Sanitario? Sueles buscar información sobre tu salud? Participa en la encuesta y, entre todos, sabremos mejor cómo usar ternet, las app o los relojes inteligentes para mejorar nuestra salud. ociedad Española de Medicina Familiar y Comunitaria, semFYC, a través

### **Preliminary results**

They have participated 924 people in the form. 74,5 % were female, 25,1 % were male, and 0,4 % were non-binary. 87,6 % have university studies.

- 55,9 % have consulted about their health on the internet in the last month, and the most frequent topics have been symptoms, prescription drugs and healthy lifestyles.
- 58,9 % use digital devices related to their health, mainly used to measure daily steps, heart rate and monitoring of physical activity.
- 76,6% have an APP related to their health, used to check their medical history and to make an appointment with their health.

- WHO guideline on self-care interventions for health and well-being, 2022 revision: executive summary. Ginebra: Organización Mundial de la Salud; 2022.
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### Graphical tools for visualizing the results of network meta-analysis of multicomponent interventions

Georgios Seitidis, Sofia Tsokani, Christos Christogiannis, Katerina-Maria Kontouli, Ourania Koutsiouroumpa, Alexandros Fyraridis, Stella Zevgiti, Stavros Nikolakopoulos, Areti Angeliki Veroniki, Dimitris Mavridis

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### Goal of this work

We propose novel ways of visualizing network meta-(NMA) with multicomponent results explore the behaviour of the interventions to to identify which component and components (combination) works better.

### **Quick Revision**

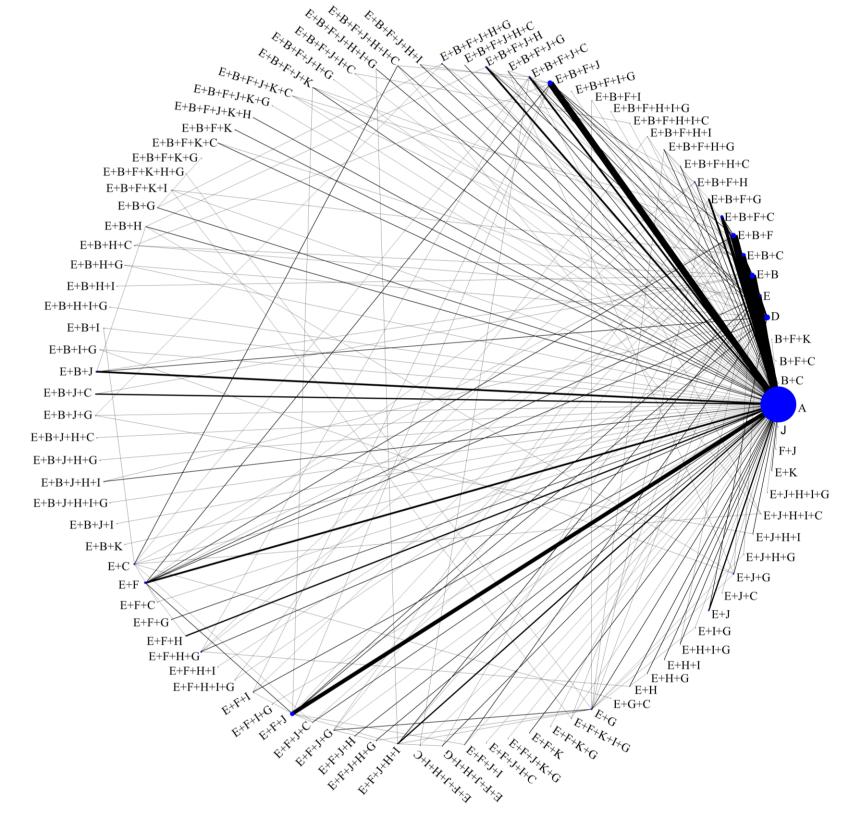
multicomponent interventions are typically sparse and classical NMA inference is not straightforward.

Component NMA (CNMA) is typically used to analyze multicomponent interventions, however, in sparse networks transitivity is challenged.

The proposed figures are based on the NMA estimates.

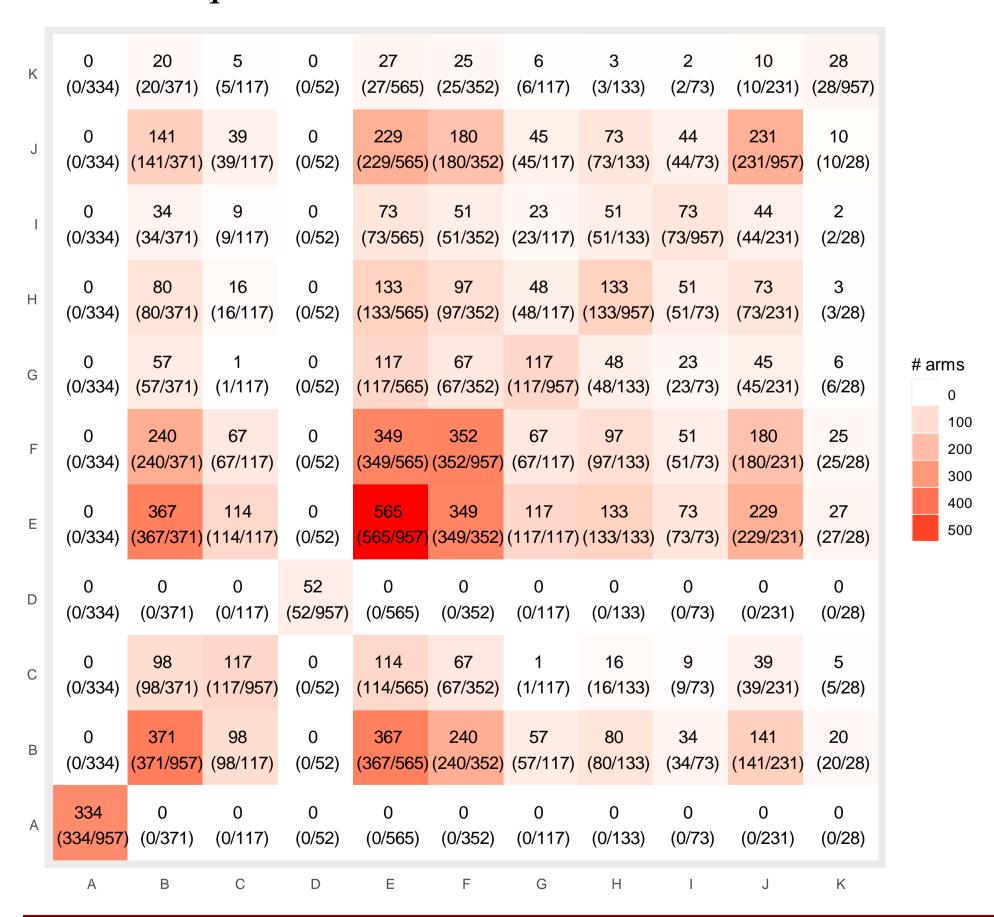
### **Dataset**

- 461 studies,
- 97 self-management interventions
- 11 components



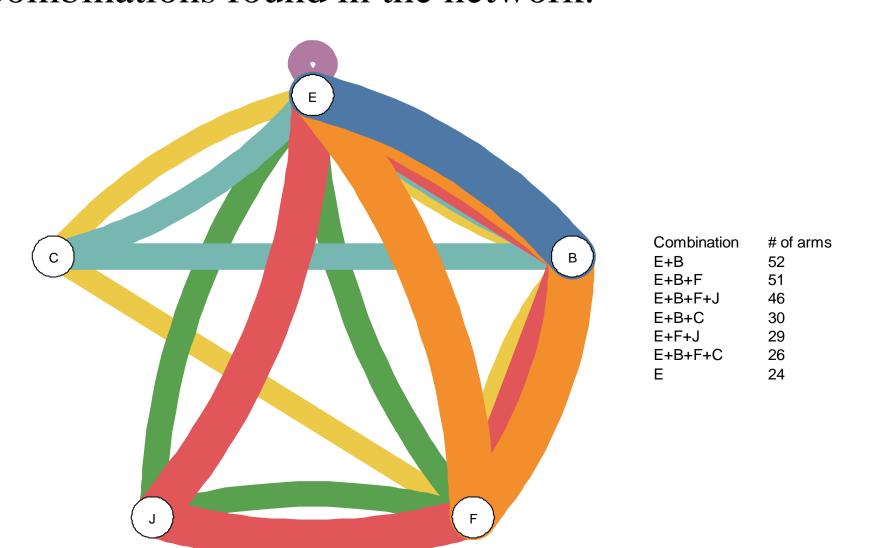
### Crosstable

Visualizes the components' frequencies in order to identify which components (combinations) are the most frequent.



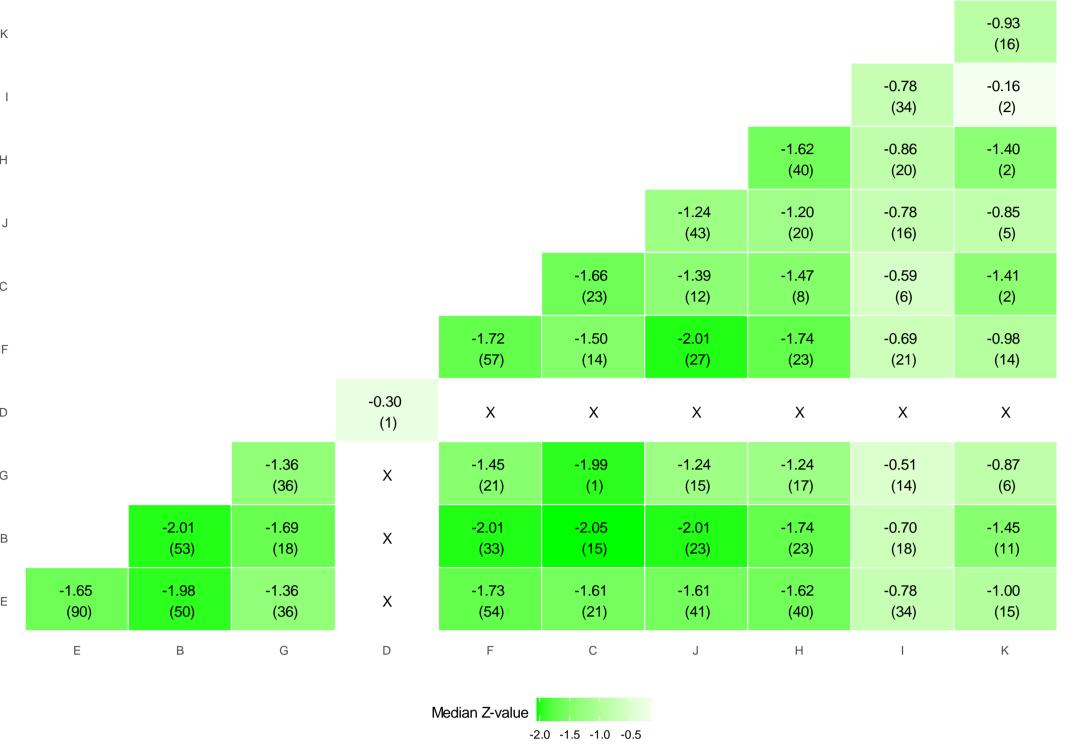
### **Components Network Graph**

Visualizing components' the frequency combinations found in the network.



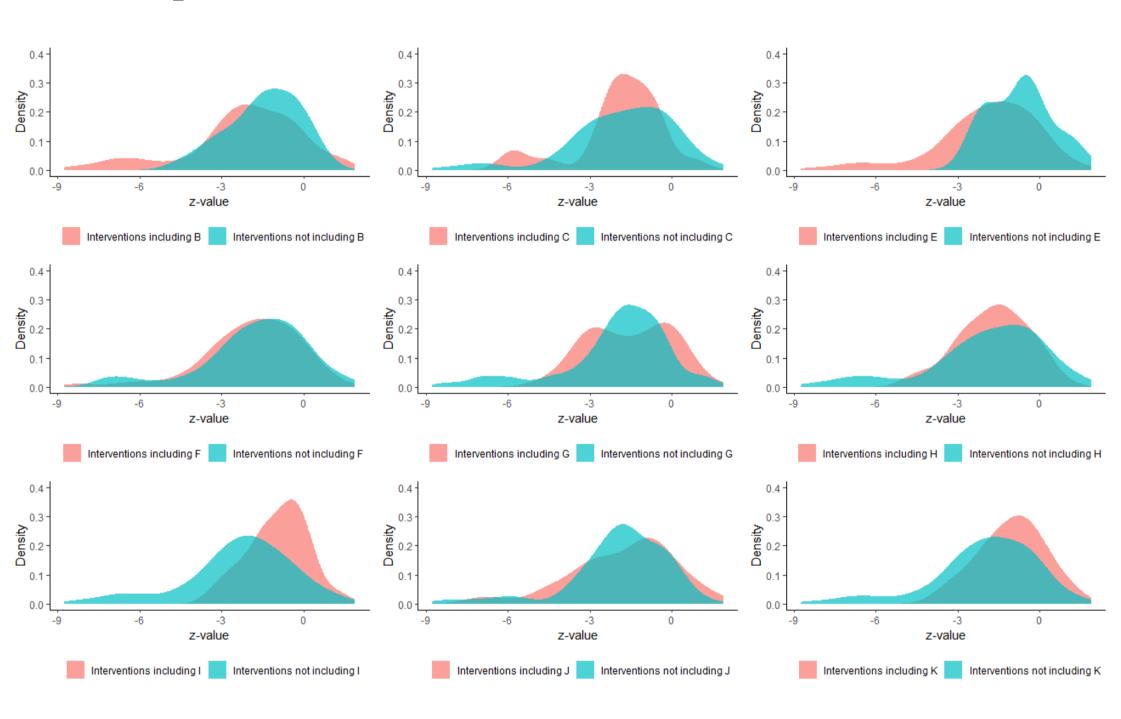
### **Components Heat Plot**

Explores the efficacy of component pairs of interventions.



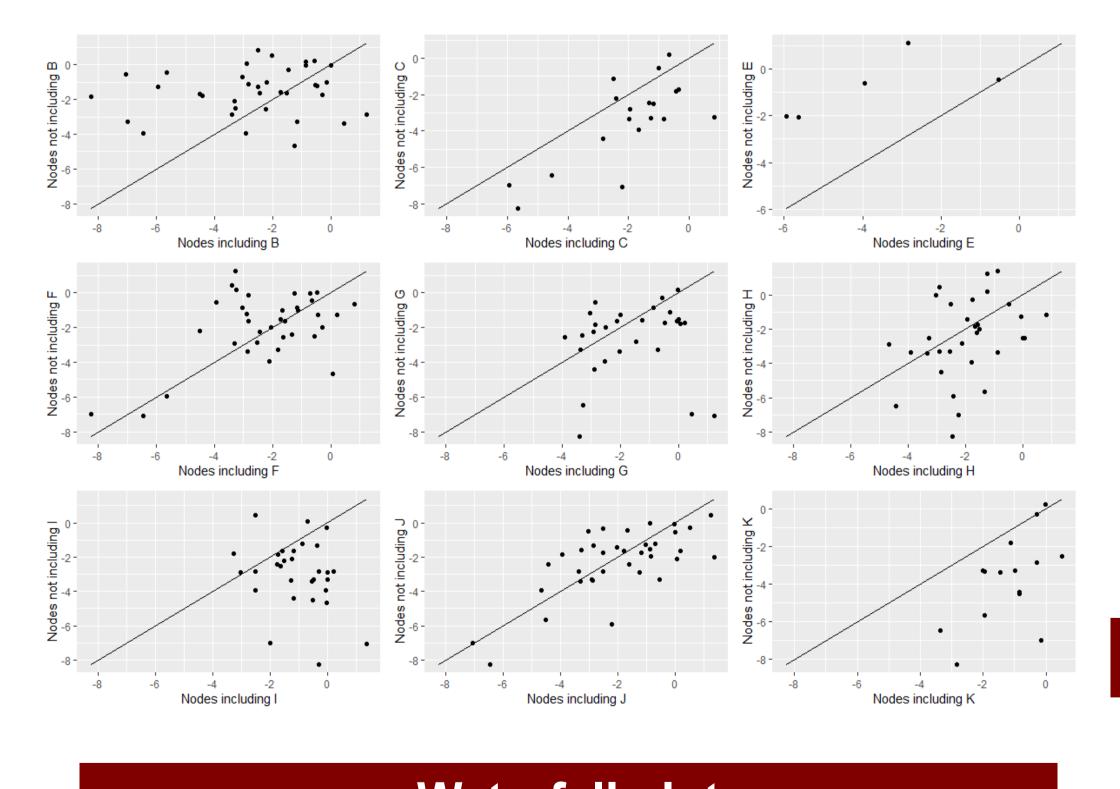
### **Density Plot**

Compares the corresponding density of all z-scores that include each of the components (or a combination of them) to those not including the component(s) of interest.



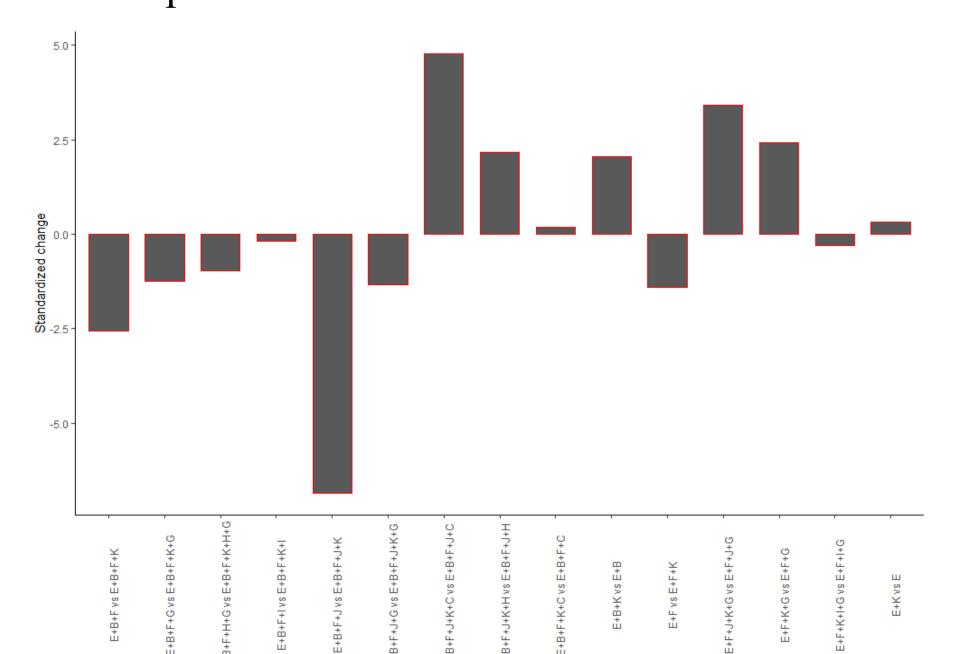
### Leaving one component out scatter plot

Explores whether the inclusion or exclusion of a component has a positive or negative impact on the efficacy of an intervention.



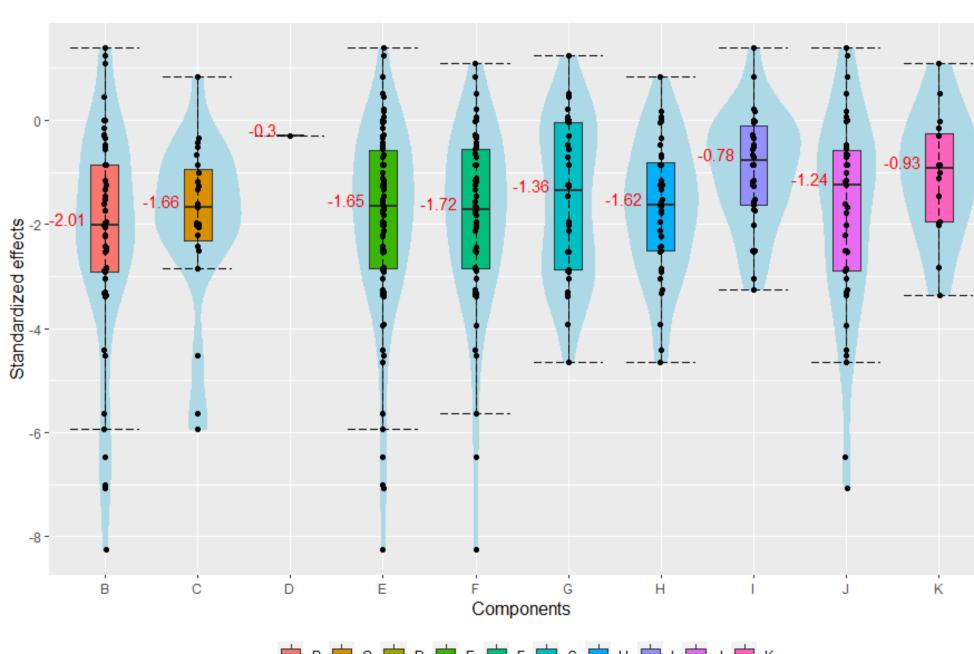
### Waterfall plot

"leaving one component out An alternative to scatter plot".

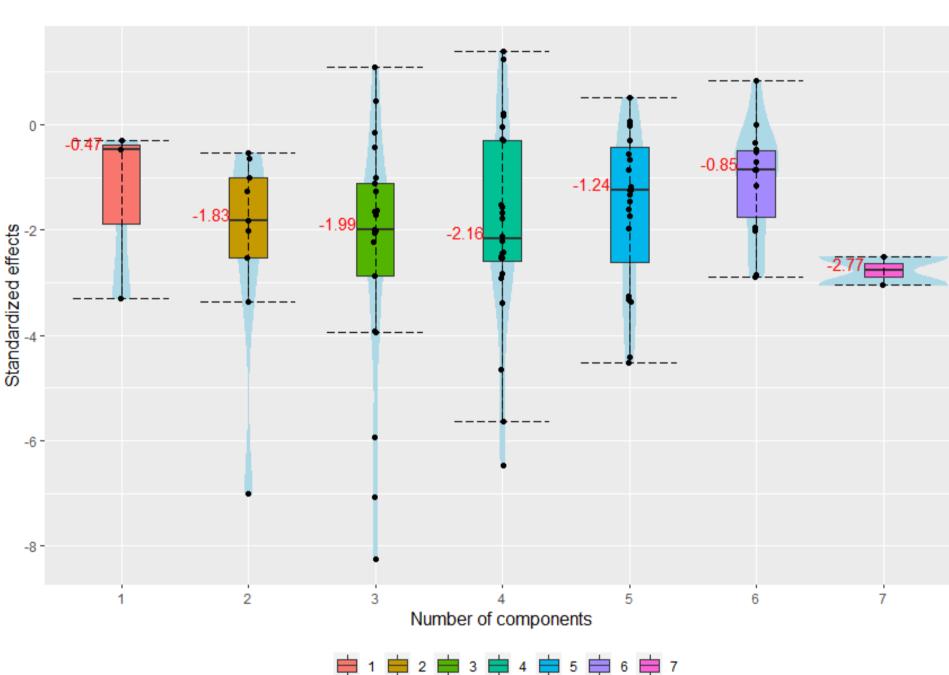


### Violin plot

points the denotes z-scores interventions include the corresponding that component.



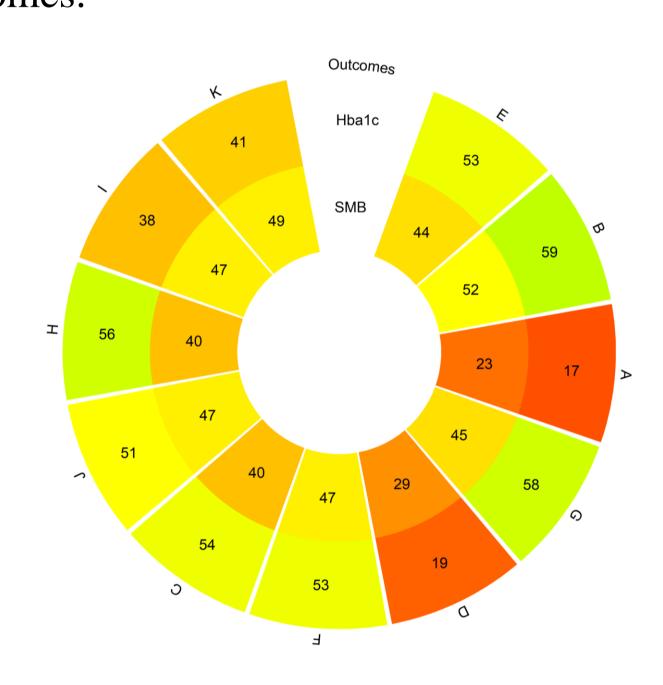
Data points denote the z-scores for the interventions that includes the corresponding number of components.



### Rank-heat plot

Useful when dealing with multiple outcomes.

Summarizes the components p-scores for multiple outcomes.



### Conclusion

- Perform both NMA and CNMA when dealing with multicomponent interventions.
- figures insight offer proposed components' efficacy and help on understanding their behavior.

### **Contact Information**

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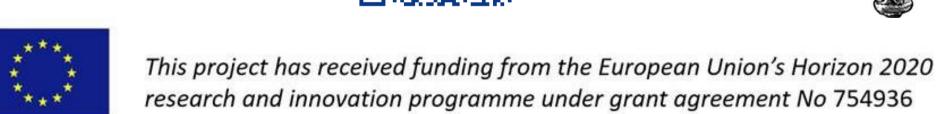


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# Knowledge and self-care behaviors of patients hospitalized for acutely decompensated chronic heart failure: a neverending work in progress

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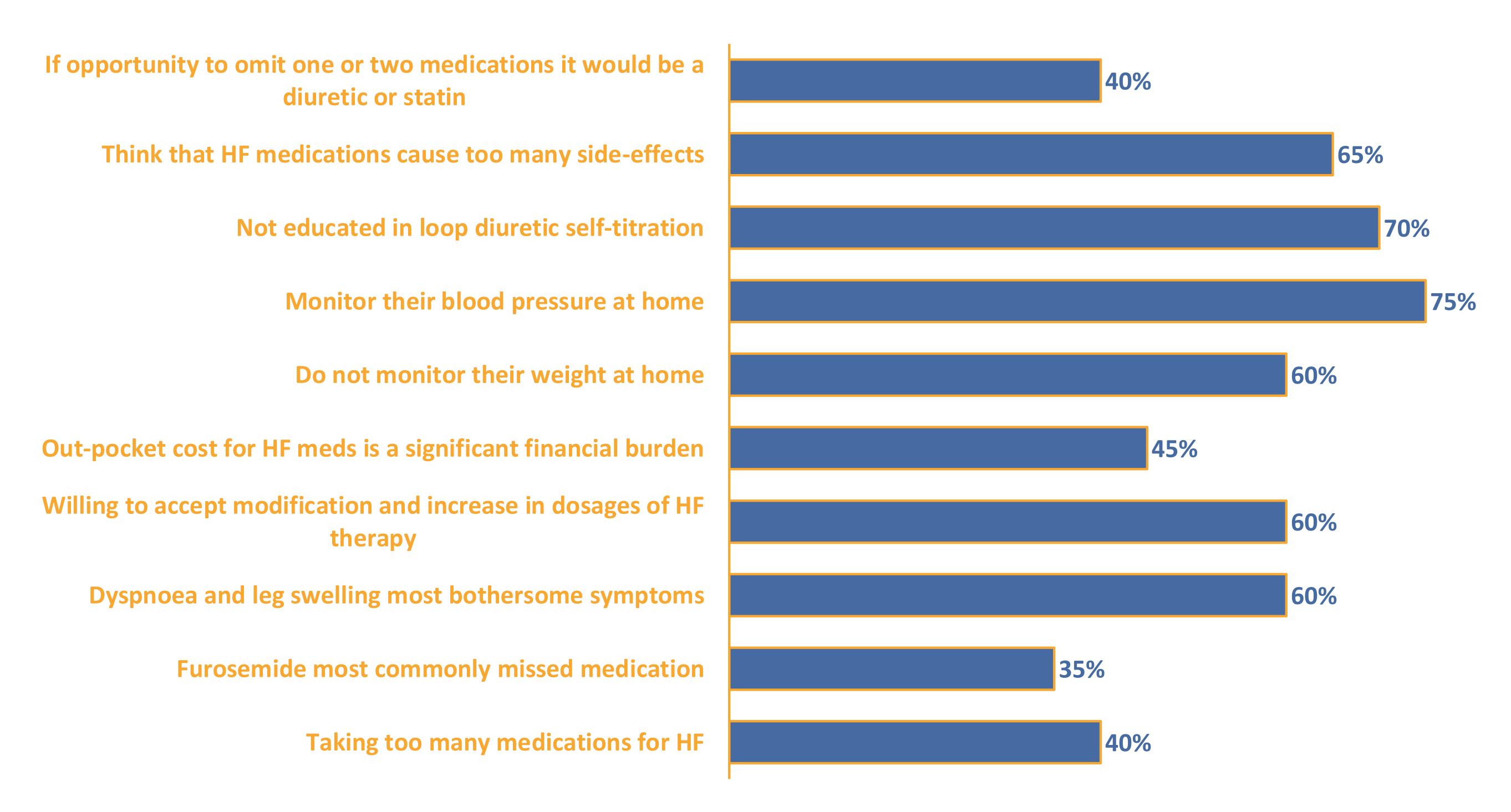
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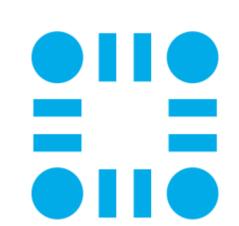
**BACKGROUND:** To assess inpatient behaviors toward HF medications and self-care measures in the setting of acutely decompensated chronic heart failure (ADHF) prior to discharge from a tertiary clinical center.

METHODS: Twenty patients with ADHF were provided an educational HF booklet and completed a 20-item questionnaire before discharge.

FINDINGS: The mean age of patients was 70±11.8 years and 85% were male. Mean dyspnea per VAS scale prior to discharge was 2.9/10 points. Shortness of breath and leg edema were the most bothersome HF symptoms in 60% of patients. Forty percent of patients reported they feel they are taking too many medications for HF while 65% thought these medications cause them too many side effects. However, all patients reported that they would take as many HF medications as needed to treat their disease. Nearly half of patients (9/20) reported that financing and out-of-pocket costs for HF medications impose a significant financial burden on them. Up-titration of HF medications, as self-reported, did not occur in 70% of a patient during the period of last 12 months while 45% of patients were hospitalized due to HF at least once during the previous year. In terms of self-care, 40%, 75%, and 70% of patients reported they are regularly monitoring their weight, blood pressure, and salt or fluid intake at home, respectively. More than two-thirds of patients revealed they are not educated about the self-titration of diuretics at home. Patients identified antihypertensives and diuretics as the most important drugs for HF management while 50% of them would remove either diuretic or statin if they could omit one medication.

DISCUSSION: Patient knowledge and self-care incentives regarding heart failure management were insufficient in several domains. Therefore, more educational interventions geared towards patients with ADHF are urgently needed to improve self-care behaviors thus potentially impacting relevant clinical outcomes. Main results are presented in the **Figure** below.











### Exploring efficacy of self-management interventions in selfefficacy on chronic disease

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### Background

Self-management support may improve self-efficacy but there is uncertainty about which type of support is the most effective to manage chronic diseases.

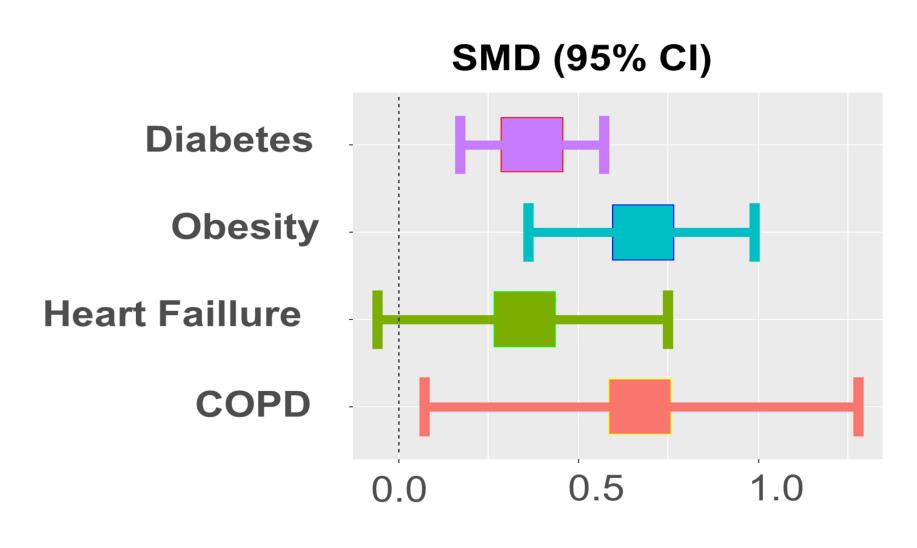
### Introduction

Self-efficacy is an outcome in the COMPAR-EU explored across 4 chronic diseases: Diabetes Type-II, Obesity, Heart-Failure and COPD.

A total of 111 studies involving 14684 participants met the criteria for inclusion in our component and standard network meta-analysis (NMA). This represented 86 distinct types of interventions and 116 comparisons (61 for diabetes, 14 for Obesity, 18 for COPD, and 42 for Heart failure).

### SMIs vs UC/UCP

Self-management interventions (SMI) improved self-efficacy compared with usual care. Specifically, for diabetes SMD= 0.27 [0.22, 0.31], for obesity 0.62 [0.46, 0.78], for heart failure 0.09 [0.03, 0.16] and for COPD 0.40 [0.29, 0.50].



### Network Meta-Analysis

Network Meta-analysis is a very useful statistical method that synthesizes direct and indirect evidence and allows estimation of the relative effectiveness between any pair of interventions within a network of treatments<sup>1,2</sup>. Additionally, NMA can rank all the available treatments in the network. We ranked all treatments in each outcome by using P-scores<sup>3</sup>. P-scores assume values from zero to one and the larger the p-score the better the treatment.

### C MPAR-EU

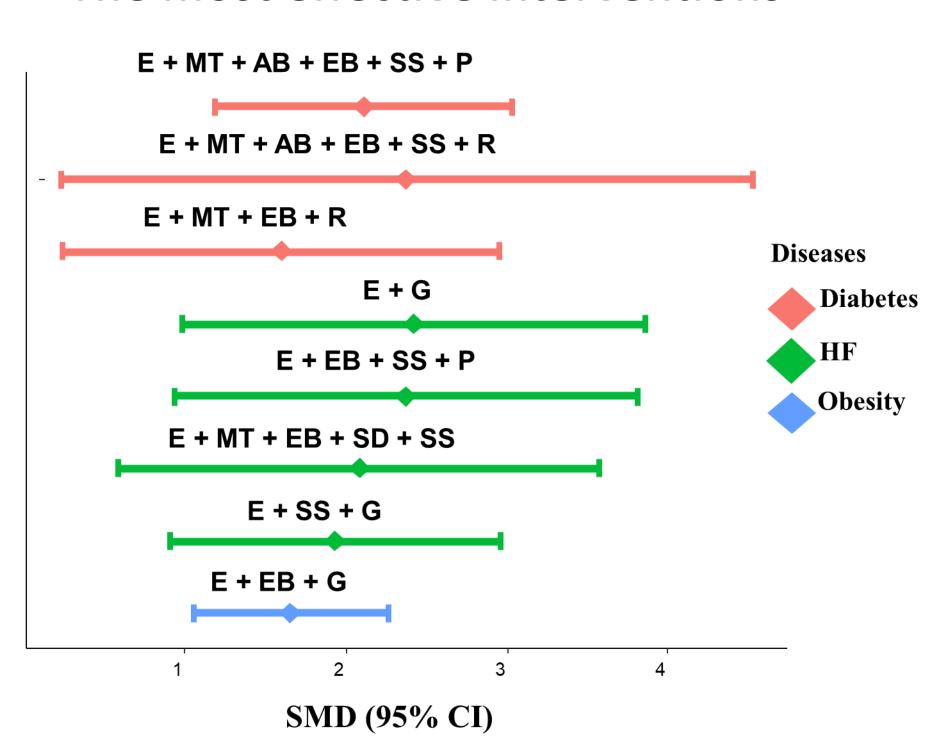
Figure 1

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 754936

### NMA results

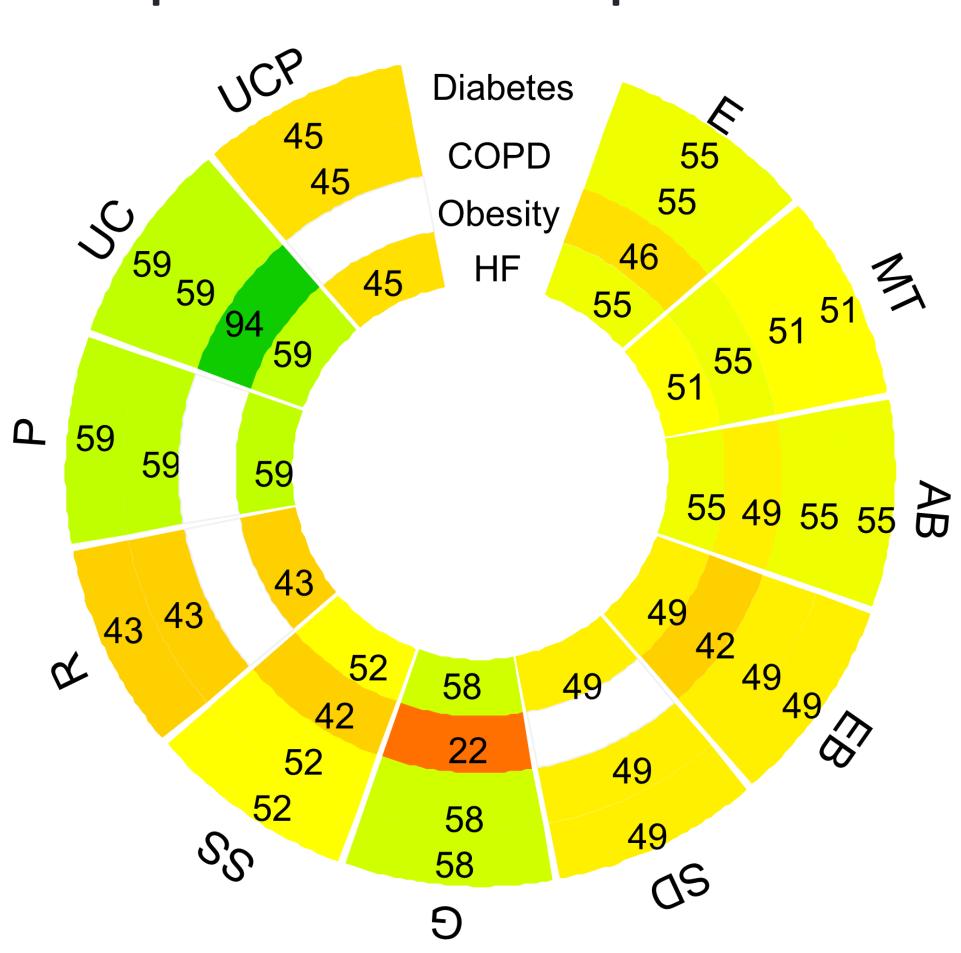
In Figure 2 the most effective treatments according to their P-scores are presented. A threshold of 80% was used for P-scores. However, for COPD, the included interventions did not achieve a P-score greater than 80%.

### The most effective interventions



### Rankheatplot:

Components across multiple outcomes.



### Component Network Meta-Analysis (CNMA)

In NMA, interventions can be multicomponent/complex; for example, some interventions may be combinations of others or common components.

In standard NMA, all existing (single or combined) treatments are different nodes in the network. However, sometimes an alternative model is of interest that utilizes the information that some treatments are combinations of common components, called component network meta-analysis model<sup>4</sup>.

In our project, there are 11 components, presented their abbreviation.

	Abbreviation	Component			
1	AB	Action - based behavioural change techniques			
2	E	Education			
3	EB	Emotional - based behavioural change techniques			
4	G	Group			
5	MT	Monitoring techniques			
6	Р	Peers and lay persons			
7	R	Remote			
8	SD	Shared decision making			
9	SS	Social support			
10	UC	Usual Care			
11	UCP	Usual Care Plus			

### **CNMA** results

Most efficacious components

Diabetes

EB: 0.44 [0.11, 0.78] SS: 0.35 [0.02, 0.68]

Heart Failure

E: 0.95 [0.41, 1.49]

### Discussion

- Most NMA intervention effects were associated with much uncertainty.
- CNMA showed that the education component improves self-efficacy considerably for all 4 chronic diseases.
- Most of the trials had medium or high risk of bias.
- In all analyses, we identified substantial heterogeneity.

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et de recherche en soins FBM









### INSIGHTS INTO THE SWISS SYMPTOM NAVI PROGRAMME

Evaluation of a nurse-led self-management support intervention for people affected by cancer

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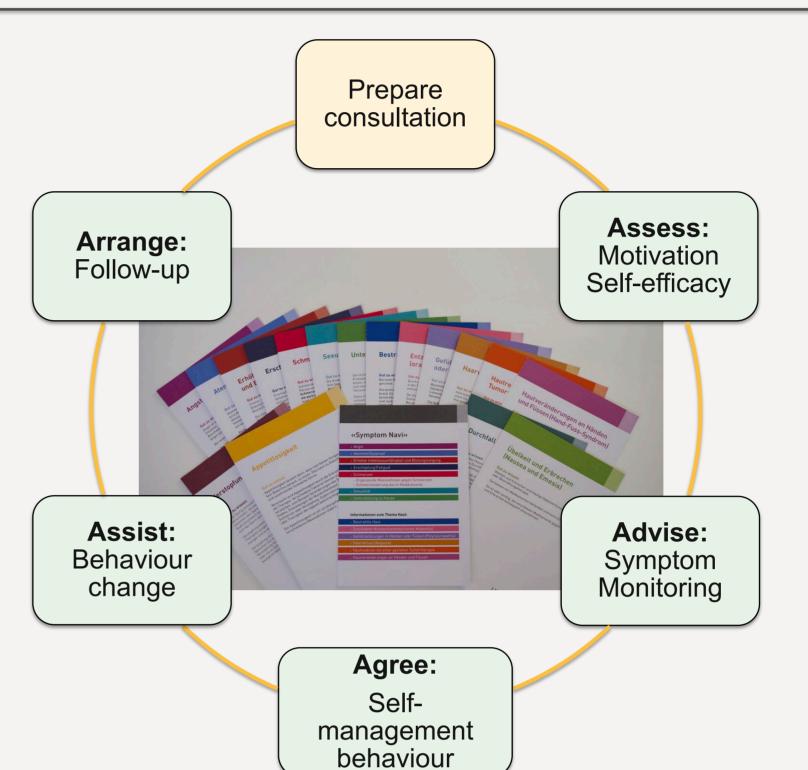
Contact: marika.bana@symptomnavi.ch / marika.bana@hefr.ch

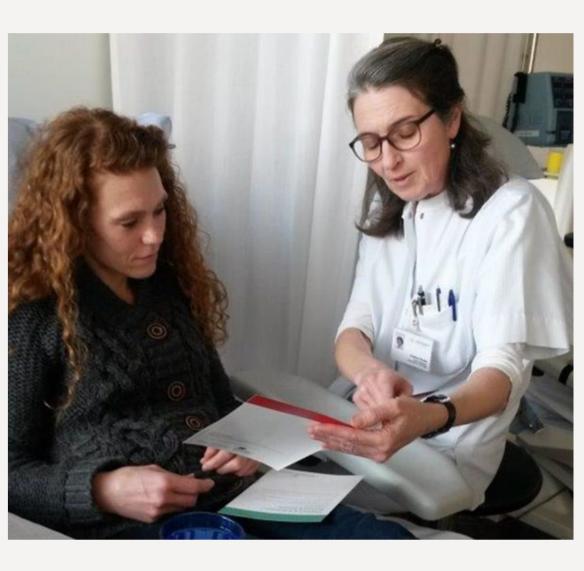
### Background

Cancer can cause early and long-term consequences that ask for tailored selfmanagement support (SMS) during and beyond cancer treatments. The Symptom Navi Programme (SNP) is an SMS intervention based on coaching and facilitating patients' self-efficacy. It consists of leaflets providing evidenceself-management recommendations, semi-structured SMS based interventions, and standardised implementation training.

### **Objectives**

- People affected by cancer in Switzerland will have access to evidence-based self-management recommendations.
- Nurses and other health care professionals will support self-management behaviour and facilitate the self-efficacy of affected persons.





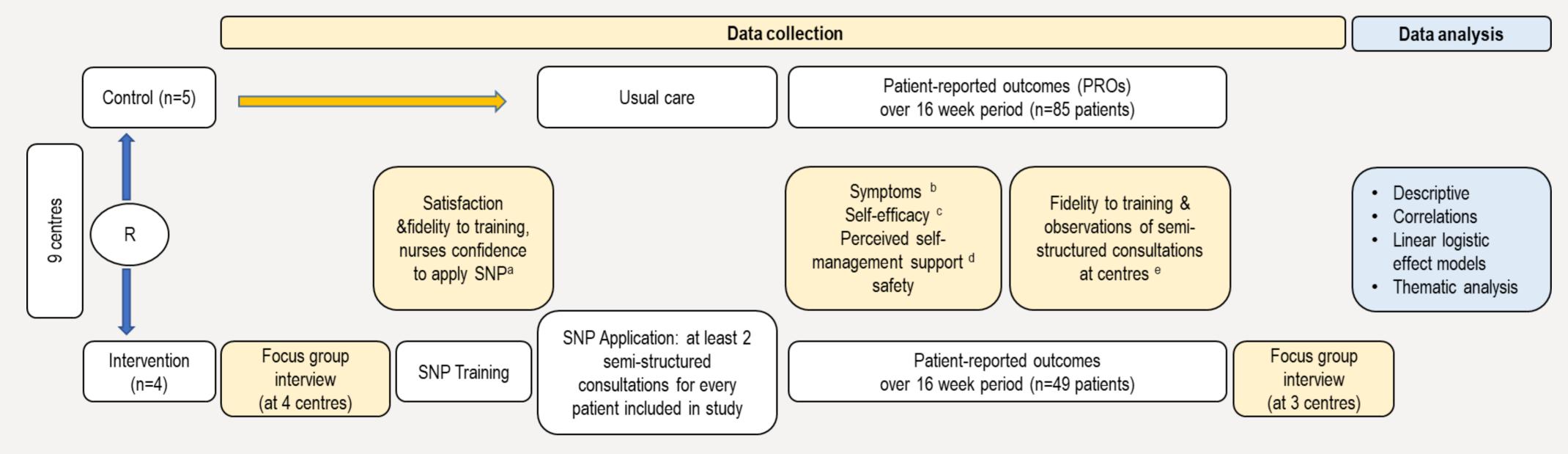
Semi-structured consultations based on the 5 As (1)

### Methods

We used patient and family involvement and collaborated with health care professionals to develop the SNP programme.

**Programme evaluation:** Patient and family experience were explored using semi-structured interviews (completed before the pilot study (2))

Cluster-randomised pilot study (3): evaluation of the programme's implementation in nine outpatient cancer centres in Switzerland.



### Symptom Navi pilot study procedures

### Legend:

R: randomisation of clusters (=centres)

- a: study specific questionnaires completed by nurses after training PROs:
- b MD Anderson Symptom Inventory,
- c Self-efficacy for Chronic Disease 6 item Scale,
- d Patient-Reported Chemotherapy Indicators for Symptoms and Experience (reduced and adapted version for pilot study)
- e: study specific questionnaires nurses completed after every performed intervention

### Results

Patients and family members reported that leaflets were helpful and that nurses' consultations were supportive.

Nurses reported applying 92% of training content (95% CI: 87-95%). However, direct observation (n=6) and focus group interviews revealed rather poor implementation on coaching behaviour and the facilitation of self-efficacy (see diagram on the right)

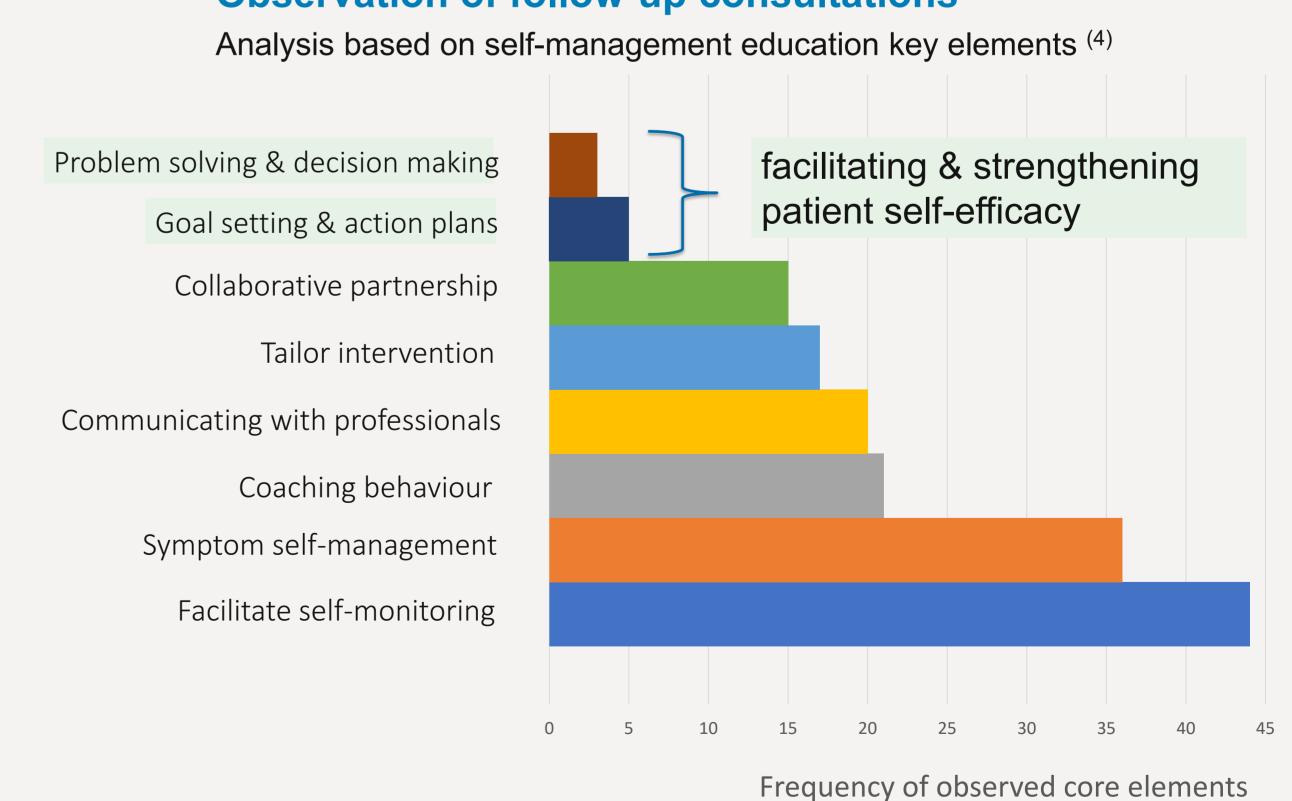
Nurse confidence to use the SNP in daily routines was positively correlated with working conditions (r  $\pi$  =.47, p = .04).

On average 88% of patients received the semi-structured consultations as planned (range related to centres 75-100%).

Over 16 weeks, the intervention showed no impact on any patient-reported outcomes compared to the control group.

No adverse events were reported.

### **Observation of follow-up consultations**



### **Discussion / Conclusion**

Nurse-led consultations with leaflets are safe and the implementation of SNP at cancer centres is feasible. We improved training regarding coaching behaviour, self-efficacy support, and the adaptation of support to context. Online training modules and a trilingual website now facilitate access to self-management recommendations. We plan for the next year an evaluation study concentrating on effectiveness related to patient self-management behaviour.

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### Developing recommendations of self-management interventions in patients with chronic conditions: the importance of working with panels

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### Background

Current knowledge suggests that self-management interventions(SMIs) may improve clinical outcomes of patients with chronic conditions(1). COMPAR-EU project aims to identify, compare and rank the most effective and cost-effective SMIs in four high priority chronic conditions in Europe. We assembled four multidisciplinary panels to formulate evidence-based recommendations on SMIs for patients living with Type 2 Diabetes Mellitus (T2DM), Obesity, Chronic Obstructive Pulmonary Disease (COPD) and Heart Failure (HF)(2).

### Objective

To describe the experience of working with panels to formulate recommendations on SMIs in the COMPAR-EU project.

### Methods

### Recruitment and selection of panelists

Panel members were recruited via open call, through social media, the project website, and referrals from the consortium, were selected according to their expertise or experience in the chronic condition (patient or clinician), selfmanagement, guideline development, or health care research. All members disclosed their potential conflicts of interest.

### Panels composition

Panels included representatives from a variety of backgrounds, such as: health services researchers, guideline methodologists, academics, clinicians, selfmanagement experts, and patients and patient advocates.

### **Panels activities**

1) Surveys: all panels answered two surveys. The first evaluated the level of agreement with the core outcome set (COS) for each condition.

The second, evaluated the level of agreement with the magnitude of effects thresholds (e.g. large vs a moderate effect) for the selected outcomes. Both surveys used Likert scales.

- 2) Training sessions: through videos and online meetings, panels were briefed on the project methodologies, like the GRADE methodology; and in particular the Evidence to decision frameworks (EtD) to develop recommendations.
- 3) Preliminary judgments and recommendations: panels made preliminary judgments for each EtD framework criterion, using the GRADEPro online tool (Panel voice feature). The results, including the degree of agreement, were discussed during online meetings.
- 4) Final report: draft of a report including the methodology, results of the process, and final recommendations. This needs to be approved by all panels. A manuscript for each condition which will be submitted for publication separately.

#### Results **Conditional** Panels' feedback recommendations for the Panels composition We explored the panels' views about interventions their participation. The results, 37 recommendations using the Panel View instrument (3), T2DM based on low or very low certainty of for all SMIs vs usual care and most 11 members show that overall the methods were the evidence effective interventions, per condition total. perceived as optimal. Below results for those strongly agreeing or agreeing on some key aspects. Obesity 10 members Panels participation **Appropriate** 93% total. **logistical Support 75% COPD** Adequate time to 93% 15 members T2DM complete tasks total. **Adequate process** Obesity 10 HF 87% methodology 12 members information Panels' level of agreement total. with preliminary judgements **COPD** Transparent summary 93% **Panels activities** on EtD criteria of evidence 9 Two initial surveys per panel (n=8) HF Five online meetings per panel (n=20) 82% 41 Panel voice surveys **Appropriate** One Final Report per panel (n=4) 87% consideration of the (ongoing) patients' perspective A process survey per panel (n=4)

### Conclusions and lessons learnt

Our results highlight the importance of working with panels; their input is crucial for the development of trustworthy recommendations. The process was feasible and acceptable for most of the panelists; however, it is important to be aware of panellists' needs of tailored training, especially in the case of patient representatives.

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### Self-management interventions for chronic diseases: Identifying factors to facilitate the implementation of selfmanagement decision-making tools into routine healthcare practice. A qualitative study.

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### **OBJECTIVES**

A growing body of literature documents the value of self-management interventions (SMI) for chronic diseases, but their implementation in clinical routine is rare. As part of the COMPAR-EU project, this study aims to identify factors for the use of decision tools and furthermore the requirements necessary for an incorporation of evidence on SMI into the clinical environment.

### METHODS

A directed qualitative content analysis and rapid analysis was used to evaluate semi-structured interviews in order to identify factors on a micro-, meso- and macro-organizational level that support or hinder the implementation and use of SMI decision tools. The interview guideline and the deductive coding system were developed in reference to the Tailored Implementation for Chronic Diseases (TICD) framework<sup>1</sup>. Inductive codes were obtained from the interviews through a three-cycle crossnational coding process.

Preparation phase

skills

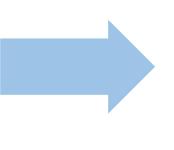
guide

Conducting and

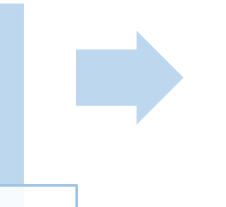
Acquisition of general

Developing an interview

transcribing interviews



Organisation phase



### Reporting phase

- 1st coding cycle
- 2<sup>nd</sup> coding cycle
- 3<sup>rd</sup> coding cycle

- Quote selection
- Translation of the quotes into English
- Structuring and reporting of the results

### **RESULTS**

The findings of this research are based on 37 semistructured interviews with healthcare professionals (HCPs) and decision makers (DMs) from Germany and Spain. Five main dimensions with key facilitators for implementation emerged from the data analysis: (a) factors of decision tools (added value through structured access to clinical evidence and strengthening collaboration between primary care and hospitals), (b) individual health professional factors (perceived benefit in workflow of decision tools), (c) factors of interaction (shared understanding about decision tools and defining responsibilities in clinical teams), (d) organizational factors (capacity of organizational change and financial, personal and time resources), (e) social, political and legal factors (consistency of decision tools with ways of working in the healthcare system).

"Our colleagues from other hospitals, or another region, should explain to us the benefits that the tool brings. I think that that is the strategy we should follow. First, explain the purpose of the tool, then, have the experience of another place where we can see the health results that have been achieved thanks to the tools. Show us the experience of patients that are using the tools, and, especially, seeing results. I think that is the key, implementing tools that have an added value in improving health." (Spanish DM8, primary care)

"Well, it's always nice when you see progress in your patients that you've been caring for over a long period of time. And I personally find it very pleasing when you see that someone is feeling better again and you've given them good advice, and through selfmanagement, the patient who is so obese has perhaps lost ten kilos in weight. We are for the patients or work for and with the patients. And when someone comes and has a much better quality of life, is satisfied, that has an effect on the whole environment." (German HCP8, primary care)

Organizational Factors of factors interaction Individual Social, political health and legal professional factors factors Factors of decision tools

"Right, it goes hand in hand with what I said before, resources, employees and time. Because when these innovations are added on their own and they add a workload that doesn't change anything, it means that, if we are going to work with a new tool, with a new process, it needs to substitute the old tool/process, and not be added on top of the old one, because then you start saturating the work capacity." (Spanish HCP2, hospital)

> "I don't have the insight on how it is in the outpatient area, what the general practitioners perhaps have, but I think at least from my current state of knowledge, there are not so many tools that could reach the patient. So, I would find it absolutely useful in the health system to implement something like that." (German DM16, hospital)

"I think leadership has to be shared in this moment. I mean, in the hospital you have the head of a service or the one who knows the most about that disease but the patient comes from primary care [...]. We are here to help primary care, and collaborate with them because they are the ones responsible for the patients." (Spanish DM11, hospital)

### CONCLUSION

Decision support tools can promote the use of evidence from SMI by making evidence accessible in a structured way. Existing understanding of the benefits of the tools, organizational resources, and political support are a prerequisite for sustainable implementation. The results of this study can contribute to the meaningful use of evidence on SMI in clinical practice, promote collaboration between care sectors, and thus lead to positive changes for patients.

### **Keywords:**

Self-management interventions, Decision aids, Chronic diseases, Implementation, Evidence-based practice, Qualitative content analysis, Semi-structured interviews

### Funding & Acknowledgements

This work is a part of the COMPAR-EU project. COMPAR-EU has received funding from the European Union under the Horizon 2020 research and innovation programme, under grant

### Literature

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### Exploring comparative effectiveness component network meta-analysis

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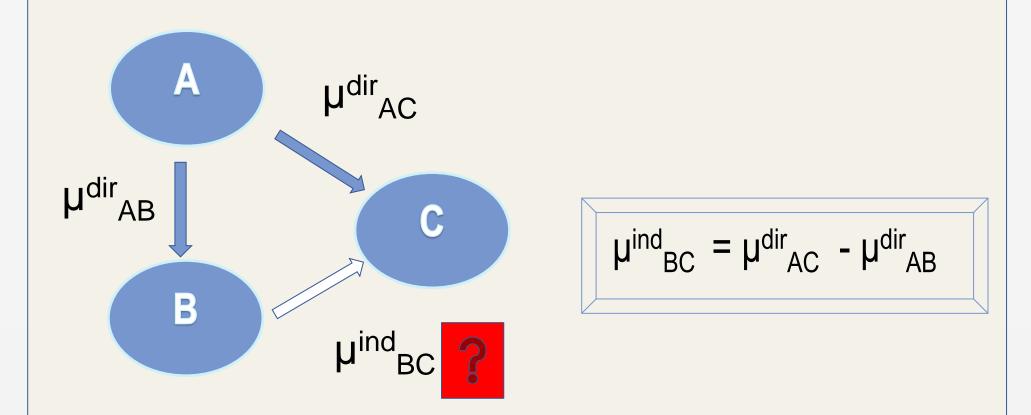
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### Introduction

- Network meta-analysis (NMA) is a powerful tool in clinical decision-making.
- NMA is a statistical method which simultaneously compares multiple (three or more) interventions within a single framework, by synthesizing direct and indirect evidence from multiple studies, addressing the same scientific question.
- Interventions may consist of multiple interacting components.
- Component NMA (CNMA) can estimate both component and intervention effects.

### Network meta-analysis (NMA)

Consider the simple example in which we have some trials comparing A versus B and some trials comparing A versus C, where A is the control treatment and B, C are two active treatments.<sup>1,2,3</sup>



In this case, network meta-analysis (NMA) combines direct and indirect evidence to estimate the relative efficacy for each pair of interventions irrespective of whether these have been directly compared.

### **Assumptions of NMA**

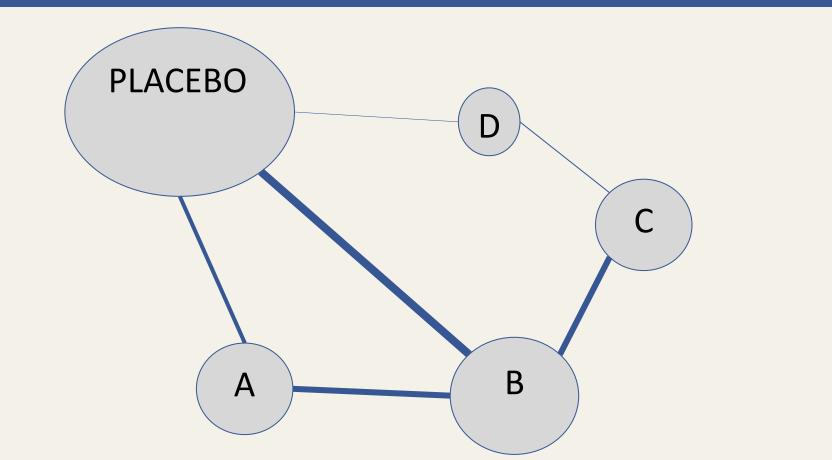
Like any statistical model, NMA makes assumptions and validity of its results depends on the plausibility of the assumptions made.

- The key assumption is that of transitivity, stating that one can learn about B versus C indirectly.
- We approximate transitivity <u>statistically</u> by comparing direct and indirect evidence (consistency assumption).

### What transitivity means

- The distribution of a-priori chosen effect modifiers is similar across treatment comparisons. It is typical to compare publication year across treatment comparisons as it is a proxy for quality of trials, risk of bias and so on.
- Treatments should be similar when they appear in different comparisons (e.g. usual care should be similar across trials).
- Participants, could have been, in principle, randomized to any of the available interventions.

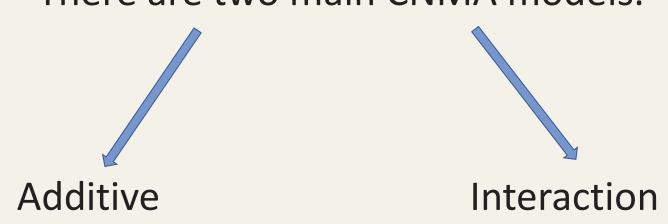
### Network Plot



### Component network meta-analysis (CNMA)

- While NMA focuses on estimating intervention effects, component NMA (CNMA) extracts the effect of each component. <sup>4</sup>
- Such interventions are characterized as 'complex' or 'multicomponent'.

There are two main CNMA models.



Which components work or do not work?

### Additive model

- The main idea of CNMA lies in the decomposition of multicomponent interventions to estimate the effects of their components.
- The additive effects model firstly estimates the effect of each component and then the effect of each multicomponent intervention is estimated by summing the relative effects of the components comprising this intervention (additivity assumption).

For example, according to CNMA the effect of intervention: effect(A+C) = effect(A) + effect(C)

Assumes: NO interaction term

### Interaction model

 Suppose for example that interventions A and C interact with each other. According to the interaction model the effect A + C is:

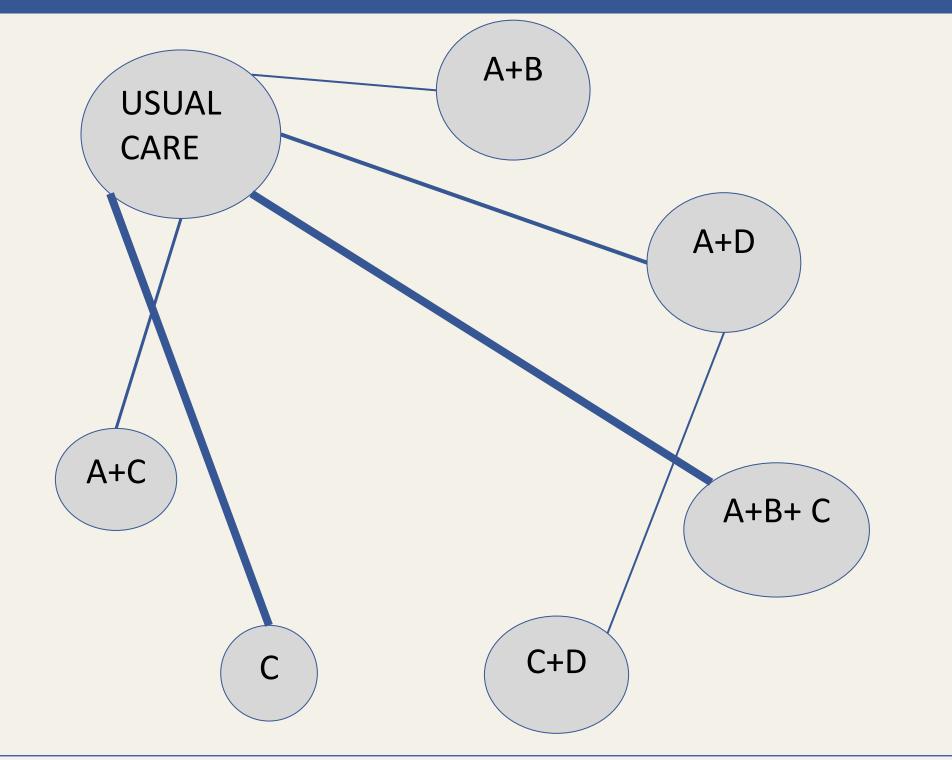
effect(A+C) = effect(A) + effect(C) + interaction(A,C)

- ➤ If interaction(A,C) > 0. They work synergically and the model has a bigger effect.
- ➤ If interaction(A,C) < 0. They work antagonistically and the model has a smaller effect.

### **CAUTION:**

The number of interaction may be large and we do not have data to inform all of them. The decision to choose the interaction terms should be based on plausible reasons and they should be defined in the protocol of the analysis.

### **Network Plot**



### **CNMA vs NMA**

To use any statistical method first we should be sure about the assumptions.

- NMA can not be applied to disconnected networks, while CNMA can be applied if the subnetwork share at least one common component.
- ➤ When are few head-to-head comparisons and most interventions are compared with Placebo/Usual care, then results are likely to be confounded with study characteristics. In CNMA the effects are informed from studies that share the same components and typically there is much more evidence.
- Transitivity assumption and the statistical equivalent consistency from NMA are difficult to test in CNMA.

### Conclusion

- New methods in NMA for testing and accounting for inconsistency, and for ranking the available treatments are constantly being developed.
- ➤ CNMA models represent a generalization of NMA models which can be utilized in disconnected networks. An example of an application of CNMA to a disconnected network is given in Pompoli et al. (2018).<sup>5</sup>
- ➤ Before use a statistical model make sure that the assumptions hold otherwise the results are biased.
- Thanks to R (programming language) both NMA and CNMA can be analyzed in 'netmeta' package.<sup>6</sup>

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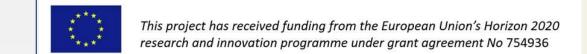
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#### **Self-Management and Related Concepts**

#### in Rare Diseases -

#### **Empowerment, Implementation, and Relevance**

#### **Background**

- Self-management of rare diseases is of the utmost importance.
   Most rare diseases lack a cure, and many lack effective treatment.
   The rarity of the disease comes with a rarity or even lack of expertise, be it clinical or in living with the disease.
- Acknowledging the importance of self-management and self-management support in this field is even rarer.
   Our project aims to boost this acknowledgement and facilitate subsequent implementation.
- This project is a spin-off of the joint guideline-development program
  of the global organisations of professionals and patients involved with
  Gaucher disease.

#### **Step 1: Thorough exploration of literature**

This project was initiated by the discussion on Gaucher disease management guidelines by the International Working Group on Gaucher Disease.

We started out by doing a thorough literature review to get ourselves well acquainted with the field. Our extensive findings are compiled into a comprehensive toolbox.

We did not find any differences between Gaucher disease self-management and self-management of rare diseases in general, so our review bears on rare diseases as a whole.

We are currently formatting our findings tentitatively into an article to be published.

#### Contents of the paper to be published

A real life scenario	2	Support programs	27
Rare diseases	2	Measurement tools	29
Definition	2	Paediatric empowerment and support	30
Challenges	3	Childhood	30
Self-management and related concepts	6	Young people	31
Self-management and self-care	6	Parents and siblings	32
Self-management - a closer look	8	Implementation	33
Identity, personality, and narrative	10	Ethics	33
Health literacy	13	Organization	34
Self-regulation, self-efficacy, and control	14	Instrumentation	36
The activated patient	15	Digital Health Interventions	37
Empowerment and support of adults	16	Data management	37
Patient empowerment	18	Knowledge management	38
Self-management support	19	Information management	38
Patient-centred care	20	Relevance	39
Partnering as experts	21	In conclusion	41
Practical and managerial empowerment	23	Appendix A – Support scheme	41
Psychological and sociological empowerme	nt 23		41
Family and friends	25	Glossary	
Peer support	26	References	42

#### Discussion

- Our project focuses on rare diseases that evolve into chronic illnesses, as most of them do. For the most part, the instrumentation of selfmanagement (support) in a specific rare disease is the same for them all. Where specific insights lack, the body of knowledge generated in more common chronic diseases can be used in rare diseases too.
- Special attention is required on dealing with the rarity of expertise, also in terms of a kind of health literacy and in partnering of patient and professional as experts. And on the autonomy of the individual or dyad living with the rare disease, as usually being the expert outside the consultation room. Each individual living with a rare disease is unique in the combination of genetic mutations, epigenetics, environmental factors, and self-management potential.
- As most patients with rare diseases are children, paediatrics and family care play an important part. Siblings and (potential) partners, having their own burden, must be included in self-management support.

#### Step 2: Gaucher disease management guideline

Based on the review of literature we developed a draft disease-specific guideline on self-management. It will be finalised as soon as the review is accepted as an article for publication.

The guideline defines and describes self-management, as well as the role and responsibility of the healthcare providers involved. It touches upon the clinical relevance of self-management.

It also brings others around the patient into view, having a burden of disease in their own way as well as their own role in self-management.

Each discussed item will include recommendations on how to support self-management. The guideline concludes with suggestions for further research.

#### **Project team**

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founder Egyptian Society of Inherited Paediatric Disorders of Thrombosis and Haemostasis (ESIPTH) and Gaucher disease group

# Exploring effectiveness of self-management interventions on quality of life on chronic diseases

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- 3. University of Toronto, Canada; 4. Université Paris Cité, France



C@MPAR-EU

### 1. Background

Self-management support may improve quality of life; however, there is large uncertainty about which type of support is the most effective to manage chronic diseases.

Network meta-analysis (NMA) is highly attractive for comparing multiple interventions, whereas Component NMA allows to disentangle components' effects, in case of multicomponent interventions.

### 2. Objectives

To explore the performance of self-management interventions (SMI) in improving the quality of life of adults living in Europe with four high-priority chronic conditions: Diabetes Type-II, Obesity, Chronic Obstructive Pulmonary Disease (COPD), Heart Failure.

### 3. Methods

We explored the effectiveness of SMIs in improving Quality of Life in patients with four chronic diseases (Diabetes, Obesity, Heart Failure, COPD). We considered four outcomes in total.

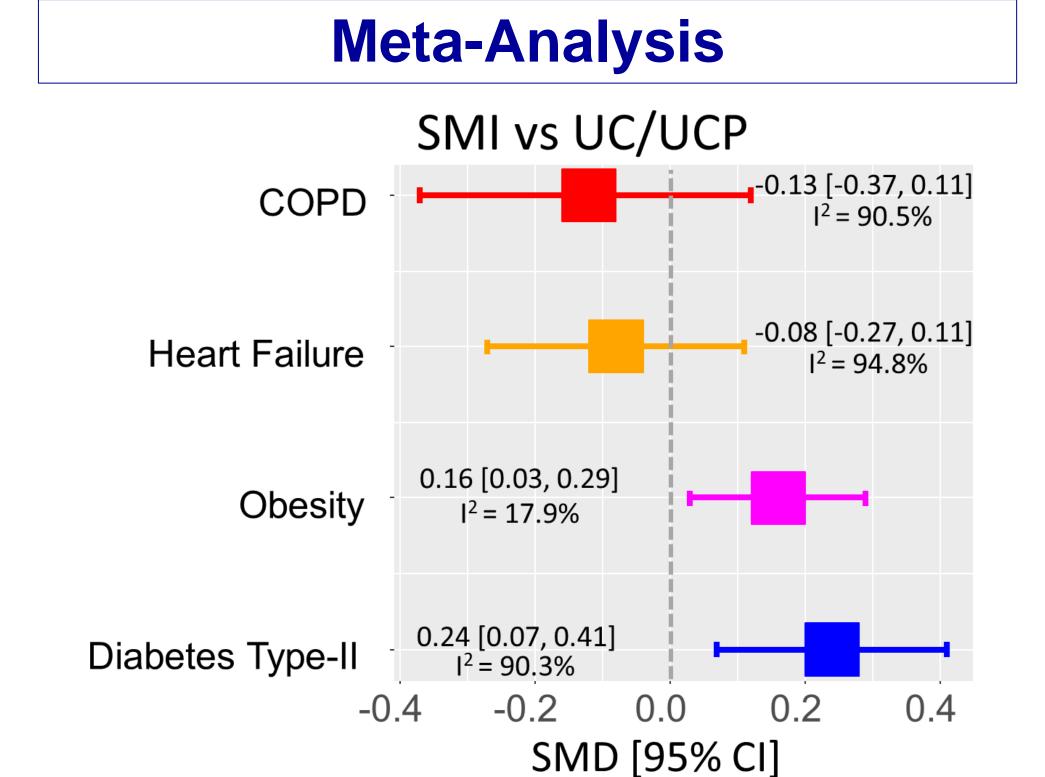
SMIs are multicomponent interventions, consisting of 11 different components. (E: Education, G: Group, EB: Emotional-based behavioural change techniques, SS: Social Support, AB: Action-based behavioural change techniques, MT: Monitoring techniques, P: Peers and lay persons, R: Remote, SD: Shared Decision Making, UC (P): Usual Care (Plus))

- Type of outcomes: Beneficial
- Effect size: Standardized mean difference (SMD) along with 95% CI
- Statistical Analysis
  - Standard pairwise meta-analysis for SMIs versus UC/UCP
  - Network meta-analysis (NMA)
  - Component Network Meta-Analysis
  - Subgroup analysis
    - Socioeconomic Status
    - Cultural/Minority background
  - Meta-regression
    - Disease severity

### • Most Efficacious interventions or components?

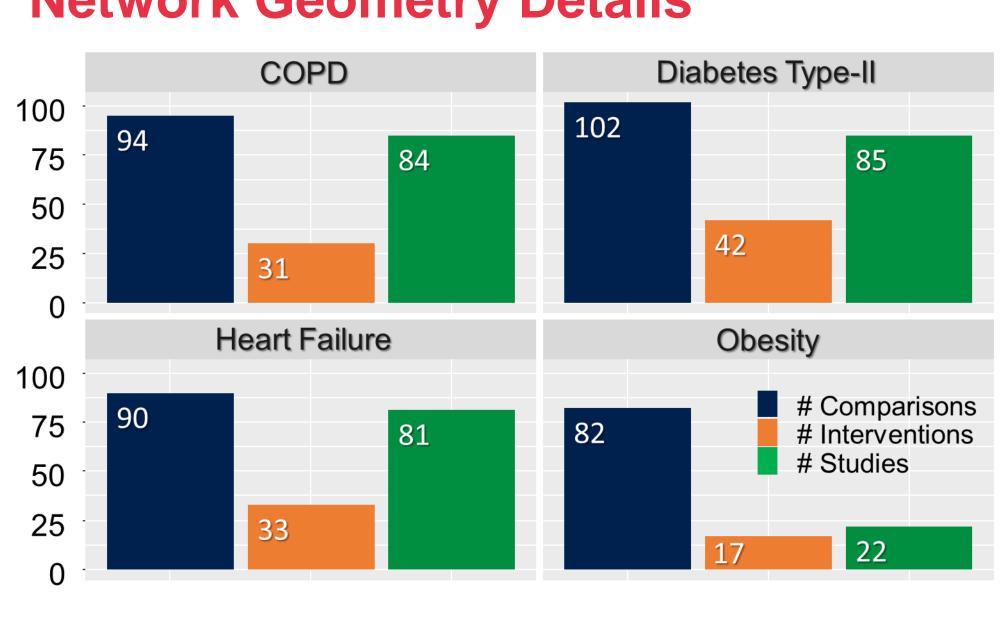
We considered NMA estimates, P-scores, confidence and prediction intervals.

### 4. Results

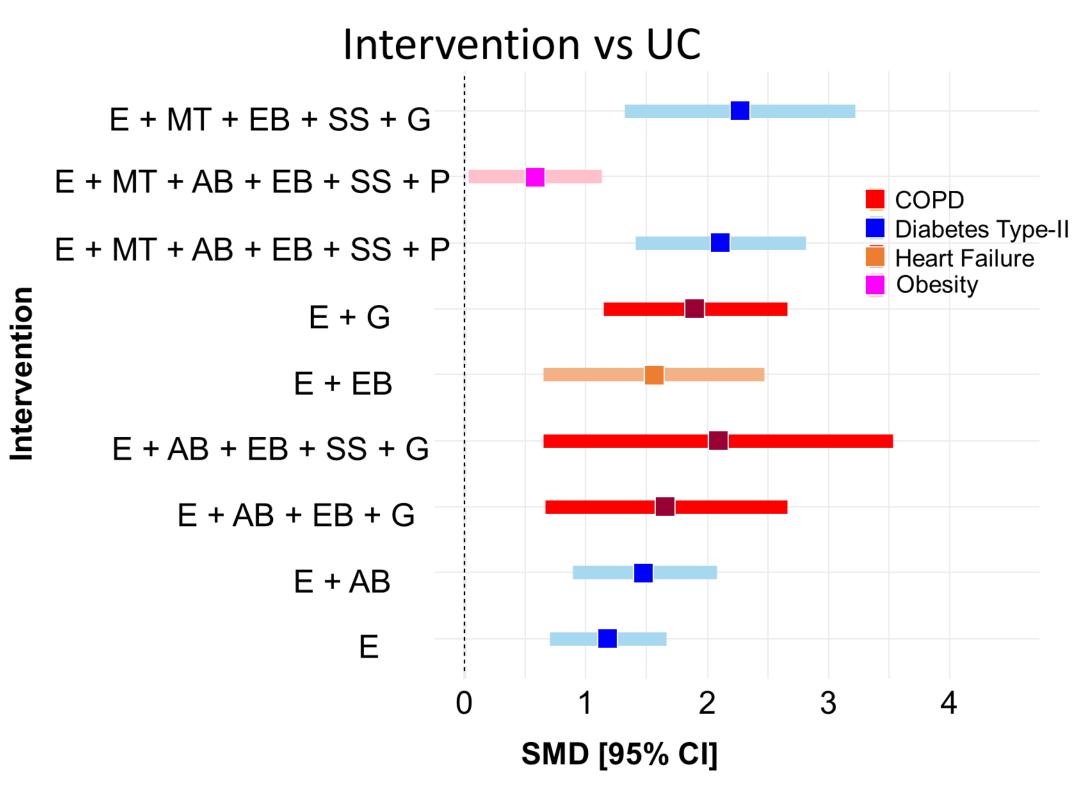


### **Network Meta-Analysis (NMA)**

### **Network Geometry Details**



### **Most Efficacious NMA Estimates**



- P-scores > 80%
- High heterogeneity
- Sparse Networks

### **Subgroup Analysis**

- SMIs worked slightly differently (P=0.02) in patients with Diabetes based on their cultural minorities:
  - Both groups seem to benefit from SMIs.
  - Stronger impact without cultural minorities.

### **Meta-regression**

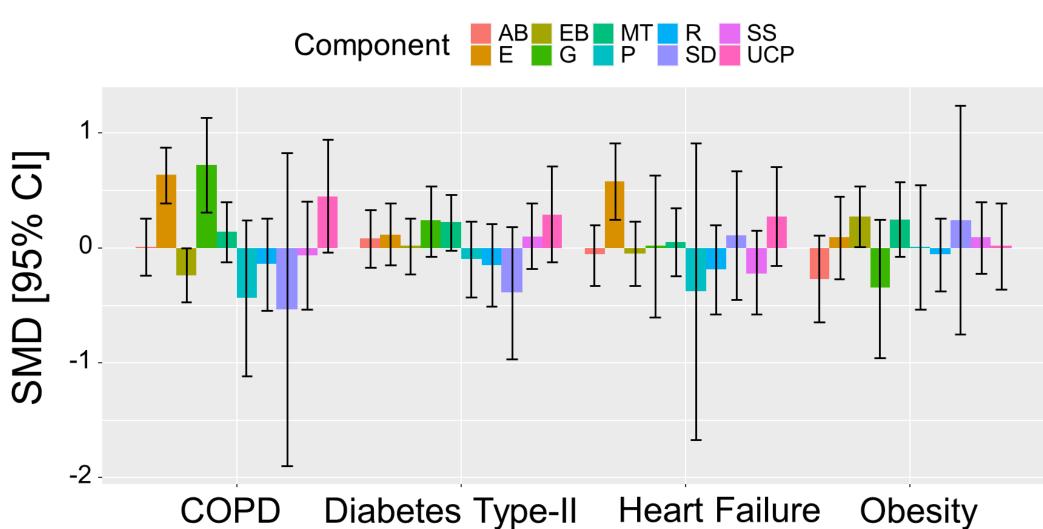
Disease	Coefficient
COPD	0.00 [-0.01, 0.01]
Diabetes Type-II	0.00 [-0.02, 0.01]
Heart Failure	1.83 [1.30, 2.35]
Obesity	0.00 [-0.04, 0.05]

### 4. Results

### **Component NMA**

### **Most Efficacious Components**

- COPD
  - o E: 0.63 [0.39, 0.87]
  - o G: 0.72 [0.31, 1.13]
- Heart Failure
  - o E: 0.58 [0.25, 0.91]
- Obesity
  - o EB: 0.27 [0.01, 0.54]



### 5. Discussion

- Most NMA intervention effects were surrounded with much uncertainty.
- According to CNMA, for people with COPD and Heart Failure, education component significantly improves their quality of life.
- The majority of trials are at high or medium risk of bias.
- All analyses revealed considerable heterogeneity.

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