

Scoping review of systematic reviews of how patients living with chronic conditions value the importance of outcomes



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Background

Methods to review patients’ values and preferences (VPP) evidence are challenging and resource intensive. As part of **COMPAR-EU**, a European project that aims to rank the most cost effective self-management interventions (SMI) for four chronic conditions (Chronic Obstructive Pulmonary Disease (COPD), Type 2 diabetes mellitus (Type 2 DM), Heart failure (HF) and Obesity), we systematically reviewed the related scientific literature about VPP. This information was used to inform the development of the corresponding Core Outcome Sets (COS) for these conditions.

Objective

To identify and evaluate values and preferences of patients living with any of these four chronic conditions in the context of self-management interventions.

Results

Search retrieved 6,067 results without duplicates, we selected 362 references for full text appraisal, and finally included 109 studies for synthesis (Fig. 1).

1. Scoping review evidence

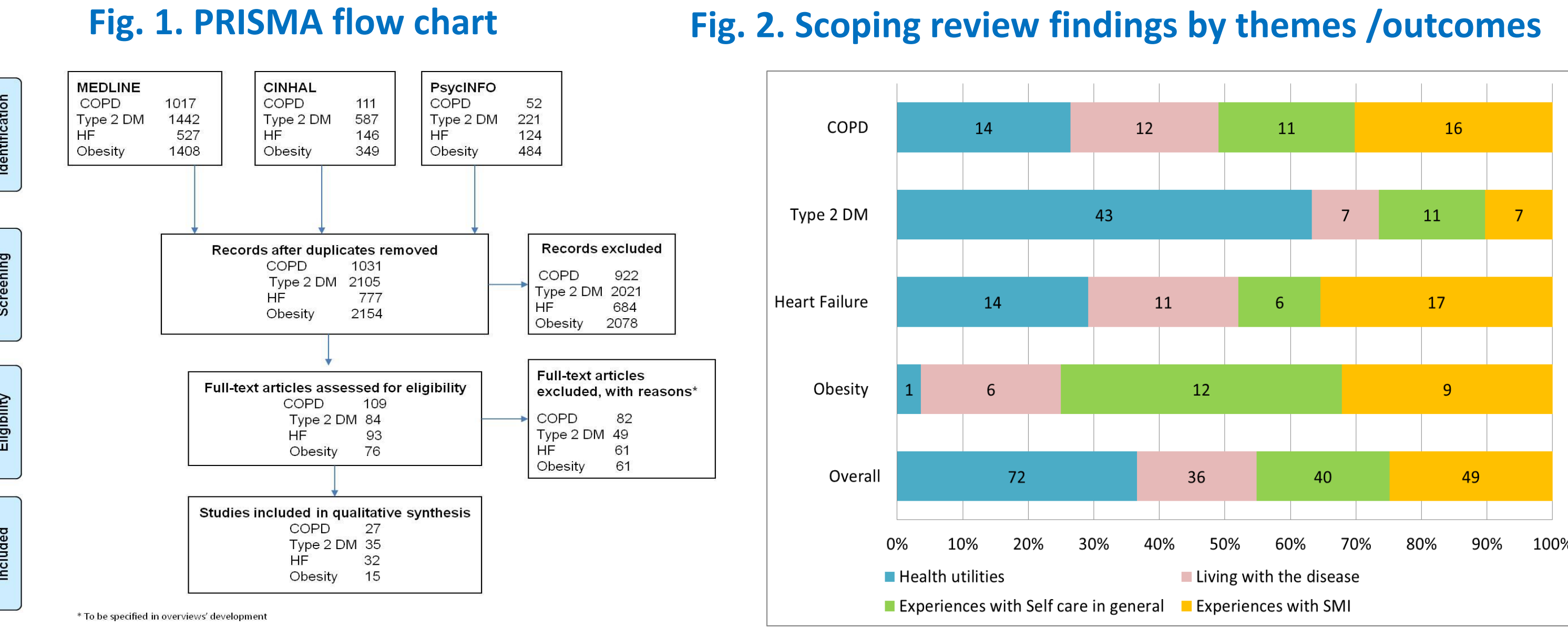
We identified 197 outcomes (resulting themes) among the four conditions (Fig. 2):

1.1 Utilities SRs

Over 17 SRs, we identified 72 outcomes. Type 2 DM 60%(43), while Obesity only one: *weight change*. Most related to complications. We found important heterogeneity in values for same outcomes.

1.2 Qualitative reviews

- **Living with the disease:** Over 33 QRs, we identified 36 themes. More themes for COPD (12), and Heart failure (11).Most were referred to *Burden of symptoms*, and *Perceptions of health care services*.
- **Experiences with self-care:** Over 41 QRs, we identified 40 themes. More studies for Type 2 DM (15) and more themes for Obesity (12).Themes with more representativeness were *Knowledge*, *Psychological distress*, and *Self-care adherence*.
- **Experiences with SMI:** Over 24 QRs, we identified 49 themes. More themes for Heart failure (17), and COPD (16). Theme with more representativeness was *Personal beliefs*.



2. Matching of results with the outcomes identified in RCTs (Table 1).

Overall, our scoping review provided evidence for 53% (169) of the outcomes from RCTs. The condition with fewer outcomes covered by the scoping review was Obesity (35%). We identified nine additional outcomes, all related to clinical complications. No evidence was found for three subcategories of *Health care use*, and *Costs* categories.

Discussion

This scoping review of VPPs-SRs allowed us to summarize the main findings of patients living with any of these four conditions in the context of SMI. It also allowed us to identify areas where de novo SRs might be need. In line with methods purposed by Arksey and O’Malley (2005) we did not perform the quality appraisal of SRs. We will develop individual overviews for each condition, these will include the quality appraisal of SRs, and the final results of the thematic synthesis. Finally, we will integrate all these findings in the context of the **COMPAR-EU** project.

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Methods

We conducted a scoping review of systematic reviews (SRs). We searched for SRs in Medline, CINHAl and PsycINFO from inception to February 2018. We included SRs of health utilities, and qualitative research (QRs) of perceptions and experiences regarding living with the disease, or being involved in SMI. We included reviews with a search strategy performed in at least one data base. We did not examine grey literature.

We performed screening, selection and extraction processes by pairs. For QRs we adopted a thematic synthesis approach: two reviewers coded the main findings, translated codes into descriptive themes, and organized them into mayor themes. For health utilities SRs, we grouped them by clinical outcomes. We did not analyse the individual studies included in the SRs.

Selection of COS comprised a three round Delphi process, patients were asked to prioritize between outcomes derived randomized controlled trials (RCTs) of SMIs (identified in previous project: PROSTEP). For the final round, we provided a summary of VPP evidence for the matching outcomes.

Per condition:

- **COPD:** we found evidence for 56% (44) of outcomes, the majority being from the *Patient’ competences in Self-management behaviours* (75%) and, *Health related* (67%) categories. In the latter we provided seven additional outcomes related to complications. No relevant evidence for the Costs category.
- **Type 2DM:** we found evidence for 62% (53) of outcomes, the majority being from the *Satisfaction with/ perception of care* (100%) and *Patient’ competences in Self-management behaviours* (85%) categories. No relevant evidence for *Caregivers quality of life / competences* category.
- **HF:** we found evidence for 59% (43) of outcomes, the majority being from the *Caregivers quality of life/ competences*, and *Satisfaction with / perception of care* categories (both 100%). We provided two additional outcomes related to complications. No relevant evidence for the *Costs* category.
- **Obesity:** we found evidence for 35% (29) of outcomes, the majority being from *Satisfaction with /Perception of care* (100%) category. More relevant evidence for the Costs category (50%).

We designed four infographics to present results to the panel. These were available for patients and physicians attending to the final round of the Delphi consensus process, where participants and moderators consulted them at their discretion.

Table 1. Outcomes from RCTs of SMI matched with VPP evidence

Categories and Subcategories	COPD			TYPE 2 DM			HF			OBESITY			Overall		
	VPP (n)	RCT (n)	%	VPP (n)	RCT (n)	%	VPP (n)	RCT (n)	%	VPP (n)	RCT (n)	%	VPP (n)	RCT (n)	%
1. Patient’s competences in SM behaviours	9	12	75%	11	13	85%	9	14	64%	9	18	50%	38	57	67%
1.1 SM competences	5	5	100%	5	5	100%	5	5	100%	4	5	80%	19	20	95%
1.2 SM /self-care behaviours	4	7	57%	6	8	75%	4	9	44%	5	13	38%	19	37	51%
2. Health related	14	21	67%	20	27	74%	11	15	73%	4	24	17%	49	87	56%
2.1 Disease management	4	12	33%	3	10	30%	4	9	44%	3	18	17%	14	49	29%
2.2 Seriousness of the disease	0	6	0%	NA	NA	-	2	2	100%	0	3	0%	2	11	18%
2.3 Complications	9	2	450%	16	16	100%	4	2	200%	0	2	0%	29	22	132%
2.4 Mortality	1	1	100%	1	1	100%	1	2	50%	1	1	100%	4	5	80%
3. Quality of life	12	21	57%	11	23	48%	13	20	65%	6	17	35%	42	81	52%
3.1 Physical functioning	2	7	29%	0	8	0%	4	7	57%	0	7	0%	6	29	21%
3.2 Treatment burden	0	2	0%	3	5	60%	0	1	0%	NA	NA	-	3	8	38%
3.3 Psychological functioning	7	9	78%	5	7	71%	6	9	67%	5	7	71%	23	32	72%
3.4 Social relations and activities	3	3	100%	3	3	100%	3	3	100%	1	3	33%	10	12	83%
4. Caregivers’ quality of life /competences	3	5	60%	0	5	0%	5	5	100%	0	5	0%	8	20	40%
5. Satisfaction with/ perception of care	3	5	60%	5	5	100%	4	4	100%	5	5	100%	17	19	89%
6. Health care use	3	9	33%	5	9	56%	1	10	10%	3	9	33%	12	37	32%
6.1 Visits or contacts with health care	3	6	50%	5	5	100%	1	5	20%	3	5	60%	12	21	57%
6.2 Emergency department visits	0	1	0%	0	1	0%	0	1	0%	0	1	0%	0	4	0%
6.3 Hospital admissions and length of stay	0	2	0%	0	3	0%	0	4	0%	0	3	0%	0	12	0%
7. Costs	0	5	0%	1	4	25%	0	5	0%	2	4	50%	3	18	17%
7.1 Cost for the healthcare system	0	3	0%	0	2	0%	0	3	0%	0	2	0%	0	10	0%
7.2 Cost for patient	0	1	0%	1	1	100%	0	1	0%	1	1	100%	2	4	50%
7.3 Cost effectiveness	0	1	0%	0	1	0%	0	1	0%	1	1	100%	1	4	25%
Total	44	78	56%	53	86	62%	43	73	59%	29	82	35%	169	319	53%

VPP, outcomes with values and preferences evidence; RCT, outcomes identified in Randomized controlled trials of self-management interventions; NA, not applicable; COPD, Chronic Obstructive Pulmonary disease; Type 2 DM; Type 2 Diabetes Mellitus; HF, Heart failure. Colors legend: green: 100% or more, yellow: between 50% and 99%, red: less than 50%

Conclusions

- Scoping reviews of SRs about values and preferences may provide relevant information for the development of COS.
- These findings may be of use for the development and implementation of recommendations. The utilities findings may be a source of data for cost-utility analysis.

References

Arksey, H., & O’Malley, L. (2005). Scoping studies: Towards a methodological framework. International Journal of Social Research Methodology, 8(19), e32

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