

ARE WE RESEARCHING IN THE AREAS THAT MATTER FOR PATIENTS?

DEVELOPING CORE OUTCOME SETS FOR SELF-MANAGEMENT INTERVENTIONS IN CHRONIC DISEASES.

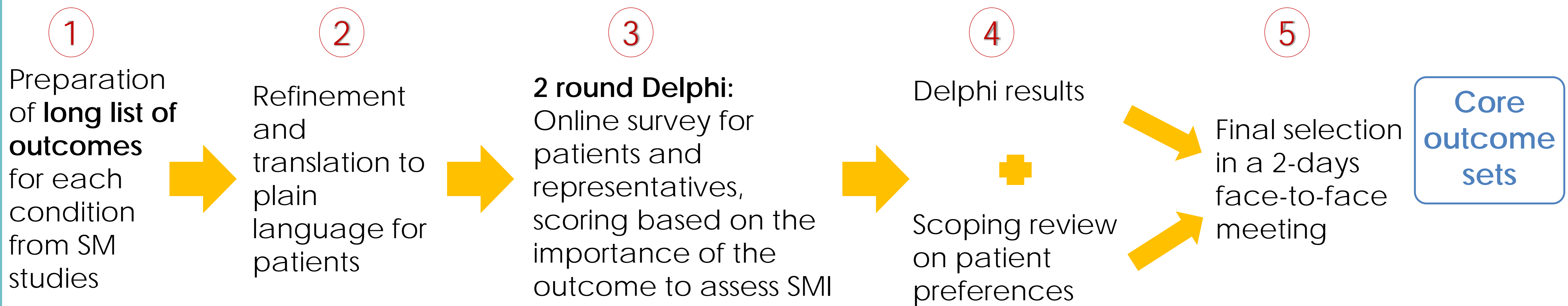
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Objectives:

To develop a core outcome sets (COS) for measuring the efficacy of self-management among adults living with diabetes, obesity, heart failure or COPD, based on patient preferences and including the views of healthcare professionals (clinicians, nurses and other health workers), researchers and civil society representatives.

Methods:



Results:

Delphi participation

39 Patients and patients representatives

9 COPD	9 HF
11 T2DM	9 Obesity

Face to face meeting participation

39 Participants

19 Patients and representatives
20 Healthcare professionals

Core Outcome Sets (COS) per DISEASE

COPD	Heart Failure	T2DM	Obesity
Patient activation	Patient activation	Participation and decisions making	Self-efficacy
Self-efficacy	Self-efficacy	Self-management competences	Participation and decisions making
Participation and decisions making	Knowledge	Self-management behaviours	Patient activation
Self-monitoring	Health literacy	Long-term complications	Adherence to programme
Smoking Cessation	Participation and decisions making	HbA1C	Self-monitoring (Including self-recording)
Taking medication or other treatment as advised (adherence) and adherence to regular visits	Self-monitoring	Hyperglycemia	Healthy nutrition habits/personalized nutrition
COPD symptoms (short term)	Taking medication or other treatment as agreed (adherence)	Hypoglycaemia event	Quality of life-Physical and psychological functioning
Sleep quality	Body Weight (Management)	Weight (management)	Coping with the disease
Exacerbation	Breathlessness (Dyspnoea)	Life expectancy	Social interactions
Physical activity - muscle strength	Mortality	Quality of life	Integration at work
Coping with the disease, including depression and anxiety	Effort test/Exercise capacity	Experience of care	Physical Activity
Activities of daily living: including sex life, social activities and work (usual activities)	Quality of life (including sex life, normality, depression, positive attitude, social activities and friends, being able to do usual activities and QALY)	Scheduled care	Weight management
Caregiver knowledge and competence	Physical Activities	Unscheduled care	Cormorbidities management
Caregiver quality of life (including burden)	Perception of health care professional relationship and communication		Patient-healthcare provider relationship
Number of emergency room visits and admissions	Number of hospital admissions		Cost-effectiveness for the health system- value based outcomes
Cost effectiveness and resources use	Value for money of the self-management intervention		

Conclusions:

- The development of COMPAR-EU COS for LTCs (COPD, HF, T2DM and Obesity) could help to homogenize research efforts.
- This can lead to the improvement of the outcomes of data syntheses and increase the value of self-management research
- it could contribute to better clinical decisions, understanding of patient's priorities, and support patients' self-management.
- It could also guide decision-making in policy since the outcome measures show what is of crucial importance to realise patient centred care.

