

# Integrating Digital Health Care – How Can Patient Reported Outcomes Data Link Up?

# Conflict of Interest

- Judit Simon: No conflict of interest.

# ‘Fitness for purpose’ in the realm of PROs: The PECUNIA PROM-MH Compendium

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# Introduction to the topic

- H2020 **PECUNIA** (ProgrammE in Costing, resource use measurement and outcome valuation for Use in multisectoral National and International health economic evaluAtions)
- 2018-2021
- **MMM EE**: multisectoral, multinational, multiperson economic evaluation
- One of the aims (*Laszewska et al. Evid Based Ment Health, 2022*) :
  - **Improve comparable outcome assessment** in (mental) health economic evaluations
  - **Systematically collate and synthesise** existing, publicly available **PROM** information suitable for **QoL/well-being** measurement in **mental health research**
  - Specific focus on **applicability in MMM EEs**
  - **Non-disease specific**

# Methods

- SLR (PROSPERO CRD42018117800)
- PRISMA guidelines
- Database searches: Embase, Medline, PsycINFO, SSCI, CINAHL (2008-2020)
- Further searches: References of existing reviews (n=21, e.g. COSMIN) and PROM databases (n=7)
- No language restrictions
- Inclusion: MH study, standardised PROM, QoL/well-being oriented PROM, non-diseases specific PROM, insuff. info (e.g. abstract)

# Assessment

- Secondary searches on identified PROMs for comprehensive meta-data: Google (Scholar/Books), PubMed, manuals, instrument websites
- Extracted information: 47 meta-data categories including basic characteristics, scoring information, validation studies, applicability in MMM EEs, etc.

**Table 1** Assessment criteria applied to the identified PROMs

Assessment category	Assessment criteria
Multiperson	(i) Availability of separate adult and child/adolescents versions (ii) Availability of a proxy-completion option
Multisectoral	(iii) Feasibility of assessing outcomes beyond a person's individual health, that is, capabilities, social outcomes
Multinational	(iv) Availability of multiple translations (two or more language versions of the instrument)
Economic evaluation	(v) Availability of a preference-based value set (vi) Availability of preference-based value sets in more than one country

PROM, patient-reported outcome measure.

# Results

- 204 unique instruments identified

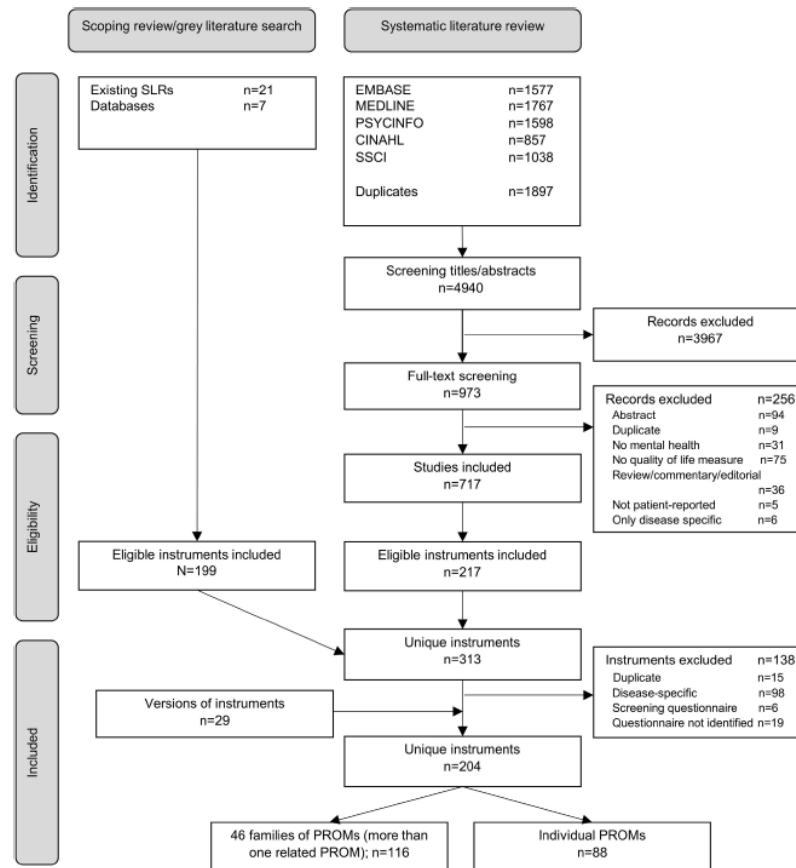


Table 2 Summary characteristics of individual PROMs

Characteristics of individual PROMs (n=204)	N	%
Target age group*		
Children or adolescents	52	26
Adults or older adults	152	74
Type of measure		
Generic	165	81
Designed for mental health	39	19
Main category of outcome measurement		
QOL/Well-being	190	93
Recovery-specific	14	7
Year of development		
1960s	1	0
1970s	4	2
1980s	16	8
1990s	73	36
2000s	70	34
2010s	40	20
Region of development		
North America	88	43
Asia	6	3
Europe	91	45
Australia	8	4
South America	1	0
International	10	5
Characteristics of individual PROMs or PROM families relevant for MS, MN and MP EEs (n=134)		
MP: availability of separate adult and child/adolescents versions	16	12
MP: availability of a proxy-completion option	27	20
MS: feasibility of assessing outcomes beyond health, that is, capabilities or caregiver, family or social care outcomes	11	8
MN: availability of multiple translations (two or more language versions of the instrument)	97	72
EE: availability of a value set	15	11
MN: availability of value set in more than one country	9	7





# Lessons learned

- **Ample options** of standardised, validated PROMs, but...
- **None** of the existing PROMs **fulfilled** all six proposed criteria for **MMM**
- Increasing use of PROMs measuring **capability well-being** (e.g. ICECAP, OxCAP-MH) due to their fitness for measuring broader aspects than HRQoL (see also *Helter et al. Qual Life Res, 2020*)
- Did not cover **non-standardized PROMs** often found as part of digital tools
- **Digitalization** of standardized tools:
  - importance of **preserving integrity**
  - **context specific**
  - difficulty of monitoring without **licensing process**
- Next steps:
  - **Up-to-date meta-information** is key to optimised PROM selection
  - **Sustainability** (potential future collaboration with Oxford University Innovation)


# Disclosure and references

- Funding: European Union's H2020 RIA grant agreement no. 779292
- References:

**Systematic review**

 **OPEN ACCESS**


Patient-reported outcome measures suitable for quality of life/well-being assessment in multisectoral, multinational and multiperson mental health economic evaluations

Agata Łaszewska, Timea Mariann Helter , Anna Nagel, Nataša Perić, Judit Simon 

Evid Based Mental Health: first publi

Quality of Life Research (2020) 29:1433–1464  
<https://doi.org/10.1007/s11136-019-02393-5>

**REVIEW**

 Check for updates

**Capability instruments in economic evaluations of health-related interventions: a comparative review of the literature**

Timea Mariann Helter<sup>1</sup>  · Joanna Coast<sup>2</sup> · Agata Łaszewska<sup>1</sup> · Tanja Stamm<sup>3</sup> · Judit Simon<sup>1,4</sup>