

One for all, all for one

– Reaching for consensus on choosing one generic PROM for all National Clinical Quality Registers in Finland

Background

Quality registers are used for systematically monitoring and improving the quality and effectiveness of social and health care services and care in different patient groups. National quality registers produce comparable data from all operators in an interoperable manner. The quality registers were subjected under THL's controller liability from the beginning of 2023. In the first phase there are nine National Clinical Quality Registers (NCQRs) in Finland:

- Cardiac Register
- Diabetes Register
- HIV Register
- Intensive Care register
- Oral and Dental Care Register
- Register for Kidney Diseases
- Rheumatology Register
- Psychosis Care Register
- Spine Register

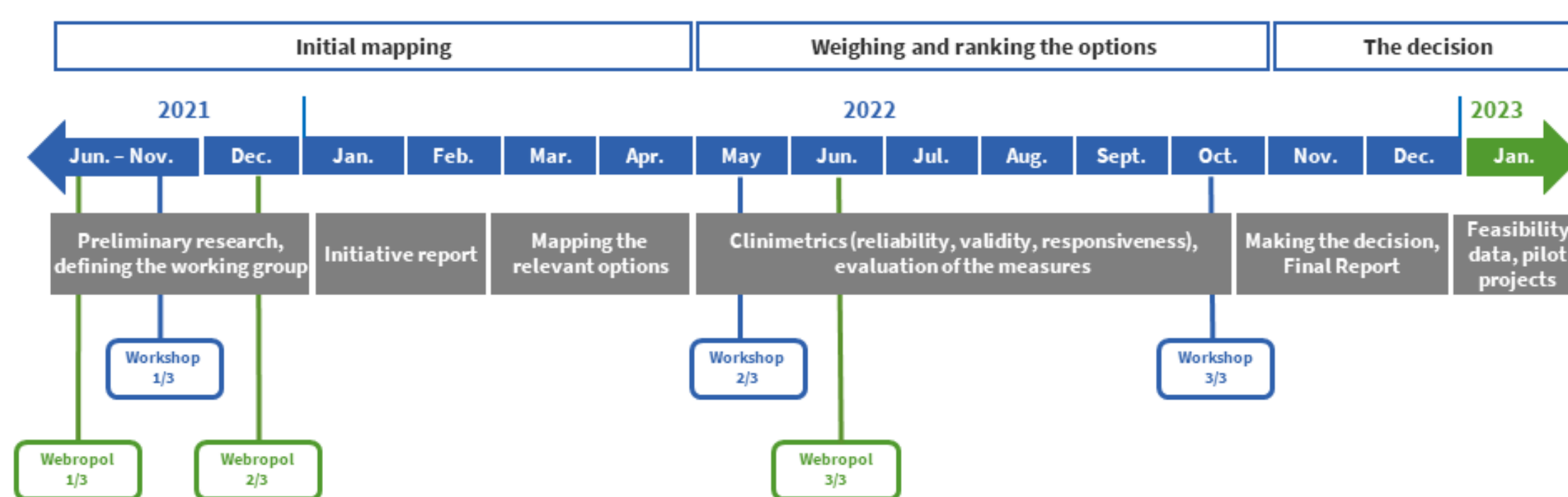
Goal of the study

To reach consensus on choosing one generic PROM (Patient Reported Outcome Measure) for all NCQRs in Finland.

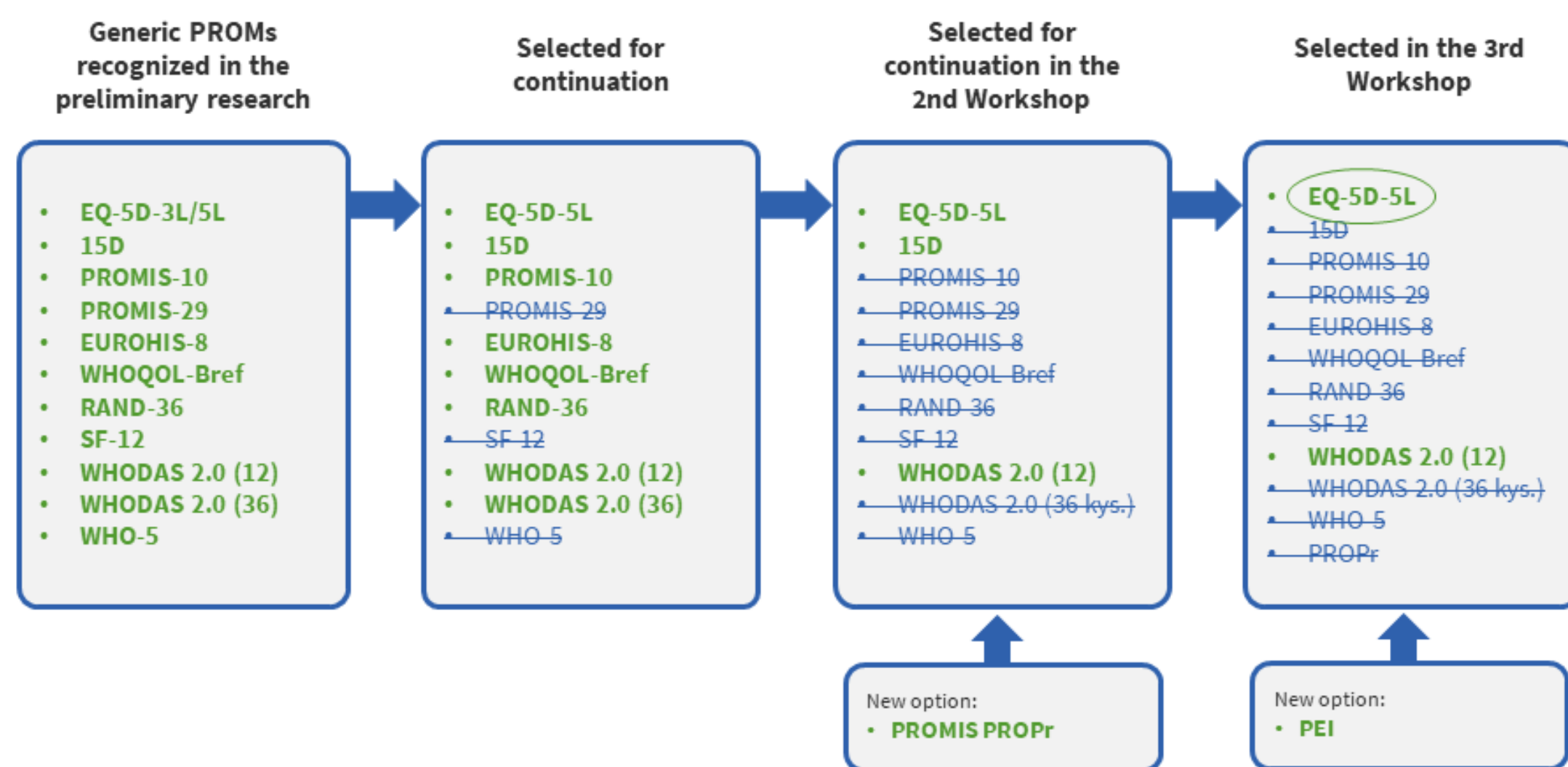
Why one generic PROM?

- For evaluating the quality and effectiveness of social and health care, between different disease groups
- For Knowledge-based management and co-developing
- To strengthen customer participation
- To support clinical work, for treatment planning
- To reduce the questionnaire burden of co-morbid patients

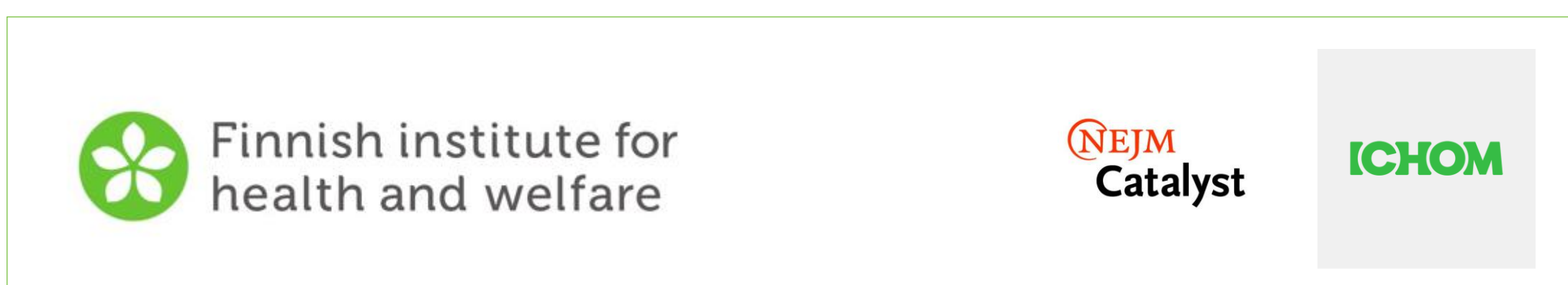
The process step by step



Mapping the options



Abbreviations:
EQ-5D-5L: EuroQol 5-Dimension Health-related Quality of Life Instrument
WHODAS: World Health Organization Disability Assessment Schedule
PEI: The Patient Enablement Instrument



References

Thl.fi/laaturekisterit

The process

A Modified Delphi process was used as the method. Various professionals were involved in the process. In addition to THL's quality register employees and PROM experts, the responsible persons of all NCQR's and each register's PROM experts participated in the work. In addition, a survey for a wider group of health care professionals and decision makers was conducted.

Results

Three measures were chosen; EQ-5D-5L as a main measure, PEI to be used especially in primary health care and WHODAS as a supplemental measure. During a transition period of 2-3 years, User Experiences with the selected PROMs will be collected. After the transition period, a decision on possible mandatory data collection will be made.

The factors which influenced the decision

- EQ-5D-5L: Internationality, Compactness, QALY-calculations
- PEI: Promising user experiences within primary health care, Compactness
- WHODAS: Internationality, ICD-11-linkage, perspective on how patient copes in everyday life, no licensing fee

Discussion

In order to reach a consensus to choose one generic PROM is a challenging task. The PROM to be chosen is also subject to a lot of conflicting interests. Despite this, decision has to be made so that steps towards to a common, jointly chosen measure can be reached.