

¹Amsterdam UMC, Vrije Universiteit Amsterdam, Department of Epidemiology and Biostatistics, Amsterdam Public Health Research Institute, Amsterdam, the Netherlands
²Dutch-Flemish PROMIS National Center (www.dutchflemishpromis.nl)
³PROMIS Health Organization (www.promishealth.com)
⁴Linnean Initiative (https://linnean.nl/)
⁵Amsterdam Rehabilitation Research Center | Reade, Amsterdam, the Netherlands
⁶National Health Care Institute, the Netherlands
⁷Medical Spectrum Twente, University of Twente, Enschede, the Netherlands
⁸Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, US

Common patient-reported outcomes across ICHOM Standard Sets – the value of PROMIS

CONTEXT

This work was done as part of a project of the Linnean initiative, a Dutch network of stakeholders from healthcare, academia, and government that aims to accelerate outcome-based health-care. The working group “PROMs & PREMS” develops guidance for the use of generic Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs) across patient populations in the Netherlands.

BACKGROUND AND AIM

Across ICHOM Standard Sets there are huge differences in selected PROs and in terminology, definitions, and recommended PROMs for the same PROs. This measurement disparity is not sustainable in the typical health system. Much preferred would be common data elements across diseases wherever possible. We aimed to identify shared PROs across ICHOM Sets and examine to what extent these PROs can be measured with one generic measurement system, called the Patient-Reported Outcomes Measurement Information System (PROMIS®).

WHAT WAS DONE?

We extracted all PROs (n=87) from all currently available ICHOM sets (n=24) and categorized them according to the categories of the PROMIS domain framework (Figure 1). We found considerable overlap in relevant PROs included in ICHOM Standard Sets. Most PROs included in ICHOM Standard Sets are included in the PROMIS domain framework and can be measured with PROMIS instruments (Figure 2).

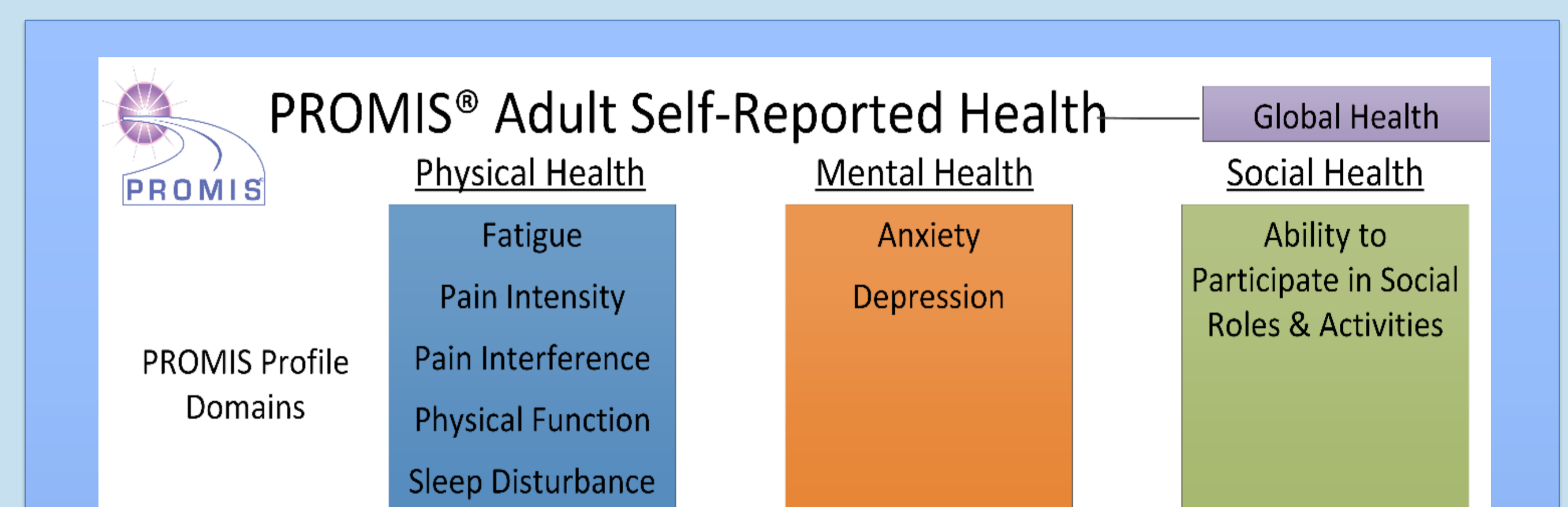


Figure 1: PROMIS Profile Domains (adult version)

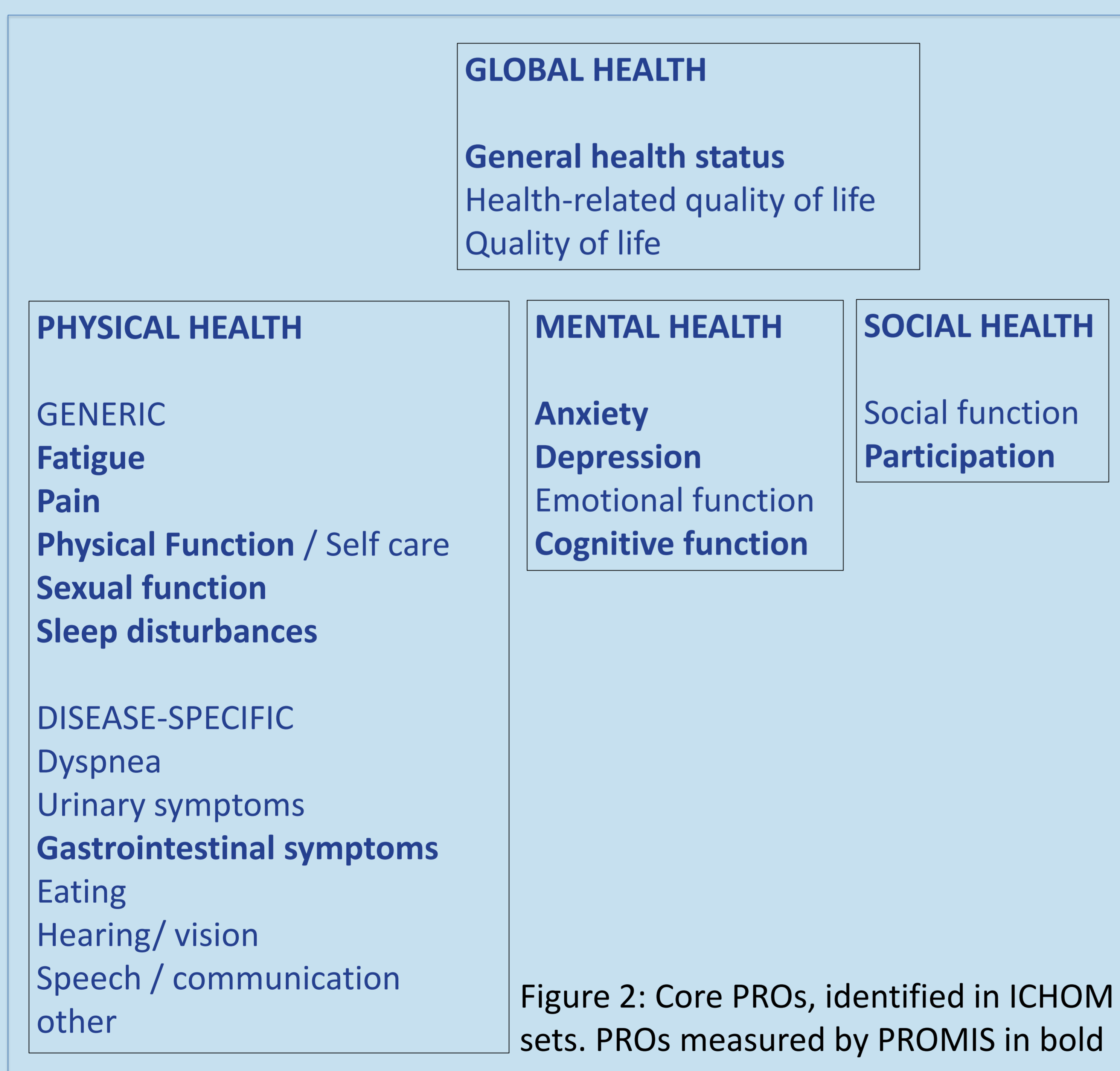


Figure 2: Core PROs, identified in ICHOM sets. PROs measured by PROMIS in bold

WHAT IS PROMIS?

PROMIS® is a measurement system that uses modern psychometric methods (Item Response Theory) to create item banks (PROMs) to measure commonly relevant PROs. Item banks allow different (sub)sets of items to be completed by different (patient) populations, while obtaining comparable scores. PROMIS items can be administered as fixed Short Forms or through Computerized Adaptive Testing (CAT), which yields highly reliable scores whilst using fewer items and thus lowering patient burden. PROMIS measures can facilitate comparisons between patient groups with different conditions and can also be applied in patients with multiple conditions. The universal applicability and possibilities of using and combining Short Forms and CATs makes PROMIS measures highly suitable for use in clinical practice across patients populations.

www.healthmeasures.net/promis
www.dutchflemishpromis.nl

RECOMMENDATIONS AND CONCLUSIONS

When developing new ICHOM standard sets, we recommend the PROMIS Domain Framework (especially the Profile Domains) as a starting set for selecting relevant PROs. If one or more PROs from this framework are considered relevant for a specific ICHOM Standard Set, we recommend considering PROMIS measures (Short Forms or CAT) to measure these PROs. Taking PROMIS as a starting point in the process of Standard Set development would make Standard Set development much more efficient, would create consistency across Standard Sets and decrease burden for clinicians and patients using PROMs. This frames a vision for ICHOM v 2.0 Standard Sets.