

# PROMs need PRIMs: Standardised outcome measures lack the preference-sensitivity needed in person-centred care

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**Abstract.** A growing number of condition-specific standard outcome sets have been developed by the International Consortium for Health Outcomes Measurement in pursuit of ‘value-based care’. These sets embrace many Patient-Reported Outcome Measures (PROMs), reflecting a simultaneous commitment to ‘patient-centred care’. However, none of these sets embody recognition of the preference-sensitive nature of the decisions that eventually generate the outcome database. ‘Patient-Reported Importance Measures’ (PRIMs) are the valid source of the required preferences. The ICHOM Stroke standard set is input into a hypothetical Multi-Criteria Decision Analysis-based decision support tool to provide simple confirmation that PROMs should be preference-mix adjusted as well as case-mix adjusted. PROMs need PRIMs if value-based care is to be personalised values-based care.

**Keywords:** Patient Reported Outcome Measures, value-based care, preference-sensitive decisions, Multi-Criteria Decision Analysis

## Introduction

Most of the development and use of Patient-Reported Outcome Measures (PROMs), has been, and still is, occurring without adequate debate about the conceptualisation of the latent (unobservable) constructs being measured. Efforts to improve patient-centred care by the systematic collection and dissemination of standardised data on the multiple outcomes that matter to patients are to be applauded. However, it is qualified applause, because the failure to acknowledge and highlight the preference-sensitivity of most decisions in healthcare will severely limit the benefits from all this activity, for two main reasons. First, the ambition to develop ‘benchmarking’ and ‘gold standard metrics’, even global/international ones, denies the existence of inter-cultural, intra-national and international heterogeneity in outcome preferences. While case-mix is addressed as a serious concern, preference-mix is ignored. Second, there is no recognition that the vast and increased amount of ‘standardised’ data being collected as a result of these initiatives, imposes - absent decision support - an almost impossible information-processing burden

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on the clinician and patient attempting to engage in person-centred shared decision making in the presence of heterogeneity in the preferences of patients in relation to the multiple considerations involved in many healthcare decisions.

The mission of the International Consortium for Health Outcomes Measurement (<http://www.ichom.org>) is ‘to unlock the potential of value-based healthcare by defining global Standard Sets of outcome measures that matter most to patients, and driving adoption and reporting of these measures worldwide to create better value for all stakeholders.’ ICHOM founder Michael Porter sees it as the vehicle to end the definition of ‘quality’ in healthcare as compliance with evidence-based practice guidelines, re-defining it as improvement in patient-relevant outcomes. ‘That means committing to measuring a minimum sufficient set of outcomes for every major medical condition - with well-defined methods for their collection and risk adjustment - and then standardizing those sets nationally and globally.’ [1] (p504-5).

ICHOM draws on the US National Institutes of Health (NIH) Patient-Reported Outcomes Measurement Information System (PROMIS®) initiative, which has used state of the art psychometric and statistical techniques to create a universal PROMs language, with potential application across the whole spectrum of health conditions, languages, and geographic location. The scores of each health domain or a standardized profile of multiple domains are all scored on a common metric scale [2]. PROMIS operates under the aegis of the PROMIS Health Organisation (PHO), with an associated user community (<http://www.promishealth.com>). Its announced long-term aspirations include ‘developing PROMIS into a gold-standard outcome metric’ and making it ‘part of routine clinical practice across multiple specialties’.

Twenty-seven Standard Sets are now available from ICHOM, with nine in production. To avoid misrepresentation it is important to quote the specific aim of ICHOM as being to

... ensure collection of comparable data for global benchmarking and learning. Each Standard Set focuses on patient-centered results, and provides an internationally-agreed upon method for measuring each of these outcomes. We do this because we believe that standardized outcomes measurement will open up new possibilities to compare performance globally, allow clinicians to learn from each other, and rapidly improve the care we provide our patients. Our Standard Sets include initial conditions and risk factors to enable *meaningful case-mix adjustment globally*, ensuring that comparisons of outcomes will take into account the differences in patient populations across not just providers, but also countries and regions ... Our aim is to make Standard Sets freely accessible to healthcare institutions worldwide to begin measuring, and ultimately benchmark the outcomes they achieve. [<https://www.ichom.org/standard-sets/#standard-sets>]. (italics supplied)

The aim here is to establish that PROMs need to be *preference-mix* adjusted as well as *case-mix* adjusted if they are to facilitate more person-centred care.

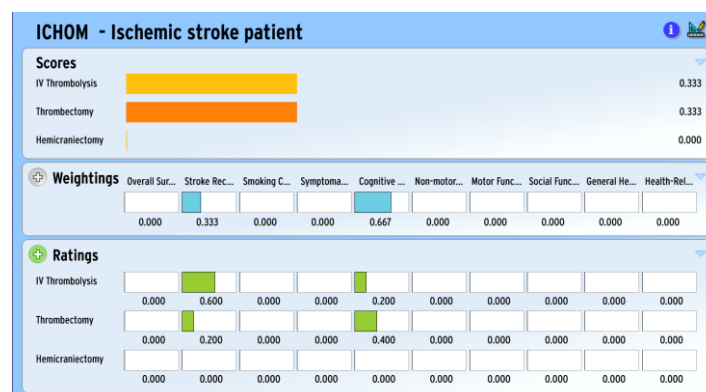
## Method

To establish why the current efforts of ICHOM (and PROMIS) can only be given qualified applause, we take the case of Stroke and input the components into a largely blank Multi-Criteria Decision Analysis (MCDA)-based decision support tool. In this way we can (i) establish the methodological problem of developing ‘benchmarks’ relevant to the *values/preference*-based care that is a condition of *value*-based care; (ii) demonstrate the magnitude of the decision burden placed on the clinical dyad by an expanded database containing a wide range of diverse and often overlapping outcome measures; but nevertheless (iii) provide both clinician and patient with an indication of the type of support needed to move towards a preference-sensitive decision.

In the Salinas paper [3] and the diagrammatic wheel presentation on the ICHOM website [<https://www.ichom.org/portfolio/stroke>] the Standard Set for Stroke has 3 domains and 10 sub-domains. [**\*\*** indicates exclusively or \* partly drawn from PROMIS GH 10]. SURVIVAL AND DISEASE CONTROL: Overall Survival; Stroke Recurrence; Smoking Cessation. ACUTE COMPLICATIONS: Symptomatic Intracranial Hemorrhage. PATIENT REPORTED HEALTH STATUS: Cognitive and Psychiatric Functioning\*\*; Non-motor Functioning\*\*; Motor Functioning\*; Social Functioning\*; General Health Status\*\*; Health-Related Quality of Life\*\*.

Patient-reported importance measures (PRIMs) are required *ex ante* a healthcare decision to establish optimal management for the individual and obtain their informed consent. Varying PRIMs within a heterogeneous patient group will impact on any PROMs collected *ex post*. Go to <https://ale.rsyd.dk> and enter survey ID 1510 for a simple hypothetical example to confirm this. Ratings and Weightings of one’s choice can be then be entered, but no data security is offered.

## Result



**Figure.** Hypothetical example using ICHOM standard stroke set with only two criteria rated and weighted. They are set at values that produce equipose (‘toss-up’).

Two *clinically identical* patients assign different weights to avoiding Stroke Recurrence and impeded Cognitive and Psychiatric Functioning. Given the different hypothetical performance rates of Thrombolysis and Thrombectomy on these two criteria, one will favour the former, one the latter. The conventionally-measured PROMs for both interventions will be affected, as will any consequent PROM-based evaluations. Patient preference-mix therefore needs to be adjusted for in PROMs, as well as clinical case-mix, most likely by sub-group clustering.

## Discussion

ICHOM standard sets are valuable *profile* measures. However, profile measures, comprising numerous individual *scales*, do not supply the aggregate outcome *index* required to decide the direction and extent of overall change. The production of a Stroke index requires weighting of the component scales. To have this aggregation based solely on the implicit preferences (weightings) of developers of the Standard Set, means the ICHOM ones are questionable facilitators of preference-sensitive values-based care. Apart from the double-counting most of them involve, the Standard Sets lack the empirically-derived group and sub-group average preferences ('tariffs') necessary to give them credible preference-sensitivity. A final irony arises in the efforts to map measures of formative constructs that have been validated as if reflective [4], on to explicitly formative and tariff-based generic constructs, for use in QALYs [5].

## Conclusion

*Value*-based care requires *values*-based, i.e. preference-sensitive, decision making. PROMs need to be preference-mix as well as case-mix adjusted and research on the development of PRIM-adjusted PROMs is needed.

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**Conflict of Interest:** Jack Dowie has a financial interest in commercial use of Annalisa.

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