

# If patient-reported outcome measures are considered key health-care quality indicators, who is excluded from participation?

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## Abstract

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Patient-reported outcome measures have received increasing attention with regard to ensuring quality improvement across the health service. However, there is a risk that people with disabilities and low literacy are systematically excluded from the development of these measures as well as their application in clinical practice. This editorial highlights some of these risks and the potential consequences of exclusion for these groups.

Recently, there has been growing interest in the use of standardized patient-reported outcome measures (PROMS) in clinical practice and for quality improvement.<sup>1</sup> The underlying premise is that patients are 'the best' judges of their own health. A PROM is a direct patient report, typically a questionnaire or a structured sequence of questions. It can be a generic or a condition-, population- or health status-specific measure. PROMS have been used for a range of purposes, including economic studies of health-care technologies, and evaluation studies at the individual, population and organizational level. In England, PROMS have been routinely collected in the NHS since 2009 for certain elective procedures such as knee, hip, varicose vein or groin hernia surgeries. Annual statistics for these conditions can be found on the Hospital Episode Statistics™ website (<http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937>).

At the moment, the potential for using PROMS in the management of long-term conditions in primary care is being explored in England by a team in the Department of Public Health at the University of Oxford. According to Dawson *et al.*,<sup>2</sup> PROMS may be used

to assess the impact healthcare interventions have on patients, assist with guiding resource allocation, evaluate the effects of changes to services, and provide feedback to consultants to assist clinical governance (p. 467).

Patient-reported outcome measures are not to be confused with patient-reported experience measures (PREMs), which involve quantitative and qualitative tools to measure the *experience* of patients with general practice, in long-term care and in hospitals in Scotland. PROMS are referring to patient-reported *outcomes* after interventions.

Under the NHS quality agenda, in which PROMS feature, the significance of the differences in how the PROMS have been developed, and for which purpose, can be easily overlooked. ‘Patient report’ suggests a patient-centred approach, and the policy discourse around PROMS reinforces the impression that outcomes are patient defined. The psychometric properties vary substantially across different measures, as does their validity. While some of the tools have been developed with service user input, most of them reflect professionally defined clinical priorities rather than what patients may define as *meaningful or relevant* outcomes at any given point. The uncritical adoption and use of these measures are reminiscent of the shift in discourse around so-called ‘quality of life’ or health-related quality of life measures, many of which had initially been designed as health status or function measures. For a critical exploration, see Rapley<sup>3</sup> who argues that...‘the forced quantification of qualitative experience permits the rhetorical invocation of ghostly “market mechanisms” driven by cost-utility analysis, and the grinding out of impressive-looking, but publicly incomprehensible, utility values to the *n*th decimal place (p. 225).’ Many of these health status measures have now been ‘re-badged’ as PROMS.

Apart from these general observations and some of the challenges associated with PROMS in terms of practicalities and interpretation that have been discussed by others<sup>1</sup>, we have substantial concerns that the routine use of PROMS at the population and the clinical level may exclude population segments that cannot understand or complete them. These groups may not have been included in the generation of topics and items of PROMS nor have they been consulted in the development of formats that would make the content accessible to them.

This carries inherently the potential for widening rather than closing health outcome disparities as people with disabilities and limited literacy are excluded from the quality improvement agenda. It is well established that people with inadequate literacy have poorer health outcomes and higher service needs.<sup>4</sup>

The number of people with cognitive impairments that affect memory and other forms of executive functioning is steadily increasing. At present, there are currently about 700 000 people in the UK with a form of dementia: 16 000 under the age of 65.<sup>5</sup> One-fifth of the adults in the UK have literacy skills that rank below the level considered appropriate for 11-year olds.<sup>6</sup> According to estimates, 985 000 people or two percentage of the population in England are considered to having a learning disability.<sup>7</sup> These groups may be intentionally excluded from participation in the assessment process due their ‘inability to understand a questionnaire, for reasons of impaired cognition or difficulty with the language in which it is available...’<sup>2</sup> p. 466. Moreover, most of the PROMS have neither been validated nor adapted for them, which raises considerable doubts about whether the perceptions of these patients are appropriately captured.

Cumulatively, the people who may find it difficult to use PROMS amounts to a significant proportion of UK health service users, with extensive health-care needs. For example, people with learning or developmental disabilities rely on appropriate health-care services, to mitigate the higher risks of epilepsy, heart disease and other conditions. Older adults with dementia may experience substantial co-morbidity in terms of diabetes, stroke, osteoporosis and fall-related hip- and knee problems.

There are concerns regarding the appropriateness of PROM content. For example, the aforementioned use of generic ‘quality of life’ measures such as the EuroQoL EQ5-D may pose problems for people who are wheelchair users. The low scores on walkability/mobility items may suggest a lower QoL than the general population, which is an artefact. The interpretability of the outcome measure also depends on the absence or presence of additional conditions, which are not always static but may demonstrate variability over time, such as an impaired mobility as a result of arthritis in addition to the functional impairment resulting from knee surgery. This has been acknowledged in the literature ‘...hip replacement may not fully restore a

patient's mobility if the patient has another coexisting condition that affects walking ability.<sup>2</sup> (p. 466)'.

Current administration practice and the required level of standardization in the use of written PROMS risks exclusion of a significant proportion of health service users. These users are also at an elevated risk of poor health outcomes. Undertaking efforts to adapt and accommodate, and validate the outcome measures for population groups that are currently at risk of exclusion can help to ensure PROMS are used more inclusively. Simple reliance on proxy responses from friends, relatives or clinicians is insufficient as this may not be an adequate reflection of self-report.<sup>8,9</sup>

The promise of PROMS may be somewhat overstated and caution is warranted on how they are being used in practice, which populations may be excluded in the process and which consequences may result in terms of resource allocation and quality improvement decisions.

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