Can the outcome of primary care be measured by a Patient Reported Outcome Measure?

WHAT ARE PATIENT REPORTED OUTCOME MEASURES?

There is increasing interest in using Patient Reported Outcome Measures (PROMs) as an indicator of the effectiveness of health care, underpinned by the principle that the patient's experience of outcome, as opposed to the absence of disease, is a key measure of success. Most PROMs do not measure outcome directly, but collect patient self-reported health status before and after an intervention or episode of care, with the change between the scores providing the outcome.

Measuring outcome in the unselected population seen in primary care requires a PROM which is applicable across a range of conditions, that is, generic. There are numerous generic PROMS, of which the most widely used in the UK is the EuroQoL group's EQ-5D. This measures health status through five tick-box questions on mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. It is recommended by the National Institute for Health and Care Excellence (NICE) for deriving quality-adjusted life years to assess the cost-effectiveness of interventions[1] and is currently used to collect data on the outcomes of hip and knee replacements, and surgery for groin hernia and varicose veins.[2] Globally, the most commonly-used generic PROM is the Short Form (36) Health Survey (SF-36). This contains 36 questions on wider aspects of symptoms and function. It is more comprehensive than the EQ-5D and there is evidence to suggest it is more sensitive to change.[3]

In this article we argue that neither generic PROM is sufficient for evaluating episodes of primary care, and that no suitable PROM currently exists. We believe we need a new measure.

THE NATURE OF PRIMARY CARE

The provision of primary care is changing, with the introduction of different providers and service models. This inevitably raises questions about how to judge the benefits of these changes. For example: what is the impact of different ways of providing out-of-hours care? Do longer appointments improve outcome? How does substituting nurses for doctors affect outcomes? Putting patients at the heart of care means using a PROM to answer such questions, but one problem with the EQ-5D and SF-36 is that many patients presenting to primary care have neither a symptomatic nor functional problem.[4] Furthermore, patients who do present with symptoms may each have different reasons for attending: one may seek to alleviate symptoms, another may need advice on sourcing further support, and another may be concerned about whether the symptom represents serious illness. Most generic PROMs are not fully responsive to these changes because they are not directly concerned with them.

These difficulties with measuring outcome arise because of the very nature of primary care, described by Starfield[5] as provision of 'first contact', 'coordinated', and 'continuous' care, while seeing patients with any health-related problem. Considering these in turn gives some insight into the problem. Because primary care is the first contact within the health system, many patients who seek primary care services do not have a health need that can be directly resolved by those services. Even if improvement in function is the ultimate goal for certain patients, it is often the outcome over which the primary care clinician has least control, and there may be a series of interim outcomes facilitated by the clinician, which work towards this.

Primary care acts to refer patients to, and coordinate the work of, a range of other health and social care providers. The care obtained from these providers may have a larger influence on the patient's health than the actions of the primary care service.

The continuous nature of primary care presents difficulties with reconciling long and short-term views. At the level of individual consultations, patients seek resolution to immediate problems. In the longer term, consultations contribute to episodes of care and the benefits of these may not be evident for many years. Furthermore, interventions to improve long-term health (for example, statins) may make patients feel worse in the short term. As experts have pointed out, using the EQ-5D to measure health outcomes over an annual period may create incentives for healthcare providers to focus on short-term gains at the expense of longer-term outcome.[6]

The comprehensive nature of care means that clinicians are often managing more than one problem or illness at a time, typically dealing with three problems or more per patient visit.[7] Additionally, many primary care interventions are preventative in nature; with no 'problem' to resolve. Thus the outcomes of primary care are very wide-ranging in nature and impact.

WHY NOT USE PATIENT EXPERIENCE AS A PROXY?

In the light of these complications, some experts have tried to measure quality in primary care through the patient's experience of receiving care, as opposed to their experience of outcome, thereby replacing a PROM with a 'PREM': patient reported experience measure.[8] Proponents argue that practices which deliver a good patient experience also perform well on clinical quality.[9] Furthermore, experience is treated as an end in itself by the NHS Outcomes Framework.

However, although patient experience clearly matters, and validated PREMs provide an invaluable view of this, experience is distinct from outcome. Recent research suggests that the correlation between a positive experience and outcome in general practice, while statistically significant, is actually fairly low.[10] Some PREMs, such as the GP Patient Survey, include aspects of outcome (for example, confidence in self-management). However, the focus is on experiences which lead to good outcomes (for example, how good was your GP at explaining tests and treatment?) rather than the outcomes themselves (for example, patient understanding and adherence).

AREN'T THERE ANY EXISTING PROMS AVAILABLE FOR PRIMARY CARE?

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none lends itself to measuring the wide range of outcomes from primary care. Consider the patient who presents with abdominal pain which he is worried might be cancer, but which turns out to be reflux oesophagitis. An improvement in symptoms following treatment would be a good outcome but so too might any combination of a reduction in concern, an increase in understanding, and knowledge of how to self-manage the condition. These last three outcomes, which contribute towards what Starfield referred to as 'resilience,' are missing from most generic PROMs.[11]

Some PROMs do come close to capturing these outcomes. The Patient Enablement Measure (PEI) consists of six questions which aim to establish how 'enabled' patients perceive themselves to be following a consultation. It has been well-validated for primary care, is short, and is acceptable to patient and practitioners.[12] However, as well as ignoring symptoms and function altogether, it is designed to measure the outcome of individual consultations. Given that primary care is, in essence, continuous care, we need a PROM to capture the outcome of an episode of care.

The Measure Yourself Medical Outcome Profile (MYMOP) offers an expanded construct through rejecting the standardised approach and instead allowing patients to define the issues to be measured.[13] While this approach is undeniably patient-centred, it lends itself more to face-to-face administration than the self-completion format needed for large-scale evaluation of services. Additionally, MYMOP emphasises symptomatology and function. The majority of patient appointments in primary care are with patients with long-term conditions, who tend to report stable symptoms and function; or people with self-limiting conditions who show improved symptoms without intervention. The omission in MYMOP of wider domains makes it unsuitable for many episodes of primary care.

CAN THE OUTCOME OF PRIMARY CARE BE MEASURED BY A PROM?

This article asked the question of whether the outcome of primary care can be measured through a PROM. In response, we believe it should be possible to define a construct which can achieve this through consulting with patients and clinicians, and drawing on the combined strengths of existing PROMs. This will be far from straightforward, and will require a multi-layered construct, encompassing aspects of enablement, resilience, symptoms and function, and health perceptions.

Experts in this field have rightly called for caution in developing new PROMs, given the proliferation of existing measures.[14] However, we believe a new measure is justified for the benefit of future and current research into different models of primary care.

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REFERENCES

1. National Institute for Health and Care Excellence. *Guide to the methods of technology appraisal 2013. NICE article [PMG9].* http://www.nice.org.uk/article/pmg9/chapter/foreword (accessed 10 Nov 2014).
2. Patient Experience. Gibbons E, Fitzpatrick R. *Patient Reported Outcome Measures: their role in measuring and improving patient experience.* http://patientexperienceportal.org/article/patient-reported-outcome-measures-their-role-in-measuring-and-improving-patient-experience (accessed 17 Oct 2014).
3. McDowell I. *Measuring health.* Oxford: Oxford University Press, 2006.
4. Binns HJ, Lanier D, Pace WD, *et al.* Describing primary care encounters: the Primary Care Network Survey and the National Ambulatory Medical Care Survey. *Ann Fam Med* 2007; **5(1):** 39–47.
5. Starfield B. Measuring the attainment of primary care. *J Med Educ* 1979; **54(5):** 361–369.
6. Valderas JM, Fitzpatrick R, Roland M. Using health status to measure NHS performance: another step into the dark for the health reform in England. *BMJ Qual Saf* 2012; **21(4):** 352–353.
7. Salisbury C, Procter S, Stewart K, *et al.* The content of general practice consultations: cross-sectional study based on video recordings. *Br J Gen Pract* 2013; **63(616):** 751–759.
8. Hudon C, Fortin M, Haggerty J, *et al.* Measuring patients' perceptions of patient-centered care: a systematic review of tools for family medicine. *Ann Fam Med* 2011; **9(2):** 155–164.
9. Raleigh VS, Frosini F. *Improving GP services in England: exploring the association between quality of care and the experience of patients.* London: The King's Fund, 2012.
10. Llanwarne N, Abel G, Elliott M, *et al.* Relationship between clinical quality and patient experience: analysis of data from the English Quality and Outcomes Framework and the National GP Patient Survey. *Ann Fam Med* 2013; **11(5):** 467–472.
11. Starfield B. Measurement of Outcome: A Proposed Scheme. *Millbank Quart* 2005; **83:** 1–11.
12. Howie JG, Heaney DJ, Maxwell M, *et al.* Quality at general practice consultations: cross sectional survey. *BMJ* 1999; **319(7212):** 738–43.
13. Paterson C. Measuring outcomes in primary care: a patient generated measure, MYMOP, compared with the SF-36 health survey. *BMJ* 1996; **312(7037):** 1016–1020.
14. Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials. *Health Technol Assess* 1998; **2(14):** i–iv, 1–74.