Title: ‘Patient activation’ as an outcome measure for primary care?

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Over recent years the push for healthcare to become more person-centred has been mounting, with increasing attention being paid to the importance of people's experiences of care, and to supporting them to manage their own health. Within the UK National Health Service (NHS), this emphasis is made clear for primary care providers and commissioners both in the direction of travel laid down in the NHS Five Year Forward Review[1] and by the continued inclusion of indicators relating to supporting self-management and ensuring people have a positive experience of care within successive NHS Outcomes Frameworks.[2] However, despite these policy drivers and good intentions, delivering truly person-centred care remains challenging.

There is no single definition of what is meant by person-centred care, and a recent review[3] identified 160 different tools all trying to measure the concept. This suggests both a welcome interest in this topic but also perhaps a lack of clarity about what exactly constitutes person-centred care and how to assess the extent to which it is being delivered. What does seem important within person-centred care, though, is that care is personalised and takes into account patient preference, that it provides opportunities for informed decision-making, empowers patients, and encourages partnership between professional and patient.[4] But how do we know if this is being achieved?

One approach currently being explored within primary care in the UK, which has been used with success elsewhere, is the Patient Activation Measure (PAM). 'Patient activation' describes the skills, confidence and knowledge a person has in managing her/his own health and healthcare. The PAM is a measurement scale of patient's activation based on their responses to questions which include measures of an individual's knowledge, beliefs, confidence and self-efficacy. The resulting score from completion of the questionnaire places a patient at one of four levels of activation, from disengaged and overwhelmed, through to maintaining self-management behaviours and pushing further.

Higher levels of patient activation have been found to be related to positive health behaviours, many clinical outcomes, healthcare costs and patient experiences, meaning that patients with higher activation are more likely to engage in preventative behaviours, adhere to treatment, and effectively self-manage.[5] Evidence suggests that patients' activation levels can be modified, and that improvements in activation levels can be maintained over time and are associated with better self-management and lower healthcare service utilisation.[6]

The PAM has been used extensively in the USA as a tool to support personalisation of care and patient engagement with self-management, particularly for patients with long-term conditions, but the potential for the PAM to be used as an outcome measure, to assess the effectiveness of interventions, or as a performance measure against which individual provider or health system performance can be assessed, is beginning to be recognised.[5]

NHS England and the Health Foundation are currently working with a learning set comprising six healthcare organisations (five Clinical Commissioning Groups and one disease registry) to pilot the use of the PAM in the UK for a range of different purposes. For example, learning set sites are using the PAM in commissioning long-term condition prevention, education and self-management programmes from NHS and independent-sector providers, and exploring its use as a tailoring tool within interventions such as health coaching and care planning.

One interesting potential use is an outcome or performance measure. Examples of this work include plans by Somerset Clinical Commissioning Group to work with providers to develop a capitated

budget, outcomes-based commissioning framework for all services for people living with long term conditions in the region. Patient activation is a core outcome measure in that framework which will become operational from April 2016. Incentive payments within the contract are currently under negotiation and will not be implemented until (at the earliest) April 2017.[7]

Within the UK context, the Quality and Outcomes Framework (QOF)[8] is the annual reward and incentive programme most commonly used within primary care to monitor and reward general practice activity. The QOF is a voluntary process introduced as part of the general practice contract in 2004. Despite doubts about whether the financial incentives are adequately aligned to maximise health gains,[9] evidence shows that QOF has changed clinicians' behaviour.[10] However, recent suggestions that QOF is becoming 'bad for health' have led to calls for a move away from this process-driven approach to one more explicitly focused on outcomes.[11] This suggests an opportunity for a tool like the PAM to become used in this way, although it is far from clear how this might work in practice.

The use of PAM as a performance measure raises some interesting questions. The tool was not initially designed to be used in this way, and how to interpret PAM scores in this context is not straightforward. The use of PAM as an outcome measure risks assuming that higher PAM scores are 'better', and that scores should increase in a linear fashion as a result of improvements in care provision, or interventions targeted at improving patient engagement and person-centred care. Evidence suggests, however, that increases in activation are likely to be greater and easier to achieve for patients who are starting from a low score.[6] There is also a possibility that patients may shift between PAM levels as their condition changes – for example, moving from a higher to a lower level of activation as their condition worsens or their treatment changes. For some patients, maintaining their PAM score at its current level, rather than increasing it, may be a positive outcome. There is also a risk that the PAM itself may act as an intervention, particularly if it is completed as part of a consultation, or referred to by health professionals as part of routine care to support self-management. This could compromise its value as an outcome measure.

We are conducting a concurrent evaluation of the learning set's work to pilot the PAM in the UK;[12] amongst other things, this will provide an exciting opportunity to explore the feasibility and challenges of using the PAM as an outcome or performance measure in UK primary care. Will PAM prove fit for purpose? If so it may be a valuable tool to drive person-centred care across primary care.

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