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# Measuring patient activation: The utility of the Patient Activation Measure within a UK context—Results from four exemplar studies and potential future applications

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ABSTRACT

*Objective:* Patient activation can be measured using the Patient Activation Measure (PAM) developed by Hibbard et al., however, little is known about the uses of the PAM in research and in practice. This study aims to explore its differing utility in four UK exemplar sites.
*Methods:* Data from four exemplars in a range of health settings with people living with long-term conditions (i.e. stroke or COPD) were evaluated. PAM scores were described and explored in relation to clinical and sociodemographic variables and outcome measures.
*Results:* PAM scores illustrated that most with COPD or stroke reported PAM levels of 3 or 4, indicating that they are engaging, but may need help to sustain their scores. The exemplars illustrate the utility of, and potential issues involved in, using PAM as a process/outcome measure to predict activation and the effectiveness of interventions, and as a tool to inform tailoring of targeted interventions.
*Conclusions:* The PAM tool has been shown to be useful as an outcome measure, a screening tool to tailor education, or a quality indicator for delivery of care.
*Practice implications:* However good demographic and patient history are needed to substantiate PAM scores. Further work is needed to monitor PAM prospectively.


## 1. Background

It is widely acknowledged that healthcare systems in the UK and worldwide are facing profound challenges [1]. In the UK, the English National Health Service (NHS) five year forward view [2] states that due to an increasingly ageing population [3], the increasing prevalence of multiple long-term conditions [4,5] and the limits to the available financial resources new models of care are needed to face the demands of the current population. Globally, there have been moves towards a culture of patient engagement and self-care with an expectation that systems will be redesigned to be more patient-centred, based on needs, priorities and experiences where decision making and care planning is in partnership between patients and professionals [6–8], such as the House of Care model [9]. The house of Care model is a coordinated delivery system for personalised care and support planning across multiple partners and sectors.

Measuring the quality and effectiveness of person-centred care, however, has its challenges [1]. A wide variety of PROMS (Patient Reported Outcomes Measures) and PREMS (Patient Reported Experience Measures) exist to measure service performance and quality indicators, or patient outcomes such as quality of life and self-management [10,11]. There is, however, no one 'right' way, and a general lack of clarity about what we mean by 'person-centred care' [12] in order to start unpicking its components. One area receiving growing attention across the UK's NHS in relation to person-centred long-term condition management is the concept of patient activation and its measurement as an indicator of quality and effectiveness, but also as a tool to tailor and stratify the delivery of care or people at risk of poor self-management.

*Abbreviations:* $FEV_1$, forced expiratory volume in 1second; MRC Score, Medical Research Council Dyspnoea score.

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Patient activation or readiness to self-manage measures individuals' understanding of their role in managing their health and their willingness and ability to take independent actions and decisions to manage their health and healthcare [13,14], either self-directed or facilitated (but not driven) by professionals and/or peers. Hibbard et al. suggests that patient activation provides a better understanding of why some patients engage fully with their health and others do not [12]. Operationally, patient activation, can be measured by the Patient Activation Measure (PAM), a 13-item scale developed by Hibbard et al. [15,16], designed to assess an individual's knowledge, skill, and confidence with respect to managing his/her health. The score ranges from 0 to 100, and determines how 'activated' a person is, as one of four stages (Level 1–4, where 1 is least activated, Fig. 1). International evidence demonstrates it has been used as an outcome to evaluate a vast array of self-management interventions [17,18] across different long-term conditions and, different counties and cultures [19–23]. with some studies showing improvement in activation scores after interventions [20,21,23]. Studies have also shown that increases in patient activation are associated with a range of positive health outcomes, including reduction in body mass index, reduced blood glucose levels, reduced blood pressure and reduced cholesterol [24–27], and positive health behaviours with regards to decision making, health information seeking, engagement in health behaviour and lifestyle changes, uptake of preventative health care, and self-management [15,16,28].

It has been reported that the PAM can be used as: i) a process or outcome measure to determine the clinical or sociodemographic characteristics that may predict level of activation in order to improve patient engagement and health outcomes, with increases in activation being either an endpoint or a tool with which to improve other health outcomes, ii) a tool to inform tailoring of targeted interventions, by assessing an individuals' capacity for self-management and enabling the type and amount of support required by the individual to be targeted towards this and, iii) an outcome measure in evaluating the performance and effectiveness of healthcare systems and interventions, by undertaking before and after evaluations of the person's level of activation (also summarised in Table 1) [29]. Recently, NHS England policy[1] has begun to advocate the use of the PAM as a 'vital sign' in addressing the challenge of providing high quality, person-centred, sustainable and cost effective long-term condition support. To date, the PAM has been more frequently used elsewhere in the World and evidence to support this policy direction in the UK and its effectiveness and appropriateness within a UK, long-term condition management context has yet to emerge and be disseminated at a national and international scale. In particular, we know little about how activated (or not) populations with different long-term conditions across the UK are, how this changes over time and whether there clinical and sociodemographic factors can predict activation levels and changes in these. We also know little about the utility of the PAM in helping to tailor the type and amount of self-management support individuals receive and its effectiveness as an outcome measure to determine the effectiveness of the interventions and services that we offer. In this paper, we draw on evidence from four exemplar studies (two prospective studies and two secondary analyses) in which the utility of the PAM within a UK context in patients with long term conditions (in these examples, COPD or stroke) was explored. This paper is amongst the first to report on the utility of the PAM within a UK context, ahead of the evidence from NHS England and the Health Foundation's pilot and evaluation sites.

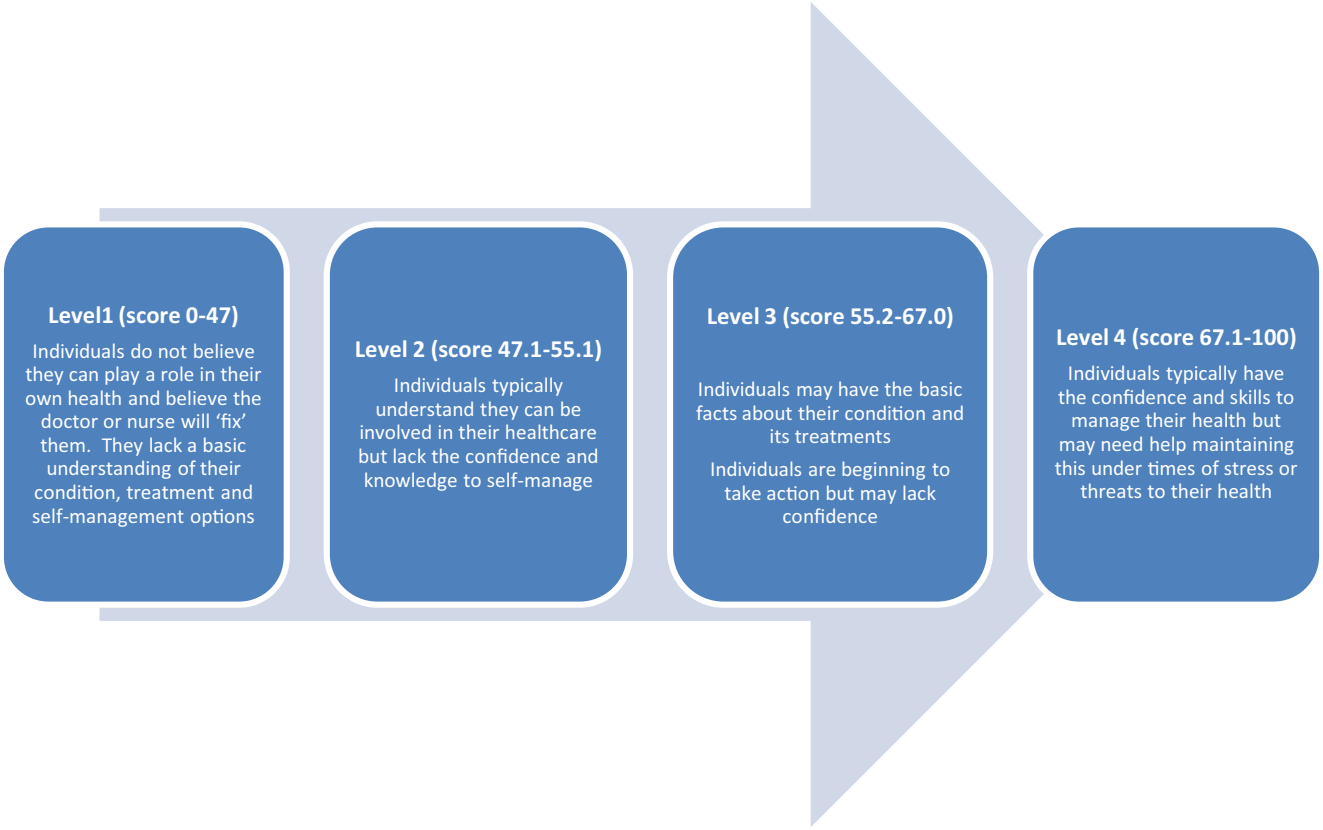


**Fig. 1.** Description of the Hibbard's four stages of the Patient Activation Framework [15].