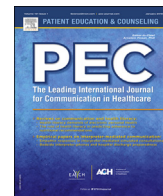




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Patient Perspectives and Characteristics

Fidelity or flexibility: An ethnographic study of the implementation and use of the Patient Activation Measure

Sarah Chew^a, Liz Brewster^b, Carolyn Tarrant^a, Graham Martin^a, Natalie Armstrong^{a,*}

^a Department of Health Sciences, University of Leicester, United Kingdom

^b Lancaster Medical School, Lancaster University, United Kingdom

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ABSTRACT

Objective: To evaluate the use of the PAM in the English National Health service. The PAM is a validated scale that measures 'activation' (people's knowledge, skills, and confidence in managing their health) and assigns patients to four categories of activation (low-to-high). Some evidence suggests that higher activation levels correlate to better clinical outcomes and patient experiences, and lower healthcare costs. Empirical studies of implementing the PAM are scarce.

Methods: An ethnographic study of six healthcare organisations' PAM implementation focused on 'core-teams' who designed projects, and frontline staff and patients' experiences of those. Data comprised 123 hours of observation, 112 interviews, and document reviewing. Analysis used a constant-comparative approach.

Results: The PAM appealed as it fitted with different logics of measurement, offering a means of quantifying soft, process-oriented qualitative constructs used in tailoring care, whilst simultaneously producing reliable high-level outcome metrics.

Data revealed challenges to these logics. The PAM's developers emphasised fidelity to ensure reliability but, in practice, flexibility was commonplace and often perceived as appropriate and beneficial by frontline staff.

Conclusion: The intended logic of measurement is important in determining an appropriate balance of fidelity and flexibility and, therefore, reliability and patient benefit.

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1. Introduction

Calls for healthcare to become more person-centred are increasing, with growing emphasis on the importance of patients' experiences of care and on supporting them to manage their health in ways meaningful to them. This shift towards person-centred care [1] has been endorsed through policy that stresses its centrality to high-quality care: paying attention to, and displaying respect for, patients' values and preferences are framed as important guards against the dangers of paternalism and autocratic practice by professionals [2], priming patients for action rather than passivity [3].

While there are competing definitions of person-centred care, one helpful synthesis sets out four underlying principles: i) affording people dignity, compassion, and respect: ii) offering co-

ordinated care, support, or treatment; iii) offering personalised care, support, or treatment; and iv) supporting people to develop their own abilities for an independent, fulfilling life [4]. Many health systems increasingly encourage people to be more involved in their health and healthcare [5].

In England, the NHS Five Year Forward View articulates a core aspiration for the NHS to better help people to manage their own health: 'staying healthy, making informed choices of treatment, managing conditions and avoiding complications' [6]. NHS England's recently-established 'Self-Care Programme' centrally positions the concept of patient activation and seeks to bolster support for people living with long-term conditions (LTCs).

'Patient activation' comprises individuals' knowledge, skills, and confidence in managing their health and healthcare [7,8]. Activation has been operationalized and measured through the Patient Activation Measure (PAM), a commercially licensed tool from the US [8,9]. PAM contains statements associated with activation about beliefs, confidence in managing health-related tasks, and self-assessed knowledge; patients rate the degree to which they agree with each. The result is a scale score which places patients at an activation level between 1 (low) and 4 (high). The

* Corresponding author.

E-mail addresses: sec55@le.ac.uk (S. Chew), e.brewster@lancaster.ac.uk (L. Brewster), ccp3@le.ac.uk (C. Tarrant), gpm7@le.ac.uk (G. Martin), Natalie.Armstrong@le.ac.uk (N. Armstrong).

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PAM has been used extensively in the US as a tool to support personalisation and patient engagement with self-management, particularly for patients with LTCs [10]. It has been translated and validated for use in several languages and countries [11].

Some research indicates an association between higher activation levels and improved health behaviours, clinical outcomes, patient experiences, and healthcare costs. It is proposed that patients with higher activation are more likely to engage in preventive behaviours, adhere to treatment, and self-manage effectively [12]. Some evidence suggests that interventions may increase activation levels [13].

Keen to explore this potential, NHS England established a 'learning set' (five Clinical Commissioning Groups (CCGs) and one disease registry), providing them with licences to pilot the PAM in diverse projects [14,15]. Table 1 describes the projects and gives a high level overview of the patient and professional groups involved in them.

Piloting was important as, although the PAM is validated for use in the UK [16], little is known about implementing it in the NHS. To capture learning across the pilots, we were commissioned to undertake a qualitative, process evaluation of implementation [17].

Previous work reporting PAM use has focused on providing evidence of the tool's effectiveness in measuring activation and demonstrating improvements in activation, using outcome data from medical records or patient self-report; no studies have focussed directly on PAM implementation in the NHS [18,19]. The context for implementation is important; better understandings of

how context influences implementation can explain why the same intervention may 'work' in one setting, but 'fail' in others [20]. Increasing attention is now paid to explicating the theories or models underpinning improvement efforts [21], including elaboration of mechanisms that enable change. Referred to as a logic or theory-of-change, the underlying idea is that of "an explicit theory or model of how an intervention [. . .] contributes to a chain of intermediate results and finally to the intended or observed outcomes [22]."

Our aim in this paper is to explore sites' experiences of implementing the PAM, revealing the intended logics of measurement behind its use and how these played out in practice.

2. Methods

We took an ethnographic approach comprising observations, interviews, and documentary analysis [20]. We sought to access all relevant data sources, using a flexible and iterative approach to question specification and data collection.

We completed 112 interviews with staff within participating organisations responsible for planning and/or monitoring PAM-related activity, and with frontline staff and patients using the PAM. These are summarised in Table 2.

Interviews were semi-structured and guided by a topic guide developed through a literature review and discussions within the project team. We used this flexibly, to respond to particular interests, experiences, and roles of participants. Interviews were audio-recorded, transcribed, and anonymised.

Table 1
Outline of organisations and projects using the Patient Activation Measure in the NHS England Learning Set.

Learning Set site	PAM project name/service	No. of PAM licenses ^a	Patient populations	Providers
Site 1 (CCG) City and rural, in the top 20% least deprived districts in the country, 10% of the population is BME (black and minority ethnic)	Health coaching	2000	Long-term conditions/medium risk of increased health service utilisation	Health coaches
	Musculoskeletal service Weight management service	2600 400	Rheumatoid arthritis Obesity	MSK service staff Multi-disciplinary team
Site 2 (CCG) Inner city, in the top 20% most deprived districts in the country, 26% of the population is BME	Care planning	28,000	Long-term conditions	GPs
	Diabetes self-management programme	10,000 patients	Diabetes	Secondary care staff
	Expert Patient Programme Bariatric service weight regain programme	across 3 services	Long-term conditions Obesity	
Site 3 (CCG) City and rural, in the top 20% most deprived districts in the country, 18% of the population is BME	Long-term condition management care planning	5000	Long-term conditions/those at risk of unplanned hospital admissions	General practice staff and community nursing
	Diabetes self-management	400	Diabetes	GPs
	Community mental health management	40	Mental health	Community mental health teams
Site 4 (CCG) City and rural, above average deprivation overall, but includes some very deprived rural areas, 2% of the population is BME	Outcomes based commissioning, including several smaller pilots Complex care work	Area population	Long-term conditions, including COPD, chronic heart failure, diabetes, mental health conditions Patients with three or more long-term conditions	Two accountable care organisations Primary and secondary care NHS and two voluntary sector organisations
Site 5 (CCG) Inner city, in the top 20% most deprived districts in the country, 69% of the population is BME	Commissioning diabetes self-management support	Not known	Diabetes	NHS and two voluntary sector organisations
	Self-management support intervention	220	Long-term conditions and mental health conditions	NHS and voluntary sector organisations
	Self-management support intervention	75	Long-term conditions and those with uncontrolled symptoms	NHS and voluntary sector organisations
	Self-management support intervention	55	Older adults with long-term conditions including dementia	NHS and voluntary sector organisations
Site 6 (Disease registry)	Transforming Participation in Chronic Disease	30,000	Chronic Disease	Secondary care treatment units

^a This typically represents the number of licences requested by sites at the outset, not necessarily those ultimately used.

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