Patient Perspectives and Characteristics

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

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**A B S T R A C T**

**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 appeared 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).
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 preventative 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.

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

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

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We observed 123 hours of centrally-organised learning set events, frontline meetings and workshops, and frontline use of the PAM in clinical settings. Field-notes were taken in situ and were audio-recorded and transcribed. We also collected approximately 180 documents including project plans, reports, and training materials. Fieldwork was conducted between November 2014 and November 2016.

All data collected was used in the analysis, which was based on the constant comparative method. Supported by NVivo software, we initially generated open codes and then grouped them into themes. Analysis was recursive, constantly moving from the specific to the general, allowing us to identify commonalities and patterns and to produce generalisable explanations for our findings into higher-order themes; [23,24] regular checks on coding and interpretation were undertaken.

3. Results

We begin by showing how sites thought the PAM could be used and what it could deliver. We then move on to describe how the PAM was used in practice. The PAM was seen as a natural fit with the outcomes and care sites were encouraged to deliver. Sites were already engaging with broader changes to care outlined in policy, for example, taking a holistic view of patients, reducing acute-care use, making care more community-focused, and integrating commissioning [5,6]. Through previous initiatives, sites were aware that individuals needed different kinds of self-management support but a tool to determine who needed what level and type of support was lacking. Many felt frustration at being encouraged to focus on relatively ‘soft’, process-oriented, qualitative changes (e.g. to the practitioner-patient relationship, to approach to LTC management, and to individuals’ ideas about medicine), without any obvious way of measuring such changes.

Staff were convinced of the potential gains from helping people to manage their health using person- and community-centred approaches, but had struggled to find measures to demonstrate their value. They worried that, without measures, initiatives and projects could be questioned and progress could stall. Having a validated tool that produced relevant metrics was seen as essential to convince decision-makers to invest further in interventions which might be vulnerable to cuts despite their prioritisation in policy.

As CCGs, if we’re wanting to create change in service delivery and implementation, we need evidence to write a business case. You’ve got to have something with some certainty that says, ‘Okay, it’s this thing that made the difference and these are the outcomes’. (Core team-member 1, site 1)

Many believed the PAM could fill the measurement ‘gap’ as it was a simple, quick, reliable instrument that satisfied different logics of measurement: the category scores could indicate what level and type of support patients needed; the scale score could be used as an outcome measure. As the PAM was made available by NHS England it was seen to have legitimacy, and because it was not disease-specific it could be used in different clinical, social, and public health initiatives.

Online training and guidance about using PAM was available to the six organisations, and its developers presented further information at several learning events. Audiences were informed that the PAM could be self-completed by patients or administered by a healthcare professional. The PAM was presented as a sensitive, precise instrument that should be administered with care by well-trained staff for its data to be valid. This positioned the PAM as an objective, validated tool able to produce ‘hard’, unbiased data.

[Developer] stated that ‘that is why it’s important to be trained, because PAM has a lot of precision’. (Observation, learning event)

Sites were warned about the potential that bias that could arise in verbal administration. Professionals were advised to introduce the PAM to patients with a preamble that stressed there were no right or wrong answers and emphasised the need to answer honestly. Professionals were to adhere to the wording of questions, ask them in order, and not deviate or elaborate. The developers acknowledged that small changes might be necessary if a patient were unable to understand a question, and provided strict guidelines including a glossary of permissible alternative words. The implication was that if PAM was not administered properly, the validity and reliability of the data would be compromised.

In the sites, projects were designed to address issues at individual, service, or population level. We identified two core ideas about how the PAM, and the data it generated, could be used: as an outcome measure and as a tailoring tool. These ideas were premised on the assumption that the PAM would generate data appropriate to the underlying logic of measurement.

In one CCG, strategic-level staff planned to use PAM data as an outcome measure. PAM scores were collected for all patients with LTCS at baseline and one year later, to use the data to assess the impact of a care planning initiative. Elsewhere, before-and-after PAM scores were recorded for patients in discrete interventions to support self-management, such as health coaching or structured education. The logic of measurement in such cases centred on the notion that PAM would deliver robust metrics able to ‘speak’ to decision-makers and inform commissioning decisions.

Using PAM to tailor care more effectively for individual patients (to be more person-centred) also appealed and strategic-level staff were positive about using activation as a key indicator. Scores could be used to identify the most appropriate intervention(s) for any particular patient (tailoring selection of interventions) or, to adjust delivery of a given intervention to a specific patient’s activation level (tailoring application of interventions). In this example of ‘tailoring application’ of a health-coaching project, the PAM score was discussed as a means for coaches to assess a patient’s level of activation, and tailor their approach accordingly.

PAM will be used as a tool for knowing what that starting point is and then being able to tailor the coaching that they offer to meet that person’s needs. (Core team-member 3, site 1)

Sites began to think about maximizing benefit from PAM-generated data and two approaches emerged: i) using the same...
data for different purposes, to assess the impact of interventions and tailor intervention delivery; ii) aggregating scores collected in different care contexts into a population-wide data set. In health-coaching and health-education interventions, in addition to collating scores from patients receiving particular interventions, it was thought that aggregating scores across areas of activity could allow monitoring of changes in population-level scores. Strategic staff in organisations thus viewed PAM as an objective measure that could be used for multiple purposes and at multiple levels. Delivering the PAM in the validated manner had been positioned as straightforward; correspondingly, few problems were anticipated.

Our data showed, however, that administering the PAM in practice was not as straightforward as expected. Moreover, professionals who understood administration guidance in principle struggled to comply in practice. In all settings, irrespective of the kind of project or patient group, we found evidence of ‘mediated completion’ (whereby the PAM was completed with significant input from others).

When professionals adhered to the guidance and avoided elaboration, problems often arose. Below, a health coach administering the PAM during an introductory call with a patient describes struggling to reproduce the precise wording of the questionnaire when asked to clarify questions. They indicate how the range of responses was problematic for some patients who wanted some discussion before committing to an answer.

"Probably the main challenge has been in relation to the categories of answers that we’ve been given [. . .] and I know that with the e-learning we did around like the PAM training, [. . .] sticking as closely as you can to the wording of the questions [is important, but] when people want some sort of clarification, it’s difficult not to sway them either way. (Frontline staff-member 1, site 1)"

One strategy was simply repeating the statements to patients. He said they had been told very, very clearly that they do not, or must not, change the wording, try and explain [the questions] in any way. All they can do is keep repeating them. (Observation, site 1)

This could have negative consequences and compromise communication: not answering the patient’s questions could appear unhelpful and even obstructive. Another health coach was observed attempting to use the PAM with a potential new patient: ‘[The patient] got confused about who the ‘I’ was, so he thought that [the coach] was the ‘I’ so she was saying ‘I am responsible for taking care of my health’ and he just couldn’t understand what he was being asked to do. He said ‘yes, yes that is alright’ but wasn’t engaging with the options to agree or disagree with that statement. And [the coach] just repeated the question, she didn’t try and explain it or clarify. She repeated the question about four times and he just couldn’t get to grips with it, and then he asked to stop, saying ‘I don’t think this is working’. (Observation, site 1)"

Many professionals believed there were good reasons for taking a flexible approach. Language and translation posed challenges, and although the PAM is available in translation, most pilot sites worked with the English version. Consequently, in areas with diverse populations, mediated completion was often inevitable. Some translations of the PAM were used but they necessitated mediation as they were too ‘literal’ and did not work on a cross-cultural conceptual level. Further, sites noted some languages have no written tradition and sought alternative ways (audio or visual) of delivering the PAM.

"Most of our patients involved in the pilots will need a translation or a facilitated approach to the questionnaire rather than just filling it in themselves. (Core team-member 1, site 5)"

In many households there’s somebody who speaks English who can read correspondence, [. . .] But whether the patients themselves would have been able to read it for themselves, there would have been patients who couldn’t have. (Core team-member 2, site 2)"

Furthermore, many English speakers found the PAM difficult to complete. In this observation from general practice, the patient had trouble making sense of the assessment process. She repeatedly sought guidance from the health professional who engaged in discussion about selecting the most appropriate response.

"Whilst she might have known what the words were, she really struggled to form them into any coherent ‘what is being asked of me here?’ question, because virtually every time she got to the end of a question she said ‘what does that mean?’ It was a case of ‘what does it mean?’, ‘I will give you some examples’; ‘I think this is my answer. Help me work out the right option to choose’. It was very co-produced. (Observation, site 3)"

Mediation was identified across the sites; one site found over 40% of those completing PAMs had received help from staff or relatives. Yet time constraints meant it was not always possible to support patients to complete PAM even though those running interventions were willing, resulting in a very mixed bag of completed assessments:

"I realise that some people might have needed help, because some came back not completely filled in and not done right. And maybe we could have offered more support, but we were two [staff] and we had 17 [patients]. (Frontline staff-member 12, site 3)"

Sometimes professionals initiated mediated completion. When professionals had pre-existing knowledge of their patients, they might use that knowledge to evaluate patients’ responses and intervene if they doubted their validity. When asking patients to complete the PAM in consultations, professionals were often alert to ‘erroneous’ responses. ‘Extreme’ and ‘socially desirable’ responding were commonly cited reasons to intervene.

"I have said ‘do you want me to go through it with you because I have seen you at the start filling it in strongly agree, strongly agree’—so I say ‘shall we go through it together?’ That is what I did with the third lady today, I intervened a bit. [. . .] People panic a bit and think ‘I will do that because that’s what they want me to say’. (Frontline staff member 1, site 3)"

Intervention often occurred when PAM was being used to tailor care and professionals emphasised the need to get ‘accurate’ answers so that patients would get the most out of an intervention. Some professionals were deliberately flexible and constructed mediated completion as a valuable exercise that could help to align the patient’s and professional’s views of the patient’s activation level. Thus the PAM could be used to collaboratively co-construct a mutually agreed level of activation, strengthening the therapeutic alliance.

"I’ve seen a few patients and they’ve done a PAM, and they’ve come out maybe quite low, like one or a two. I know the patients and I’m really quite surprised, because I might think that they’re actually quite good self-managers, quite knowledgeable. I’ll have a talk through their answers with them and after talking through them again, they might say ‘oh, well actually I perhaps didn’t answer that quite honestly’ or ‘I didn’t understand that’, and then we might go through the answers again, and I actually find I can show that they’re higher than they thought. (Frontline staff-member 1, site 3)"

Reaching consensus was seen as important from both relational and therapeutic perspectives. One professional described a patient with a low PAM score whom she would have classed at ‘activated’ as she independently sourced and used mobility aids. Through conversation whilst completing the PAM, it emerged that the patient had not related her behaviours to the PAM statements. The professional enabled the patient to understand her behaviour as relevant to ‘activation’; consequently the patient viewed herself as

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more active, re-answered more positively, and was left feeling validated. The professional was emphatic that caution was needed when taking answers at face value because it was uncertain that everybody shared understandings about activation and the PAM.

You need to read through and interpret what you understand by the questions and what the patient understands by the questions, so it can help you to structure a conversation with them; that may even be about understanding what the actual PAM itself means.

And what it means to the patient, and what it means to the nurse, and how they can then bring those two understandings together. (Frontline staff-member 5, site 3)

4. Discussion and conclusion

4.1. Discussion

Despite increased interest in patient activation and the PAM, studies of its implementation in practice are lacking. We have reported the first qualitative, process evaluation in this area. By focusing on how the PAM fitted with strategic-level staff’s logics of measurement and its implementation in practice by frontline staff, we surface important tensions between imagined use at the ‘blunt end’ and actual use at the ‘sharp end’ [25]. Such tensions are not unexpected as, in healthcare, ‘work as done’ often differs from ‘work as imagined’ [26]. Strategic-level staff saw activation as aligning well with person-centred care. The PAM appealed as a means of quantifying soft, process-oriented qualitative constructs. They saw potential for different logics of measurement: as an outcome measure and a means of tailoring care.

Importantly, they also often envisaged these logics as being complementary, assuming that PAM data collected through standardised administration would be equally suitable both for aggregation across populations and for tailoring care for individual patients. Because the PAM was framed as a precision instrument, participants had believed it to be less vulnerable to the well-known problems of bias and differences in interpretation which could impact on the robustness of the resulting data and limit the uses to which these could be put.

Implementation in practice challenged these anticipated logics. While the PAM’s developers advocated close fidelity, this was often not how frontline staff used it; instances of flexible, mediated completion were common. These occurred for various reasons, and were perceived as appropriate and beneficial by many frontline staff who prioritised forms of PAM completion that they regarded as meaningful. For them, the value of the PAM resided at the individual level rather than in generating data suitable for aggregation and use elsewhere. It was not the case that mediation occurred because professionals ignored, or were unaware of, the guidance about PAM administration.

This unanticipated difference between imagined and actual PAM administration arguably has important implications for intended logics of measurement. What constitutes fitness for purpose—even validity—in data is not fixed, and context and intended use are important factors; in other words, the use to which data are put dictates the type of data required and, conversely, the nature of any data will limit the uses to which they can be put [27,28]. Mediated completion, more likely with some kinds of patients and professionals than others, may prove problematic if the intention is to aggregate data at population level. This use demands reliable data fit for aggregation and fine-grained statistical analysis (for example, to detect significant changes in activation), requiring a more standardised method of administration to reduce variation and potential bias [29].

Conversely, taking a more flexible approach to PAM administration may be beneficial when tailoring within or between interventions for individual patients. For many frontline staff and patients, the emphasis was on better understanding an individual patient to inform their care. When a third party engaged in dialogue around the intended meaning of PAM items, or questioned patients’ answers if they seemed inappropriate, a more meaningful response seemed to be elicited; thus, individual-level validity takes precedence over administration fidelity.

Arguably, irrespective of how it is produced, an accurate assessment of a patient’s progress in managing their LTC is of prime importance if the data are to inform how best to care for that patient. Activation remains a novel construct and it cannot be assumed that everybody, professional or patient, shares a similar frame of reference on which to base their responses to the PAM; consequently mediated completion may be important in aligning understandings. Sometimes the process of completing the PAM itself may be of value regardless of the output: there is value in starting conversations about person-centred care and exploring appropriate care and support. Thus some concerns about bias that may apply at the population level become less salient when the PAM is used at the individual level, such that taking a more flexible approach may be legitimate.

Sometimes attempting to administer the PAM in a standardised way might be counterproductive, as professionals may feel compelled to resist patients’ requests for elaboration or explanation, with problematic consequences for the therapeutic relationship as attempts to avoid compromising data quality may mean that professionals are unable to respond to their patients’ immediate needs.

Further, it is unclear how many people will need extra time and support to complete the PAM. It is possible that over time the PAM may become more familiar and mediated completion less common. However, mediated completion may remain inevitable for some and care should be taken not to exclude them. Currently, mediated completion is difficult to avoid if the PAM is to be used across all patient groups. If fidelity is prioritised, there are concerning implications for how inclusive the PAM can be and there could be a danger of creating or reinforcing health inequalities.

4.2. Limitations

Our study is limited by its methodological approach. Ethnography is resource-intensive, and we could only observe a purposive selection of the projects. Observations of PAM use were limited to those occurring during fieldwork visits. We were, however, able to collect a wide range of other data, and our paper provides rich insights into implementing the PAM in the NHS, highlighting key challenges arising.

4.3. Conclusions

The PAM has a broad range of potential uses and functionality in the context of person-centred care, but caution is needed to use the tool and the resulting data appropriately.

Different logics of measurement for the PAM may demand different approaches to data collection. It should not be assumed that data from diverse projects can be aggregated or used for more than one purpose. It is not known how much mediation and elaboration may affect PAM scores, and we are not aware of studies examining the variation in data produced by standardised versus more flexible approaches to administration. In some cases, the need for metrics valid at the level of the population is arguably subordinate to the tool’s role in shaping the therapeutic encounter.
or informing how care can be offered in a more person-centred way.

4.4. Practice implications

Practitioners should be clear about what they are going to use the data generated by the PAM for and should administer it accordingly. Using the PAM flexibly may be of greater therapeutic benefit in person-centred settings such as care planning than using the PAM rigidly. Taking a more flexible approach may also enable the PAM to be used with a broader range of patients and give rise to greater inclusivity.

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Authors’ contributions

All authors contributed to study concept and design. NA and LB recruited participating sites, and gained ethics and governance approvals. LB, SC and NA undertook data collection. Data analysis and interpretation was performed by LB, SC, and NA with input from CT and GM. NA and SC led on drafting the manuscript, all authors contributed to revising the manuscript. All authors have reviewed and approved the final manuscript.

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