Independent evaluation of the feasibility of using the Patient Activation Measure in the NHS in England

Final report

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The Health Foundation

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1 Executive summary

Background

1. Patient activation, which describes the knowledge, skills and confidence a person has in managing her/his own health and healthcare, maps onto person-centred care principles. Person-centred care remains central to NHS priorities, and the NHS is supporting new initiatives and the integration of services.

2. The Patient Activation Measure (PAM) is a measurement scale of patient activation based on patients' responses to questions that address an individual's knowledge, skills and confidence.

3. The PAM is a commercial tool, developed in the US, and may only be used under licence. The tool produces a scale or percentage score and a category score.

4. The category score places people into four levels of activation which are:
    *   Level 1: Disengaged and overwhelmed
    *   Level 2: Becoming aware, but still struggling
    *   Level 3: Taking action
    *   Level 4: Maintaining behaviours and pushing further

5. NHS England has worked with six healthcare organisations (five Clinical Commissioning Groups and one disease registry) to pilot the PAM. These six organisations formed the PAM Learning Set (the principles behind learning sets are that members commit regular time to attending set meetings and, in those meetings, share learning and participate in problem solving for mutual benefit). The six organisations used the PAM in different ways and at different levels of scale, across a range of approaches for improving care and supporting self-management.

6. Support for the PAM Learning Set was provided via quarterly meetings in which progress, ideas and learning were shared. Some support was also provided by an independent consultant and the developers of the PAM.

7. Our qualitative evaluation sought to capture the learning from sites' experiences of using the PAM, provide formative feedback to the PAM Learning Set, and produce generalizable, practical evidence to inform future use of the PAM.

8. An associated quantitative study, led by the Health Foundation's data analytics team, is carrying out a range of analyses that will be reported elsewhere. They are using a large observational dataset to explore whether:
    *   Likelihood of response to complete a PAM varies by level of activation, patient clinical and demographic characteristics, or practice characteristics.
    *   Patient activation is associated with variation in utilisation of health services for those with long term conditions (e.g. whether lower activated patients use services more).

Evaluation methodology

9. Our fieldwork took an ethnographic approach that explicitly sought to be pragmatic in ensuring that all relevant data sources were accessed. We used a flexible and iterative approach to question specification and data collection.

10. In total, we carried out 123 hours of observation, conducted 112 interviews, and collected approximately 180 documents.

11. Our work was organised into two work packages. The first focused on the 'core teams' involved in designing and running the PAM pilot work at each site. It sought to surface the programme theory and understand the theory of change (the rationale and assumptions about mechanisms that link a programme's processes and inputs to outcomes, along with considering the context necessary for effectiveness) as it evolved through time. The second concentrated on understanding implementation and experiences at the frontline in a purposively sampled set of six projects from across the Learning Set organisations.

Overview of sites' work

12. The PAM was seen by sites as a tool that aligned well with work they already had in progress or were planning, often in response to the issues raised in the Five Year Forward View.

13. The PAM fitted a perceived gap in the toolkit needed to enact person-centred care at the strategic and frontline levels as it was seen to offer the chance to be able to quantify soft process-orientated qualitative constructs and changes linked to person-centred care.

14. Having a validated tool that produced relevant metrics was felt to be an essential requirement for the production of business cases. This could help to convince funders to invest further in interventions associated with person-centred care, such as health coaching, care planning and peer guided courses, which might otherwise be vulnerable to cuts or changes despite their prioritisation in policy.

15. NHS England's endorsement of the PAM encouraged its use, and it had broad appeal as it was not disease specific, and it could be used with different patient groups and in social and public health initiatives.

16. It was thought that the PAM could be used in a range of ways at the population, service and individual level:
    - As an outcome measure; for example, to measure how a patient's level of activation had been affected by an intervention or a service.
    - As a tailoring tool; for example, as a means of trying to ensure that patients were receiving the most appropriate type of support according to their level of activation.
    - As both outcome measure and tailoring tool; for example, as well as using an individual's activation score to tailor the delivery of a service to a patient's particular needs, changes in PAM scores across the

group of patients using a service could be used as an outcome measure to assess the impact of that service.

Implementation

17. Sites found that they had to make changes to their initial plans for using the PAM in practice over time, and many commented that it was important to be flexible and responsive.

18. Some sites made alterations to their original plans because either, the scale of interest in the PAM had been underestimated, and/or more active approaches to gaining the engagement of healthcare professionals with the PAM were needed.

19. The learning set model for sharing learning and information worked well. However, many felt that an online system for depositing and sharing information and more opportunities for networking would be desirable, especially if the online system could be freely accessible by all those who were working with the PAM in the UK. In response, NHS England have developed the PAM knowledge, skills and confidence network for their ongoing PAM testing and learning work.

20. There were advantages to integrating PAM into new services as this meant that they could be designed around the PAM. However, take up of new services could be low if busy health professionals struggled to keep on top of all new services available to them and their patients.

21. Data management proved more complex than anticipated. PAM, and the data derived from it, could not always be integrated easily into electronic health records, meaning that sites had to develop workarounds.

22. Issues with information governance, data and systems hampered implementation. Information governance arrangements took time to resolve, especially when sharing data with third parties for analysis or as part of an intervention.

23. When consent was required from patients for their data to be shared, considerable time and thought was needed to design appropriately informative, yet accessible request letters.

Administering the PAM in practice

24. Training devised by the developers of the PAM encouraged professionals to adhere closely to the wording of the questions, ask the questions in order, and not deviate from them or elaborate on them. An implicit message was that if the PAM was not administered in a consistent way, then the quality of the data derived from it could be compromised and may not be valid.

25. The PAM was not always straightforward to administer. In a range of circumstances, mediated completion occurred. By this, we mean that the PAM was completed with input or assistance from others, or that those

inputting data from completed PAMs made judgements about which answers to record. This included: when patients wanted more elaboration before answering; when problems arose with translation; when responses were incomplete; and when others were present during administration; when patients asked for clarification of the questions.

26. In some cases, mediated completion may have been beneficial, for example:
    • When patients and professionals used the completion process to come to a shared understanding of how activated a patient was through discussion.
    • Professionals and patients could ensure they understood activation in the same way.
    • Professionals could intervene if extreme responding (e.g. answering all the questions in the same way) was noticed.

27. Efforts to avoid mediated completion may have some negative unintended consequences; for example, repeating the questions and avoiding elaboration could make professionals appear unhelpful.

28. It is unclear to what extent fidelity (using a consistent approach to administering the PAM, as advocated by the developers) to the tool should be prioritised over taking a more flexible, pragmatic approach to using the PAM. Important considerations include:
    • If the PAM is to be used to generate high-quality data fit for aggregation and fine-grained statistical analysis, for example to detect significant changes in activation and commission services at a population level, then fidelity may be important.
    • Fidelity may be less important when the intention is to use the PAM to shape the therapeutic encounter or type of service in a more person-centred way. In such cases, a flexible and pragmatic use may be more appropriate.

29. For the PAM to function effectively as a tailoring tool, the validated method of administration may have to be compromised. Research is needed to understand if, and how, more flexible approaches to administering the PAM affect data quality.

30. It is not always obvious who will need help with completing the PAM, nor how long it will take. Translation is challenging because of the range of languages in the UK.

31. The views of patients towards the PAM varied. While highly engaged patient advocates of the PAM felt the score should be routinely used to enable clinicians to engage with them in an appropriate way, other patients were less sure and did not understand the concept of activation. Some had little recollection of filling out the PAM, indicating that it did not stand out from the many other questionnaires that patients fill in. Those who could remember the PAM more clearly had some concerns, including:
    • Specific questions could be problematic, for example some patients with progressive conditions felt that item 11 (*I know how to prevent problems with my health*) was inappropriate.

- Those with multiple conditions were sometimes not sure which condition to base their answer on.
- Some patients with depression were concerned that their condition would affect how they answered.
- Patients seemed keen that their answers should be seen in the context of their particular condition/s and wider circumstances.

32. Professionals' views of the acceptability and value of the PAM to them and to their patients also varied. Those who talked positively reported that the PAM was easy to use and fitted well with their existing approaches to person-centred care. They saw potential value in:
- Using the PAM to facilitate patients being directed to the most appropriate type of healthcare professional;
- Using the score to 'kick start' conversations when a professional encountered a patient they had not met before (as a proxy for the type of knowledge usually derived from a long standing relationship);
- Using scores as a marker of progress that might validate the professional's efforts and/or the worth of an intervention;
- Using responses to specific statements to identify where a patient's immediate problems might lie and allow those to be prioritised, particularly where these relate to issues of knowledge, skills, and confidence and associated behaviour change.
- Legitimating a focus on knowledge, skills and confidence with patients - subjects that are not traditionally bio-medical.
- Using it as a tool that enabled conversations about behaviour change.
- Using the score as equivalent to a biomarker, and using it to get a sense of where to target effort and resources for the greatest gain.

33. Other professionals were less positive and expressed a range of concerns, including:
- The PAM offered little because it was overly complex, lengthy and patients found it difficult to understand.
- Greater benefit could be had from having unstructured conversations with their patients.
- The tool was not acceptable to, or appropriate for, some groups of patients.
- Too much emphasis could be placed on the score in isolation and the true therapeutic or management value of the process lost.
- Lower scores could make patients feel stigmatised (although others saw potential motivational value here).
- The 'natural history' of PAM scores was not sufficiently understood, including the extent to which they could be affected by mental health issues or life changes.

Engaging stakeholders

34. All strategic-level personnel in the sites shared a sense that the PAM was an element of a 'bigger picture' that was underpinned by a moral and ethical imperative, and the move towards person-centred care heralded a welcome and inevitable change to healthcare practices. For some, the priority was realising that change, irrespective of whether it was accompanied by the hypothesised cost savings.

35. Many sites encountered challenges when trying to engage stakeholders with their person-centred care work and, consequently, with the PAM. Some of these challenges might apply to the introduction of any new service or change to practice and, as such, are not all specific to the PAM.

36. The rationale behind using the PAM and how it fitted in with a broader shift towards person-centred care was unclear to many frontline staff and stakeholders. It cannot be assumed that the range of possibilities the PAM offers will be obvious to frontline users.

37. Ongoing pressures on time and resources in primary care meant that it was often difficult to engage general practices around initiatives like the PAM. This was not because they were inherently change averse but because they operated in a climate of increasing, and sometimes contradictory, demands from both patients and policy makers. Practices needed clarity about how participating in the projects would directly benefit their patients as they had little capacity to take on anything new.

38. Consistent and clear messages about the 'bigger picture' were required when engaging with practices, and messages would have to be tailored to how well staff understood the broader context of the PAM within person-centred care.

39. Certain individuals could act as 'gatekeepers' and prevent engagement; gatekeepers were usually individuals who were in positions of power and who might resist engaging or limit the engagement of others for a range of reasons.

40. Sometimes, resistance to engagement reflected deeper issues associated with professional boundaries. Often, self-management was not perceived as something especially 'medical' and was therefore not something that GPs felt was part of their remit.

41. Getting information about projects to the frontline was generally challenging and sites had to be proactive about publicising their projects. Many sites found that they had to bolster their approaches to communication by investing more time and identifying which approaches would be best suited to reaching their target audience.

42. Generally, it was felt that professionals on the ground were often confused about who was offering what and, if two interventions appeared to offer equivalent patient benefit, then financial considerations would take precedence.

43. Incentivising practices to participate in PAM-related work was treated with caution by some as it was felt that paying for compliance could be unhelpful and encourage a box-ticking approach. Incentivisation paired with support was believed to be more effective.

44. Many strategic level staff commented on the importance of identifying stakeholders early on, and getting information out to the broadest possible range of these. It was noted that the process of communication also acted as a means by which people could be educated about, and recruited to, the broader ethos of person-centred care.

45. Many spoke of the value of individuals who could act as champions. Any stakeholder could be a champion. Champions in the projects included nurses, healthcare assistants and patients, and often, they took on the role spontaneously.

46. One of the most powerful drivers for engagement was the clear alignment between what service users wanted and what the PAM could deliver. Many reported that emphatic messages about wanting to take control were coming from patients and that they used those to make a case for their work.

Impact: evaluations, next steps and reflections

47. Sites believe that the work they are doing is paying off, and many have framed the impact of their work in terms of having made a contribution to the spread of person-centred care.

48. The contribution of the learning set to the UK PAM evidence base remains unclear as many projects are still ongoing. There is also variability in the way they have collected and analysed their data, and in the type of data they have collected. A range of evaluation work will be needed for the further PAM testing work taking place.

49. All sites intend to press ahead with their work to embed person-centred care into healthcare. For some sites, the next steps are to progress their work and to continue to refine their approaches through using the PAM in Phase 2 of the feasibility study.

Discussion

50. Professionals leading the PAM work in the sites saw the construct of activation aligning well with the person-centred agenda, and the PAM as offering a means to measure impact and demonstrate effectiveness.

51. Some frontline professionals, including those working in strategic roles, gave examples of how 'changing the conversation' had directly benefited patients and how the new way of working had led them to re-evaluate the way they work.

52. In general, sites believe that the work they are doing is paying off, and many have framed the impact of their work in terms of having made a contribution to the spread of person-centred care.

53. While activation and the PAM are believed to have fulfilled some of their promise, residual challenges and uncertainties remain.

54. A tension arises between using the PAM as a means to generate robust comparative outcome data required for commissioning purposes and using the PAM as a less sensitive tool to provide more immediate benefit to individual patients. Any users of the PAM must give careful consideration to the possible tensions and trade-offs between maintaining fidelity for data validity and allowing flexibility for more pragmatic purposes.

55. Policy makers and commissioners may set greater value on robust comparative outcome data, while frontline staff may prioritise using the PAM in a more flexible, mediated way.

56. Mediated completion may be difficult to avoid if the PAM is to be used in a truly inclusive way. If fidelity is prioritised, then there are likely to be implications for how inclusive the PAM can realistically be and creating or re-enforcing health inequalities may be a risk.

57. Staff have commented that those with higher levels of activation can often benefit from lighter-touch care and that this will release time and resources for those at lower levels. Although many believe the biggest gains might be made by targeting resources at those with lower levels, there are concerns that they are also the hardest to reach meaning that they may be less likely to engage with the PAM.

58. The views of patients toward the PAM were varied – many had paid it little attention, but others found at least some elements of it problematic, e.g. some patients found specific questions inappropriate for them and others were not sure which condition to base their answers on.

59. Generally, we found that patients were keen to make sure that their responses to the PAM were seen by health professionals in the context of their specific condition(s) and wider circumstances.

60. Assumptions of individual agency (that is, the means to make choices and the power to act on them) are embedded within the concept of activation and some individuals' social contexts and conditions constrain agency, making change difficult to achieve, irrespective of their level of activation.

61. Professionals' views of the acceptability and value of the PAM to them and to their patients varied:
    - Those who were more negative did not perceive it as offering anything new, and some were concerned about the role of quantification in the context of person-centred care.

- Those who were more positive believed that the PAM aligned well with their existing approaches to patients and they could perceive clinical benefit to its use.

62. The extent to which the current desire for a stronger evidence base can be met by the Learning Set's pilot work, at least in the shorter term, is not clear. Producing robust evidence of change in outcomes over time that can be linked directly to patient activation and use of the PAM may still be a way off.

63. While many feel that 'proof of concept' has been achieved and that the potential utility of the construct of activation and the PAM should be pursued, a range of evaluation work will be needed for the further PAM testing work taking place.

2 Background

Person-centred care remains central to NHS priorities, building on the strategy laid out in the NHS Five Year Forward View.[1] This has been demonstrated in support for new initiatives, including the Coalition for Collaborative Care,[2] Realising the Value,[3] Think Local Act Personal,[4] and the New Care Models Programme (known as the 'vanguard sites').[5] The investment in testing and sharing new ways of integrating services to deliver person-centred care offers both opportunities and challenges for the NHS.

There is no single definition of person-centred care, and a recent review identified 160 different tools all trying to measure the concept.[6] This suggests both a welcome interest in this topic but also a lack of clarity about what exactly constitutes person-centred care and how to assess the extent to which it is being delivered. In order to try to move forwards, the Health Foundation has developed a framework that sets out four principles of person-centred care:[7]

- Affording people dignity, compassion, and respect
- Offering co-ordinated care, support, or treatment
- Offering personalised care, support, or treatment
- Supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life

'Patient activation', which describes the knowledge, skills, and confidence a person has in managing their own health and healthcare, maps onto these person-centred care principles. Patient activation is closely linked to other concepts such as 'self-efficacy' and 'readiness to change', but is argued to be a broader and more general concept, reflecting attitudes and approaches to self-management and engagement with health and healthcare, rather than being tied to specific behaviours.[8] While relevant to the principles of person-centred care across the board, the concept of patient activation is potentially most applicable to the principles of seeking to offer care that is suitably personalised, and supporting people to recognise and develop their own strengths and abilities.

The Patient Activation Measure (PAM) is a hundred point measurement scale of patient activation based on patients' responses to questions in the domains of an individual's knowledge, skills, and confidence. [9] The resulting score from completion of the questionnaire places a patient at one of four levels of activation, each of which reveals insight into a range of health-related characteristics, including attitudes, motivators, behaviours, and outcomes. The four levels of activation are as follows:

- Level 1: Disengaged and overwhelmed
- Level 2: Becoming aware, but still struggling
- Level 3: Taking action
- Level 4: Maintaining behaviours and pushing further

There is a significant and growing body of research around patient activation, its links with a range of health and health-related outcomes, and how a patient's activation level could be modified.[10] Research has suggested that improvements in

patient activation levels can be maintained over time and are associated with better self-management and lower healthcare service utilisation.[11]

A recent systematic review [12] also sought to bring together evidence on the association between patient activation levels, hospitalisation, emergency department use, and medication adherence. The review concluded that if patients were at a higher level of activation, their use of emergency services and their rate of hospitalisation were both lower. No evidence was found of a relationship between activation and medication adherence. Ten studies were included in the systematic review, all observational cohort studies. Three of the included studies used outcome data from medical or health insurance claim records, with the other seven using patient-reported data. The review urged caution, as patients in studies included in the review appeared to be more highly activated than those reported in previous studies. It concluded that further evidence is needed to fully understand the relationship between activation levels and patient outcomes, though the included studies showed some promising evidence that clinical outcomes were better for patients with higher levels of activation. Because the evidence of an association between patient activation level and the use of healthcare services comes almost exclusively from cross-sectional cohort studies, [13-20] any causal relationship between the two remains unclear. Evidence is, therefore, currently lacking that improvement to a patient's activation level, as measured by an increase in their PAM score, will lead to a change in their subsequent outcomes and healthcare utilisation, especially in the NHS in England, which has a healthcare system that is quite different to those elsewhere.

Despite a relatively large body of research surrounding the association between patient activation and healthcare usage, [13-15] there has been little robust statistical analysis of the patient and practice factors associated with return of a completed PAM. Previous analysis of the response rates for PAM questionnaires have been restricted to 'in person' collection for patients in the US. Rates of response in those studies ranged from 18% to 54%.

Previous research on the response rates of health questionnaires [21, 22] suggests that a range of patient factors could affect the probability of response to a PAM questionnaire. There have been recurrent concerns that, since less activated patients show decreased levels of engagement with other related behaviours, [16, 17, 23, 24] they may be less likely to respond to PAM questionnaires than more highly activated patients. [24] This may lead to biases in the observed population. Additionally, the characteristics of a patient's GP surgery, such as the workload of the practice, the amount of administrative support or staff engagement in the PAM initiative may also be linked to response rates. Despite the acknowledged possibility of bias in non-response to the PAM collection, there has yet to be analysis of the characteristics and behaviours of those people who return PAM questionnaires.

The PAM has been used most extensively in the US to support the management of patients with long-term conditions. A recent review identified three distinct approaches to using the PAM:[10]

- Intervening to improve patient engagement and outcomes
- Population segmentation and risk stratification to target interventions

- Measuring the performance of healthcare systems and evaluating the effectiveness of interventions to involve patients.

Although it has been validated for use in the UK, [25] little was known about how this tool could best be implemented and used in the NHS context. To try to answer this question, NHS England worked with six healthcare organisations (five Clinical Commissioning Groups and one disease registry) to pilot the PAM and supplied them with licences to use the tool. These six organisations formed the PAM Learning Set and used the PAM in different ways, at different levels, across a range of projects designed to improve care and support self-management. Support for the PAM Learning Set was provided via quarterly meetings in which progress, ideas, and learning were shared. Some support has also been provided by an independent consultant and the developers of the PAM.

In order to maximise the knowledge generated from the experiences of the six organisations involved in the PAM Learning Set, NHS England jointly funded the Health Foundation to commission an independent qualitative evaluation of the feasibility of using the PAM in the English healthcare context.

Alongside this, the Health Foundation's in-house data analytics team is conducting a quantitative study of PAM use and outcomes. Their analysis focuses on one of the Learning Set Clinical Commissioning Groups (Islington), which has the largest available sample for analysis. PAM questionnaires were sent out twice, first in November 2014 and then 12 months later in November 2015, to all patients who were aged 18 years or over, registered at the participating general practices and identified as having one or more long-term condition on the electronic medical record in primary care. Their analysis aims to answer two questions:

- First, whether likelihood of response to a PAM questionnaire varies by level of activation, patient clinical and demographic characteristics, or practice characteristics; and
- Second, whether patient activation is associated with variation in utilisation and usage of a local health economy in those with long term conditions. At the time of writing, the results of these analyses are not available and will therefore be published separately.

Interest in the use of the PAM has been steadily growing within the UK over the course of this evaluation, with organisations outside of the PAM Learning Set using the tool in a variety of contexts. In 2016, NHS England developed a new menu of local CQUINs (Commissioning for Quality and Innovation), and the menu contains 7 priority areas and 30 indicators. The Person-Centred Care local CQUIN advocates the use of the PAM, but will not be available beyond 2016-17. However, PAM is encouraged as part of the Personalised Care and Support Planning CQUIN (2017-19).

In 2016, NHS England made 1.8 million licences available as part of its work on supporting people to self-care. NHS organisations and their partners were invited to apply to use the licenses in their areas. About 50 organisations were granted PAM licences for various projects that envisage using the PAM in a range of ways and at

different levels. These will contribute to ongoing testing and learning about using the PAM in England. [26]

In summary, momentum is building behind a system-wide shift to a more person-centred form of localised care and the PAM is seen by many to have a key role in this, but questions remain about what that role can pragmatically be and how it can be optimised. In this report we highlight some key issues that have surfaced, reflect on how they can pose challenges for using the PAM in practice, and describe some solutions that sites have used.

2.1 Summary

- Patient activation, which describes the knowledge, skills and confidence a person has in managing her/his own health and healthcare, maps onto person-centred care principles. Person-centred care remains central to NHS priorities, and the NHS is supporting new initiatives and the integration of services to this end.
- The PAM is a measurement scale of patient activation based on patients' responses to questions in domains covering an individual's knowledge, skills, and confidence.
- The PAM is a commercial tool, developed in the US, and may only be used under licence. The tool produces a category score and a scale score.
- NHS England has worked with six healthcare organisations (five CCGs and one disease registry) to pilot the PAM. These six organisations formed the PAM Learning Set and used the PAM in different ways and at different levels of scale, across a range of approaches for improving care and supporting self-management.
- Support for the PAM Learning Set was provided via quarterly meetings in which progress, ideas and learning were shared. Some support was also provided by an independent consultant and the developers of the PAM.
- The qualitative evaluation reported here sought to capture the learning from sites' experiences of using the PAM, provide formative feedback to the PAM Learning Set, and produce generalizable, practical evidence to inform future PAM use.
- A linked quantitative study seeks to reveal the patient and practice factors associated with the return of the PAM and the relationship of the PAM score to healthcare utilisation.

3 Evaluation methodology

3.1 Aims and approach

Our qualitative evaluation of the feasibility of using the Patient Activation Measure was intentionally in-depth, multi-method, and theory-oriented. It sought to:

- Understand how the PAM was being used in practice.
- Understand whether and how its use changed over time, and why that was.
- Explore the impact of using the PAM in participating organisations at a range of organisational and individual levels.
- Explicate the mechanisms of change and contextual influences on the use of PAM, using a programme-theory guided approach.
- Provide formative feedback to the PAM Learning Set during the programme, prioritising information of value for optimising the use of the PAM.
- Produce generalizable, practical evidence for the future; share knowledge and learning; and disseminate research findings.

Located within the broad tradition of theory-based evaluation methods,[27,28] we drew on diverse forms of evidence including interviews, observations, and electronic and documentary material. Data collection continued throughout the course of the evaluation period. Our approach was deliberately flexible to ensure that the evaluation could respond to change within the projects in each of the six organisations, and capture the unfolding issues and processes associated with using the PAM in practice over time.

The fieldwork used ethnographic methods[27,28] and explicitly sought to be pragmatic in ensuring that all relevant data sources were accessed, for example by deciding to include PAM questionnaires that had been spontaneously commented on by patients.

We used a flexible and iterative approach to question specification and data collection. We recognised the need for a nuanced understanding of the role of contextual factors in determining what happened when the PAM was implemented in local settings.

All interviews were informed by a topic guide (Appendix 2), and were recorded and transcribed verbatim. All observations were informed by an observation framework. Observers made written notes and subsequently 'de-briefed' these, by which we mean the notes were talked through, expanded upon, and discussed in relation to existing knowledge. This de-briefing was done either by the researcher alone or within the team. De-briefs were recorded and transcribed verbatim.

3.2 Work packages

Our evaluation was broadly split into two work packages and more detail on the focus of these is given below. Across the evaluation as a whole we completed 112 interviews, conducted 123 hours of observations, and collected approximately 180

documents. The table below presents an overview of our interview data collection and the kinds of participants involved.

Participant group	No. of participants	No. of interviews
Core team members	33	61
Frontline staff	35	35
Patients	16	16

We have taken steps to protect the anonymity of our participants and throughout this report we use the following labels when attributing quotes to individuals:

- 'Core team members' - those who were involved in strategic decision making and/or implementation work at the six organisations
- 'Frontline staff' – those who were involved in delivering or supporting PAM-related projects on the ground
- 'Patients' – those receiving care provided or commissioned by the six organisations and who were asked to complete the PAM

3.2.1 Work Package 1: Surfacing programme theory and understanding the theory of change as it evolved

The organisations included within work package 1 were self-selected by virtue of having joined the PAM Learning Set. This is important to note as it inevitably means they were already engaged with the PAM and therefore the views expressed by individuals working within them may not be transferable to others outside this group.

This work package focussed on the 'core teams' involved in designing and running the PAM pilot work at each organisation and included:

- Interviewing key members of each project team.
- Conducting ethnographic observations at relevant events, including training sessions and consultation events.
- Collecting documents, such as project plans, meeting agendas and minutes, reports, training materials, and publicly-facing online material.
- Conducting ethnographic observations of the experiences and learning of all sites by attending Learning Set events and other relevant meetings.

As the first step of our evaluation, we began by having introductory telephone calls with each site and reviewing materials related to their project planning, including their initial theories of change generated from work conducted by an independent consultant. This first stage helped us better understand their projects and informed our early interviews and observations.

Across the evaluation period (from November 2014 to November 2016), we conducted five rounds of formal interviews with core project team members, and were also in touch with them informally during the evaluation period e.g. via email or when observing at events. We did not necessarily interview each team member at each of the interview rounds, but rather were guided by sites as to who was more or less closely involved at various points. Alongside these interviews with core team

members, we also conducted 123 hours of observations at both Learning Set and project-specific events.

3.2.2 Work Package 2: Understanding implementation and experiences at the frontline

Our early findings from work package 1 fed into our strategy for work package 2. We purposively sampled six projects from across five CCGs to study in detail.[29] We aimed to study a diverse sample of sites and based our selection on a number of factors including: the way in which the PAM was being used; the size of the project; the patient populations involved; the care providers involved; and the type of intervention. The projects selected allowed us to examine implementation and experience at the frontline, e.g. consultations in general practice, self-management training programmes, or other interventions.

Our core focus in work package 2 was on understanding the PAM in practice, specifically its use and function amongst different groups of staff and patients. We were also interested in the wider conceptualisations of the relevance of patient activation for both those living with long-term conditions and those involved in supporting self-management. Though we were unable to interview as many patients as we had hoped, we were able to gain further insight into patients' views and experiences by supplementing the interviews with observations of consultations and by collecting some PAM questionnaires upon which patients had written comments.

The projects included in this work package were:

- Tailored health coaching at Horsham & Mid-Sussex and Crawley CCGs
- Care planning in general practice at Islington CCG
- City-wide care planning at Sheffield CCG
- Diabetes self-management in primary care at one general practice in Sheffield
- Somerset CCG's outcomes-based commissioning framework
- Esteem self-management pilot at Tower Hamlets CCG

Details of these projects are included within the site summaries found at Appendix 1.

Data collection for work package 2 involved:

- Interviewing clinical and non-clinical staff involved in the use and/or delivery of the PAM; participants were NHS or third-sector NHS-commissioned employees such as GPs, practice nurses, healthcare assistants, administrators, and health coaches.
- Interviewing patients about their experience of the PAM and any impact on the healthcare they received, how they approach managing their health, and their response to the concept of activation.
- Conducting ethnographic observations at appropriate events and activities, agreed with the teams, including clinical consultations and other interactions in which the PAM (or data derived from it) was used.
- Collecting documents, such as meeting agendas and minutes, templates, locally-produced guidance or instructions, and copies of completed PAMs that patients had annotated with comments or questions.

3.3 Analysis

We conducted in-depth analysis of all data in order to generate on-going learning. Our analysis involved moving between different viewpoints, data sources, and theoretical perspectives to achieve a comprehensive understanding of why, and how, processes gave rise to different consequences.[30] Analysis was supported by an electronic qualitative data analysis package, NVivo, and our analytical work used constant comparative and thematic analytic techniques that were consistent with the iterative approach we took to data collection.[31,32] By combining work packages 1 and 2, we were able to explore both the 'blunt end' and the 'sharp end' of PAM implementation. Paying attention to strategic and practice perspectives on the PAM has enabled us to make connections and see the inter-relationship between the two perspectives.

3.4 Ethics and research governance

We gained ethical approval from the University of Leicester Research Ethics Committee for work package 1 and from an NHS Research Ethics Committee (South East Coast-Surrey; reference number 15/LO/0860) for work package 2. We ensured appropriate research governance arrangements were in place at all participating sites. Informed, written consent from each participant was obtained for interviews and for observations of clinical consultations.

3.5 Outputs to date

Over the course of our work we generated and maintained an up-to-date description of all the projects at participating sites and compiled case studies or site summaries that described how each site used the PAM (Appendix 1). We have produced an early findings report,[33] and an interim report in both full and summary[34] versions. We have also fed learning back throughout the evaluation by way of presentations and contributions at relevant meetings and events.

3.6 Summary

- Our fieldwork took an ethnographic approach that explicitly sought to be pragmatic in ensuring that all relevant data sources were accessed; we used a flexible and iterative approach to question specification and data collection.
- In total we carried out 123 hours of observation, conducted 112 interviews, and collected approximately 180 documents.
- Our work was organised into two work packages. The first focused on the 'core teams' involved in designing and running the PAM pilot work at each site, and it sought to surface the programme theory and understand the theory of change as it evolved through time. The second concentrated on understanding implementation and experiences at the frontline in a purposively sampled set of six projects from across the Learning Set organisations.

4 Overview of sites' work

All sites worked across multiple projects to measure patient activation in different contexts, with different patient groups, and with different aims. Their work broadly centred on the aim of improving person-centred care and improving patient self-management. Sites took slightly different approaches to structuring their project teams (see the site summaries presented in Appendix 1) but, typically, teams were multidisciplinary.

An overview of sites' projects is provided in Table 1 below, while full summaries of all projects are available in Appendix 1.

Table 1: Outline of NHS organisations and projects using the Patient Activation Measure in the NHS England Learning Set					
Learning Set site	**Project name/ service**	**No. of PAM licenses#**	**Patient populations**	**PAM function**	**Providers**
NHS Horsham and Mid-Sussex and NHS Crawley	Tailored Health Coaching Pilot	2,000	Long-term conditions/ medium risk of increased health service utilisation	Tailoring and outcome	Trained health coaches
	Musculoskeletal (MSK) service	2,600	Rheumatoid arthritis	Outcome	Sussex MSK partnership
	Tier 3 Weight Management Service	400	Obesity	Outcome	Multidisciplinary team including bariatric physicians
NHS Islington	Care planning in General Practice	28,000	Long-term conditions	Outcome	GPs
	Diabetes Self-Management Programme	10,000 patients across 3 services	Diabetes	Outcome, with the potential for tailoring	NHS Whittington Health Trust
	The Expert Patient Programme		Long-term conditions		
	Bariatric Service: weight regain intervention programme		Obesity		
NHS Sheffield	City-wide long-term condition management care planning	5,000	Long-term conditions / those at risk of unplanned hospital admissions	Tailoring	GP practices and community nursing staff
	Diabetes self-management in primary care	400	Diabetes	Tailoring and outcome	GPs
	Community mental health management	40	Mental health	Tailoring	Community mental health teams
NHS Somerset	Outcomes based commissioning, starting with the Somerset Practice Quality Scheme (SPQS) outcome framework – including several smaller pilots	Whole population	Long-term conditions, including COPD, Chronic Heart Failure, diabetes, mental health conditions	Outcome	Two accountable care organisations
	Symphony complex care model work		Patients with three or more long-term conditions	Outcome	Symphony consortia
NHS Tower Hamlets	Commissioning diabetes educational self-management	Requested but not used	Diabetes	Tailoring and outcome	NHS and two voluntary sector organisations
	Esteem self-management	220	Long-term conditions and mental health conditions	Tailoring and outcome	NHS and voluntary sector organisations
	Managing your health and well-being	75	Long-term conditions and those with uncontrolled symptoms	Tailoring and outcome	NHS and voluntary sector organisations
	Your Move	55	Older adults with long-term conditions including dementia	Tailoring and outcome	NHS and voluntary sector organisations
UK Renal Registry (UKRR)	Valuing Individuals: Transforming Participation in Chronic Kidney Disease	30,000	Chronic Kidney Disease	Tailoring and outcome	Renal units

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

4.1 Potential of the PAM to contribute to delivering person-centred care

The PAM was seen as a natural fit with sites' aims to respond to the outcomes and care they were being encouraged to deliver. Sites were already engaging with the broader changes to care outlined within the NHS Outcomes Framework and the Five Year Forward View, for example taking a holistic view of patients, keeping people out of acute care, making care more community focused, and integrating commissioning.[1,35] Sites were convinced of the potential gains to be made by helping people to manage their own health using person- and community-centred approaches, even though results from their previous initiatives had been mixed. They had become increasingly aware that different people needed different kinds of support with self-management. The PAM offered the opportunity to understand which patients need what level and type of support, and so fitted a gap in the 'toolkit' for enacting change at both the strategic and frontline level. As the PAM was made available by NHS England, it was seen to have high-level endorsement, and because it was not disease specific it could be used with different patient groups and in both social and public health initiatives.

> 'The outcomes that matter to clinicians, the outcomes that matter to patients, the outcomes that matter to finance managers, you can tell a story that brings everybody together around the PAM.' (Core team member 2, site 4)

It was clear that many people felt some frustration at being encouraged to focus on what were often regarded as relatively 'soft', process-oriented and qualitative changes. These could be changes in the relationship between practitioners and patients, the ways that individuals lived with their condition, and changes in individuals' attitudes and beliefs towards medicine. However, there was no obvious way through which these changes could be measured. They were worried that if the issue of measurement could not be addressed, then there was a danger that the initiatives and projects they were putting in place could be questioned, and their progress could stall.[36] The PAM was seen as offering a welcome solution to the problem of measurement.

> 'Actually as CCGs, if we're wanting to create change in service delivery and implementation, we need evidence to write a business case and 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 that we've achieved', to use that to write a business case.' (Core team member 1, site 1)

Much of the PAM's appeal lay in the fact that, unlike other tools, it was broad in scope and validated, and it could be used to measure the capacities that people have to manage their health.

> 'I think it covers lots of different components and because it is a validated tool and I think each question has been validated to understand an individual's level of…you know it is a measure of knowledge, skills, and confidence. I think it probably gives a far more comprehensive assessment of someone's ability to take an active role in their own self-care whereby it is not clear whether the other sort of measures were able to do that.' (Core team member 1, site 2)

For all sites the PAM was seen as a tool that could augment their ongoing efforts to embed person-centred approaches to care, and thus many saw the PAM's potential as a measure that could be used to bolster existing approaches rather than as an additional 'standalone' element of their interventions.

> 'I was going to say it is very much a bolt on to what we are already planning but it is more than that, it is our marker of progress in some regards.' (Core team member 1, site 1)

For example, Horsham already had an ongoing commitment tied to the person-centred care agenda and previous work had led to the recognition that patients' concerns were not always aligned to medical concerns. As a result, core team members in this site wanted to find a way to understand patients' concerns better. For Horsham, the PAM was a tool that could be used to structure a patient's engagement with, or participation in, a service (e.g. tailored health coaching). Further, it offered a way of understanding how the service was making a difference.

> '[The PAM] gives us a structure by which we can uniformly measure where somebody is when they enter the service and perhaps where they are when they are discharged.' (Core team member 3, site 1)

In another case, one practice identified a group of 'hard-to-reach' patients linked to diabetes self-management. The PAM was seen to offer the possibility of understanding those patients better and, potentially, to provide a better sense of how to engage them with the person-centred approaches to care offered by the practice.

> 'And I'd say maybe out of a list of 250 people you might have 30 who don't [engage]. So it's not loads and loads of patients.' (Frontline staff member 3, site 2)

In the context of the city-wide care planning initiative in Sheffield, it was felt that the PAM could contribute to enabling more person-centred care. Practitioners may be able to more effectively identify which interventions or services would be most appropriate for which patients, and to prompt practitioners to consider alternatives to medication.

> 'I think the idea is to try and identify the people who are going to benefit most from the interventions […] So I think, I think the idea is to try and, A, identify people who are likely to engage with that, and B, suggest it to them, remind you to actually suggest it to them, rather than just saying "oh, here, have some more tablets".' (Frontline staff member 2, site 3)

In other settings, the PAM was seen as less linked to existing initiatives and interventions. Instead, it was seen to have potential as a tool for generating data that could be fed into the design of future person-centred initiatives and interventions. This was the case in the Symphony complex care model in Somerset.

> 'One of the things we wanted to do was really promote people to be able to take a much greater role in managing their own conditions, and the PAM seemed ideal in terms of a way of actually measuring that, but also helping us to understand where individuals are starting from, and then tailoring our kind of interventions accordingly.' (Core team member 3, site 4)

In another instance, the PAM was used alongside another patient-reported outcome measure and one patient-reported experience measure in an element of a national programme run by the UK Renal Registry (UKRR), "Valuing Individuals: Transforming Participation in Chronic Kidney Disease".[37] The aim was to begin to build a sustainable method of collecting a range of relevant data that could improve patient experience and outcomes in the long-term.

> 'So what they're aiming to do in this programme is to use assorted measures, [….] one patient experience measure, one patient outcome measure, and the PAM, to think about how to put in place interventions to improve people's scores in all three areas, and how to commission for this going forward. So while it's a two-year project, their real aim is to create something to collect data that will be sustainable in the long-term, and so will add to the registry, and will help to improve kidney patients' lives.' (Observation, site 6)

4.2 How sites used the PAM: when, and for what purpose

In the preceding section we described how sites thought that the PAM could fit in with their broader aspirations to embed person-centred care. This section describes sites' plans for using the PAM in practice and documents their underlying logic (why and for what purpose) for using the PAM.

The diversity of the projects provided an opportunity to explore patient activation and the potential uses of the PAM across different care settings and long-term conditions, and within different interventions and approaches. Across the projects there was wide variety in the:

- Type of condition/patient group involved

- Type of intervention
- Type of health professional or other service provider involved
- Scale of the project (in terms of number of PAM licences requested)

There were different logics behind using the PAM as a tool in practice, and it was used most commonly as:

- An outcome measure (for example, used to measure the impact an intervention or service had on a patient's level of activation
- A tailoring tool (for example, used as a means of trying to ensure that patients were receiving the most appropriate type of support for their level of activation)
- Both outcome measure and tailoring tool (for example, as well as using an individual's activation score to tailor the delivery of a service to their particular needs, changes in PAM scores across a group of patients using a service could be used as an outcome measure to assess the impact of the service)

Sites often employed one or more of these uses across their work, and applied the PAM to one or more levels of scale:

- The population level
- The service level
- The individual level

Different uses of PAM across these varying dimensions are represented in Table 2, below.

Table 2. PAM logic of use, level of use, duration of use and level of resource required

Level of use	Logic of use (why it was used and for what purpose)			Duration of use	Resource
	Tailoring tool & outcome measure	*Tailoring tool*	*Outcome measure*		
Population Level	Population-level tailoring tool	Population-level tailoring tool	Population-level outcome measure	Long term	High
Service Level	Service-level tailoring tool	Service-level tailoring tool	Service-level outcome measure	Medium term	Medium
Individual Level	Individual-level tailoring tool & outcome measure	Individual-level tailoring tool	Individual-level outcome measure	Short / medium term	Medium

4.2.1 Outcome measure: population, service and individual level

The potential for the PAM to be used to evaluate and assess care provision at a service level was of interest to all sites. Two sites (Islington and Somerset) aimed to use the PAM as a population-level measure. It was thought that the data generated by the PAM could be used as a measure of the effectiveness of any intervention in supporting patient activation, and as a means of gauging activation levels in a population. In Islington, the PAM was used as a longitudinal measure to assess changes in levels of activation across the long-term condition population over time. It is intended that there will be a retrospective audit on 10% of patients with long-term conditions who have had two PAM scores. This will explore how their activation levels may have changed and it is hoped that this work may enable the development of more targeted approaches to improving activation within practices. The process for conducting the audit has been piloted in one practice. The Health Foundation's data analytics team has been working with the data generated by Islington (see chapter 2).

In 'South Somerset Together'[1], the PAM is positioned as a high-level outcome measure allied to work designed to embed person-centred care at a system-wide level by using the PAM not only to measure change, but also to drive change.

> 'It started to become clear for most people that activation was going to become a core outcome measure – mediator, proxy outcome measure, whatever you want to call it – which could help us work clearly with providers to support them to transform what they are doing from disintegrated towards integrated and person-centric.' (Core team member 1, site 4)

At the service level, use of the PAM as an outcome measure was typically linked to some form of distinct intervention or service that patients had received, either in the context of their existing care, or as some additional intervention that had been offered. Because of known challenges with demonstrating the effect of person-centred initiatives, Tower Hamlets decided to use the PAM within their already-commissioned, third sector provided, self-management pilot projects.

> 'It's hard to kind of demonstrate the impact of voluntary sector or self-management support generally, so we wanted to use PAM as a way of doing that which is the reason we increased [the pilots'] scope and included them in the evaluation.' (Core team member 1, site 5)

At the individual level, the PAM was used to measure how patients' levels of activation had been affected by an intervention or a service, for example in the case of a small–scale peer learning course in the example below.

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[1] 'South Somerset Together' is a Local Strategic Partnership in South Somerset. It consists of public, private and voluntary organisations working to improve the quality of life in South Somerset. The partners initiate and facilitate multi-agency projects.

> 'Twelve people finished [the course], and really interestingly they all went up in activation, some of them quite significantly, and it seemed to be quite a useful measure for that sort of intervention.' (Core team member 2, site 3)

4.2.2 Tailoring tool: between and within interventions and services

While some participants hypothesised that it may be possible to use the PAM as a means of tailoring services at a population level by using a population-wide activation level assessment to inform commissioning decisions, no site had developed this approach within the timeframe of the PAM Learning Set's pilot work. Some, for example Somerset, have framed this as a long–term aspiration. Similarly, the UK Renal Registry has aspirations to tailor at the service level through offering patients services and interventions appropriate for their PAM level. Within the scope of the PAM Learning Set's work to date, use of the PAM as a tailoring tool has tended to be predominantly at the individual patient level.

At the individual level, the PAM was often used for tailoring *within* interventions as a means of trying to ensure that patients were receiving the most appropriate type of support for their level of activation. The following example describes how the PAM was used in the context of telephone health coaching in Horsham to enable coaches to tailor the delivery of the coaching according to a patient's activation level.

> '[The coaches are] taking a PAM at the beginning… and then they are using that to influence the way that they work with that person and manage that person. What I've got anecdotally is that the PAM is helping with the way that they motivate that person to set their goals and to achieve those goals.' (Core team member 3, site 1)

As sites began using the PAM in practice, they began to identify other possible ways in which it could be used to tailor *within* interventions that had not been identified previously. For example, it was noted that the PAM could have a role in patient/professional interactions as a conversation starter, as a means of aligning patients' and professionals' understandings and perceptions. There was some suggestion that administering the PAM could make a therapeutic contribution in its own right as it enabled patients to have conversations with professionals about what mattered to them by making it legitimate to focus on their individual context rather than their disease. However, as we discuss later, these required deviating substantially from prescriptions for how the PAM should be administered.

4.2.3 Blended uses: outcome measure and a tailoring tool

In some cases, the PAM was positioned as both a tailoring tool and an outcome measure within the same intervention. In health coaching in Horsham, an individual's activation score was used to tailor coaching to their particular needs. Also, changes in PAM scores across the group of patients using the service were used as an outcome measure to assess the impact of the coaching.

Interest in the potential for the PAM to be used as a combination of both an outcome measure and a tailoring tool within the same service or intervention grew over time, with sites that were previously more focused on one of the two uses becoming increasingly interested in exploring the other.

> '[We've been] thinking through how we could use it both as a feedback tool, to gauge the effectiveness of what we're trying to do, but also as a clinical tool to sharpen some of those service offerings, and to basically make sure our services are better tailored to people.' (Core team member 4, site 5)

Although it made intuitive sense to maximise the utility of the PAM by using it both as an outcome measure and a tailoring tool, as time progressed, it became evident that using it for both purposes could be challenging. Arguably, and as we will go on to explore in subsequent chapters, there may be a tension between the kind of PAM implementation and data collection processes needed to generate 'clean', robust outcomes data, and approaches to implementing PAM that are more suited to its meaningful contribution to informing how a professional works one-to-one with a patient.

4.3 Summary

- The PAM was seen by sites as a tool that aligned well with work they already had in progress or were planning, often in response to the issues raised in the Five Year Forward View.
- The PAM fitted a perceived gap in the toolkit needed to enact person-centred care at the strategic and frontline levels.
- The PAM offered the chance to be able to quantify soft process-orientated qualitative constructs and changes linked to person-centred care.
- Having a validated tool that produced relevant metrics was felt to be an essential requirement for the production of business cases. These could convince funders to invest further in these interventions associated with person-centred care, which might otherwise be vulnerable to cuts or changes despite their prioritisation in policy.
- Endorsement of the PAM by NHS England encouraged its use, and it had broad appeal as it was not disease specific.
- It was thought that the PAM could be used in a range of ways:
  - As an outcome measure at the population, service and individual level,
  - As a tailoring tool at the population and service level and, at the individual level, to tailor within and between services, and
  - As a blend of both outcome and tailoring tool.

5 Implementation

Sites found that they had to make changes to their initial implementation plans over time. Most of these changes related to the practical and social challenges of implementing the PAM and the associated system change. For example, on a practical level, the UK Renal Registry had originally hoped to start to capture data from the PAM, along with other patient-reported outcome measure (PROM) and patient-reported experience measures (PREM) data, following their programme launch event in early 2015. As their work on person-centred care attracted more attention than originally anticipated, the collection of data was delayed until the feasibility of supporting renal units on a larger scale was assessed. It was decided to use a staged approach, whereby ten renal units would start and then the remaining units would begin their work later that year, enabling learning from the sites in the first step to be passed on to the sites in the second step.

'We're going to have a sort of a step-wedge approach if you like. So the first ten units will be involved as from September [2015], and then depending on the lessons learned with those ten renal units, then we'll move to the remaining 13 at a subsequent date later on in the year.' (Core team member 4, site 6)

For a number of sites, problems had been caused by delays between administering the PAM and acquiring the scores. For example, the Symphony project in Somerset used their local Commissioning Support Unit (CSU) to process the scores and it was found that this delay sometimes meant that the scores generated did not feedback to practice in a timely fashion.

Sites often encountered delays caused by governance arrangements associated with sharing patient data. Though sites were able to successfully resolve many problems, the time taken to do so meant that the start of some projects was pushed back and project momentum was lost. Issues arising from governance and data are discussed in greater depth in section 5.3.

At the social level, the need to engage stakeholders with using the PAM in practice meant that some sites changed the cohort of patients who were the focus of the piloting work. This helped to promote feelings of ownership and engagement in the community of practitioners who were using the tool.

'And 14 practices have requested that flexibility [to work with different patients]...So we've said yes – even though it might make things slightly complex – because it actually shows that people are really taking it on board and owning it.' (Core team member 3, site 3)

Many sites had done significant promotion work before they started their projects. However, sites often found that as the projects became live, they needed to spend additional time ensuring that stakeholders understood the context and rationale for using the PAM. Recruitment and engagement was often contingent on stakeholders understanding the 'bigger picture' of the shift towards person-centred care and how

the PAM and any project fitted in with that. Chapter 8 discusses the importance of engagement in more details. In some cases, sites had incentivised primary care providers to complete PAMs. However, it was found that this could lead to 'box ticking' and do little to promote genuine 'buy-in', instead taking a more supportive approach could prove effective.

Overall, projects evolved over time, and those managing them became reconciled to taking an iterative and responsive approach to ensuring that they had workable systems in place.

> 'It has been a programme that has evolved and changed shape you know quite a lot over that six month period.' (Core team member 1, site 6)

A key learning point is that time spent early on scoping the project context and, in particular, assessing system readiness for managing data and social readiness for engagement, is likely to be crucial. The importance of flexibility and responsiveness should not be underestimated.

5.1 Learning: sharing and support

As part of the pilot work, sites became members of an action learning set. The principles behind action learning sets are that members commit regular time to attending set meetings to share learning and participate in problem solving for mutual benefit. The PAM Learning Set enabled sites to share their ideas for, and experiences of, using the PAM in practice. In addition, to attend NHS England co-ordinated training and support events where the developers of the PAM presented and were willing to engage directly with sites. Learning Set meetings were held at regular intervals, and followed a set agenda of updates on progress with an open discussion of issues faced by the sites.

A number of sites felt that it could sometimes be difficult to find information about the PAM in a timely fashion, and were concerned that they might be either reinventing the wheel or spending time negotiating known pitfalls. Core staff valued the Learning Set but, as the projects progressed, many felt that they would, in addition, have liked some form of supported online system which could be freely accessed, hold relevant documents, and be used for networking. Some felt that information sharing should spread beyond the PAM Learning Set and should be accessible by all those working with the PAM in the UK, including frontline staff.

> 'You know I think there is something about using technology to sort of help share ideas, and sort of like continue to have those conversations outside of the set time.' (Core team member 1, site 2)

NHS England are reviewing how information sharing can be best supported and are seeking to develop ways of supporting a learning network.

5.2 Integrating PAM into services

The PAM was being used in services or interventions that were newly introduced in either the current or recent commissioning cycles. As discussed in the previous chapter, the PAM was generally regarded as a tool that could enhance existing approaches to improving person-centred care. Most sites integrated it into ongoing or existing recently commissioned services, or linked it into newly commissioned pieces of work.

When integrating PAM into existing services, in some cases, the tool was seen as a potentially useful outcome measure for a service that had already been commissioned, such as in the Tower Hamlets self-management pilots. In other cases, sites incorporated the PAM into ongoing local or directed enhanced services (LES or DES)[2] schemes, such as using it in the work on unplanned admissions in Sheffield.

> '[We're] using PAM in patient centred care for the high risk group that overlap with the unplanned admission DES, the national unplanned admission DES.' (Core team member 2, site 3)

In contrast to ongoing projects, the benefit of integrating the PAM into a new service or model of care was that the service could be designed around the tool, ensuring that staff had adequate time and resources to implement it. However, where novel services were being set up the work needed for the design and implementation was often accompanied by additional communication work to establish the legitimacy of the service itself within the wider provision. Some sites reported that their efforts to get new services up and running were being hampered by the climate of information overload that typified many GPs' experience of working in primary care.

> 'It's always the case when you do some service redesign, and you're putting new services out. Actually getting the message across as to what it is that is offered. Because GPs are so up against it, actually you hear about new things all the time, and taking it on board and what it means for your patients can sometimes be quite difficult to do.' (Core team member 1, site 1)

5.3 Managing data: governance and systems

Sites encountered issues with governance and data management. At times, it took considerable time to find solutions, resulting in often quite complex 'workarounds'.

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[2] Enhanced services require a level of service provision above what is required under core general medical services contracts (GMS) contracts. Practices can obtain extra funding for offering such services.

5.3.1 Governance

Many sites found that they had underestimated the time and effort needed to negotiate the complexity of information governance requirements.

> 'The thorny ones [problems] have been the information governance and information sharing. So that whole challenge of, you know, who's allowed to know what and who's allowed to share what and all that. So that's taken a lot longer to thrash out than everyone probably initially thought.' (Core team member 4, site 4)

Managing the process for gaining patients' consent for sharing their data proved problematic when the PAM was used as an outcome measure at the population level. As mentioned above, Islington were using a third party to analyse their data and because they wished to link datasets, data had to be identifiable. This meant that each patient had to be fully informed about how their data would be used and with whom it would be shared. Here, a core team member reflects on how demanding and time-consuming it was to produce a letter that was sufficiently informative, yet not off-putting for patients.

> 'I struggled writing the letter, because I didn't know what patients really wanted to know about PAM, and whether they might feel that it was a sort of slur against them to have a low score. You know, it will require a great deal of care to write a letter to them I think, and when we're wanting to link data within, you know, within the CSU, for understanding, for commissioning purposes.' (Core team member 2, site 2)

Considerable time was taken trying to word the letter so that it could be understood by a broad range of people, and the letter went through a number of iterations. The time was considered well spent as the site was pleased with the response rate it received (25% overall, although this varied by practice) and believed that this was, in part, due to the letter. Amongst other things, it made it clear that the PAM came from GPs, which gave it legitimacy amongst patients.

Concerns about confidentiality and data protection limited what could be done with which data and by whom. In the early phases of the projects some sites had expressed interest in the idea of using a PAM 'app', which could have streamlined the data collection process by enabling a PAM to be completed 'live' and an immediate result obtained. The PAM 'app' had to be bought separately and was not included in the NHS England licence arrangements. However, because the server used by Insignia (the company which licences the PAM) was not in the EU, using the app would be in breach of the Data Protection Act which requires identifiable UK data to be stored within the European Economic Area. While one site developed a system whereby identifiers were removed and replaced with anonymised codes before completed PAMs were sent in batches for analysis, this process meant that considerable time elapsed between taking the PAM and getting the score. The absence of an 'app' meant that other systems had to be designed to manage the process, and some sites resorted to low-tech paper-based solutions which were time

consuming and vulnerable to error. The new Insignia interactive spreadsheet or so called 'paper based PAM' (see section 5.3.2 below) goes some way to address this issue.

Sometimes, solutions to governance issues created other problems further 'downstream' in the projects. In the case of health coaching in Horsham it was found that coaches could not be given access to patient records. Although the coaches could use anonymised risk scores to identify that a general practice had a number of patients that might benefit from the health coaching service, they could not link that data to a specific patient and contact them directly. This meant that the coaches had to present a practice with a list of the patient codes from which the practice generated a contact list. This meant an additional burden in terms of practice time, even though practices were paid to do this. Some practices would allow the coaches to contact the patients themselves; other practices chose to make contact with the patients and compiled the list of patients who had agreed to participate for the coaches. In cases where coaches contacted patients directly, they had some concerns that it could feel a bit like 'cold calling' and that patients were sometimes unsure quite who the coaches were and whether their offer was part of a legitimate service.

> 'It feels like cold calling and it is hard to get rid of that sense of I am trying to sell you a TV.' (Frontline staff member 3, site 1)

Governance issues could also pose problems for those sites which were using the PAM on a large scale and with the aim of assessing change in activation over time. Islington had to develop a way of interrogating their data to find out who had completed the tool twice and then link their responses. At this site, PAM scores were sent in an Excel spreadsheet from each general practice to Islington CCG. This was not originally linked to any patient data. The interactive spreadsheet that has recently been developed by Insignia can link scores for different time points. Some practices recorded the PAM score on the electronic patient record using a Read[3] Code, while others used the free text box available to them.

This arrangement posed problems for the Health Foundation's data analytics team who were seeking access to the data collected in Islington for the quantitative analyses that complement this qualitative evaluation (see Chapter 2). Ordinarily, a CCG can get permission from GPs to commission analysis of patients' electronic health records to guide commissioning and care. However, it was found that permission did not automatically apply to other data collected from surveys (such as the PAM) which a patient might be asked to submit. The data analytics team were able to get permission to extract patient record data, but not to link it to the PAM scores held by the CCG. Until they extracted the data, the team were not sure how many PAM scores were available for analysis. A further complication was that the CCG did not have an existing data sharing agreement and decision process in place between them and each GP practice, and therefore a meeting had to be arranged for

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[3] Read codes are the standard clinical terminology system used in UK General Practice. They are usually five bytes and alpha-numeric e.g.12345. There is no fixed code for PAM.

each practice to sign off on the analysis. Ideally, CCGs used to have existing agreements in place with GPs governing what data could be extracted and analysed by CSUs or third parties such as the data analytics team. Getting such processes in place is time consuming and may significantly delay any project.

For some sites, patient-held records were seen as a solution to governance issues as the patient could manage their own information sharing settings. However, this solution was only practical at scale and with significant investment. Large-scale projects, such as those in Islington and Somerset, anticipate that this will make for a more streamlined process, but it should be noted that both sites already had an aspiration to implement patient-held records before undertaking work with the PAM.

5.3.2 Systems

All sites agreed that developing a straightforward, fast system for recording and storing PAM scores was a priority, but progress was often slow.

> 'You know, there surely must in this day and age be a way of doing it so that it then bounces onto your GP record so it goes straight into EMIS or goes straight into SystmOne, which would be fantastic.' (Core team member 1, site 1)

A new so-called 'paper-based PAM' recording system with an associated spreadsheet was developed by Insignia in response to feedback from sites about the delays between administering the PAM and getting a patient's score. Using this approach, the patient completes the PAM on paper and then the scores are entered into an Excel spreadsheet which has the PAM scoring formula embedded into it, thereby enabling the immediate generation of PAM scores. This improvement means that scores can be generated quickly at the point of administration, albeit in a slightly clunky way. But there are still issues about how and where PAM questionnaires and scores can best be stored to enable all healthcare professionals to have access to them so they can become a routine part of practice. At the time of writing the spreadsheet information does not automatically link with, and populate, patient records.

> 'So if you think of GP consultations being eight – ten minutes, they're going to need to come out of their EMIS system, log on to another spreadsheet, do the questionnaire, and record it. So it's about the system mechanism that isn't facilitating that.' (Core team member 1, site 5)

Further, patient record systems such as EMIS did not, at this stage, have Read Codes for the PAM, something which many found frustrating.

> 'I don't know what the Read Codes are – but if there was a Read Code for the PAM score, to be able to cut and paste the Read Code and the score across or if there was a Read Code for each score, it would just generate and say "Here's the Read Code to use" and you'd copy that and paste in the notes and the notes go "Oh yeah, that's a Read Code, I recognise that" and fine, file.' (Frontline staff member 16, site 4)

Sheffield developed a new online care planning template which enabled the PAM to be stored within it; a Read Code on notes showed that a patient had a care plan but the PAM information within it still had to be actively sought out within the care plan. In addition, the process for managing the data and entering it into the patient record was quite laborious.

> 'It needs some processing afterwards before it's usable, our healthcare assistants usually […] would go through the PAM with the patient [..] then the actual hard copy of the PAM was then passed to one of our administrators who would then put it into the spreadsheet and upload the PAM into the patient notes in its raw form but also calculate the percentage and the level.' (Core team member 3, site 3)

Frontline staff sometimes reflected that they would be more likely to use PAM data within consultations if it was more readily available in the electronic patient record. Some Read Codes have been put in place, but until this issue is thoroughly resolved, the PAM score is unlikely to become a routine part of primary care work.

5.4 Summary

- Sites found that they had to make changes to their initial implementation plans over time, and many commented that it was important to be flexible and to take a responsive approach when designing and implementing projects.
- Some sites had made alterations to their original plans because the scale of interest had been underestimated, more active approaches to engagement were needed, and/or information governance requirements needed to be negotiated.
- The learning set model for sharing learning and information worked well. However, many felt that an online system for depositing and sharing information and more opportunities for networking would be desirable, especially if it could be freely accessible by all those who were working with the PAM in the UK. In response, NHS England have developed an online network to support the sites in their ongoing PAM testing and learning work.
- There were advantages to integrating PAM into new services as this meant that they could be designed around the PAM, but new services sometimes struggled to gain legitimacy within the NHS service offer.

- Issues with governance, data, and systems hampered implementation. Information governance arrangements took time to resolve especially when data was to be shared with third parties for analysis or as part of an intervention.
- When consent was required from patients for their data to be shared, considerable time and thought was needed to design appropriately informative yet accessible letters.
- The PAM and the information it generates is not currently easily integrated into electronic health records and many sites had to develop their own workarounds.
- All in all, making PAM compatible with existing systems (information governance, data collection, record retrieval) required a great deal of work from various stakeholders in the sites, and produced local solutions that were sometimes not perfect.

6 Administering the PAM in practice

In this chapter, we focus in particular on our work package 2 data to explore the different ways that sites have approached administering the PAM to patients and how these have worked in practice, and identify key themes related to administration which are relevant to the implementation of PAM: mediated completion; language and literacy; and acceptability of PAM.

In the course of this chapter, we focus particularly (although not exclusively) on three contrasting examples of using the PAM in practice. These illustrate different administration techniques and different logics of use at different levels of scale. While full details of these projects can be found in the site summaries at Appendix 1, short versions are reproduced in Boxes 1-3 for ease of reference.

The projects are as follows:

- Horsham: Tailored health coaching in which the PAM was administered over the phone by a health coach (see Box 1)
- Sheffield: City-wide care planning in which the PAM was self-administered by patients or administered by a professional in a general practice or in the patient's home (see Box 2)
- Islington: Population-wide measurement in which the PAM was sent to patients by post and self-administered (see Box 3)

Box 1. Tailored health coaching in which the PAM was administered over the phone by a health coach

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Using the PAM over the telephone in tailored health coaching (Horsham)

PAM is used for tailoring and as an outcome measure at the individual level

PAM is administered over the phone by a health coach

The Tailored Health Coaching Pilot was aimed at up to 2,000 patients; the PAM was used to help coaches tailor their approach to patients and as an outcome measure to assess the impact of coaching on patients. Health coaches used the online training on using the PAM provided by its developers.

Health coaching was targeted at patients with a long-term condition at medium risk of increased health service utilisation, and was conducted entirely over the phone. General Practices were paid to generate lists of eligible patients and take initial consent. Next, either the practice made an introductory call to the patient, or the health coach contacted the patient 'cold'.

If the patient wished to engage with the service, the coach administered the PAM.

The patient's activation level was then used to tailor the coaching approach. Goals were collaboratively identified between coach and patient. Enablers were discussed and could include health, social care and third sector options.

If patients were at level 3 or 4 of activation, the service mainly consisted of signposting to other services.

If patients were at levels 1 or 2, further motivational interviewing and coaching was provided.

Coaches used a re-usable laminated sheet to administer the PAM; this was then scanned, wiped clean and reused. Each coach had a spreadsheet which recorded scores and other patient details. The spreadsheets were aggregated each month to give an overview of the service's activity. Each patient had a coaching file and health coaches fed information back to a patient's GP. At the time, there was no electronic interface between the coaching file and patient records.

PAM is repeated at the end of the intervention. For some patients, the PAM is administered during the intervention to assess progress.

Box 2. City-wide care planning in which the PAM was self-administered by patients or administered by a professional in a general practice or in the patient's home

Using the PAM in citywide care planning (Sheffield)

PAM is used for tailoring at the individual level

PAM is self-administered or administered by a professional

The PAM has been used since April 2015 to help to deliver person-centred care planning.

The CCG allowed general practices to make a case for using the care planning approach with a particular cohort of patients with long-term conditions. General practices were incentivised between £2,500 and £10,000 per year for completion of care plans, depending on practice size.

Ideally, 2% of the patient population would have care plans, though a lower target of around 1% of a practice's patients was accepted. It was felt that if a practice was making progress then money would not be withheld as it was more important that practices became engaged with the underlying ethos of care planning.

A care planning template (compatible with EMIS and SystmOne) has been developed by the CCG as a tool to support the care planning process. The PAM and other information can be entered into it.

Each practice was required to send at least one clinician and manager to a training afternoon. Follow-up support was provided by the multidisciplinary locality support team (LST), who acted as champions and trouble-shooters.

At the start of the care planning process the PAM was administered by practice staff (healthcare assistants, administrative staff, and nurses), community support workers and community nurses (for housebound patients).

The patient was then invited to a care planning session with a healthcare professional who would use the PAM to tailor their approach to the patient; for example, help to identify goals appropriate for a particular activation level.

The CCG is monitoring the care planning work and, to date, 4715 care plans have been completed.

Box 3. Population-wide measurement in which the PAM was sent to patients by post and self-administered

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Using the PAM as a population-level measure (Islington)

PAM is used as a population-level outcome measure

PAM is sent out by post and self-administered

In Islington the PAM project was embedded into a long-term condition focused, locally commissioned service which was initiated in October 2013. A search of electronic patient records was undertaken in each practice to identify patients eligible to complete the PAM.

The search was locally developed and uploaded onto each practice's clinical system. Practices were paid £2.50 per score to calculate and register the PAM score.

To help practices, the project team designed a template that enabled practice staff to code the patient activation score and included a free text space to record the level.

A pack detailing how to deliver the PAM was compiled and sent out to each practice. It included:

- A letter to practices explaining patient activation, how it should be measured with the PAM, and what was expected of the practice
- A step-by-step guide for collecting the data
- A letter for patients explaining why the PAM was being sent to them
- A letter for patients who did not respond to the initial mail out
- A copy of a spreadsheet that would enable practices to calculate the PAM score and level

Patients returned their completed PAMs to their general practice.

General practices were also sent details of a retrospective review that they were

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6.1 Mediated completion

Online training and guidance for administering the PAM, produced by its developers, was available to project teams. Potential users were informed that the PAM could be self-administered or administered to a patient by a healthcare professional. At learning events the PAM was positioned and framed as a sensitive instrument with a high degree of precision that needed to be administered with care in order to be valid and useful. This meant that it was seen as important that those using it were appropriately trained.

When administering the PAM face-to-face, professionals were advised to introduce the questionnaire to patients with a preamble that emphasised answering honestly and that there were no right or wrong answers. Professionals were encouraged to adhere closely to the wording of the questions, ask the questions in order, and not deviate from them or elaborate on them. An implicit message was that if the PAM was not administered in a consistent way then the quality of the derived data could be compromised.

A common theme in our data was that administering the PAM was often not as straightforward as many had expected. In all projects we found evidence of mediated completion, which means that the PAM was completed with input or assistance from others, or that those inputting data from completed PAMs made judgements about which answers to record. Those administering the PAM were, by and large, aware that the guidance for doing so emphasised fidelity to the questions and the need to avoid elaboration and explanation; however, they believed they had good reasons for deviating from this ideal completion model.

Mediated completion could occur for a range of reasons, including:

- If professionals believed their patients were answering in a way they regarded as inappropriate
- When responses were incomplete
- When others (such as family members) were present during completion
- When patients asked professionals for clarification about the questions or possible response
- When problems arose with translation or comprehension (translation is discussed separately in section 6.2 below).

Professionals were alert to cases in which patients answered in a way that they regarded as inappropriate; extreme responding (a form of response bias where people select the most extreme options or answers available) was a common concern. Some professionals worried that social desirability – the need to achieve a favourable result – was behind a patient's answers and would intervene if a patient answered "strongly agree" to everything. This was most commonly observed when the PAM was being used to tailor care in some way. When asked about this, professionals explained that they wished to ensure that the patient gets the most out of an intervention (such as care planning). Despite the training they had received, the professionals believed it was legitimate to query a patient's responses in this context.

In some cases this kind of mediated completion seemed to be beneficial. If the response to the statements did not reflect the professional's knowledge of a patient, completion of the PAM became an activity that could help to align the patient's and professional's views of how activated the patient was. In this context the PAM could be used as a means to collaboratively co-construct a mutually agreed level of activation.

'I can actually show [patients] that they're higher [more activated] than they thought they were initially.' (Frontline staff member 1, site 3)

Reaching consensus was seen as important. One professional offered the example of a patient who was scoring very low, but whom they would have classed as 'activated' as she was independently sourcing and using mobility aids. The professional began a conversation whilst completing the PAM, and found that the patient had not related their behaviours to the PAM questions. The professional enabled the patient to understand their behaviour as relevant to 'activation'; consequently the patient viewed themselves as more active, answered more positively, and was left feeling validated. The staff member was emphatic about the need to be cautious about taking answers at face value because it was not certain that everybody in a conversation shared the same understanding about activation and the PAM.

'It may even be about understanding what the actual PAM itself means. And what it actually means to the patient, and what it means to the nurse, and how they can then bring those two conversations, those two understandings together to start a conversation.' (Frontline staff member 5, site 3)

In contrast to some professionals' willingness to engage in mediated completion, there were others who were clear that they must try to avoid this. Below, a professional talks about trying not to deviate from the precise wording of the questionnaire and struggling to achieve this when asked to clarify questions. They describe how the lack of a neutral response category was problematic for some patients, and how people often wanted some discussion before committing to an answer.

'I know that with like the e-learning we did around like the PAM training, you know, sticking as closely as you can to the wording of the questions, [but] when people want some sort of clarification, it's difficult not to sort of sway them either way.' (Frontline staff member 1, site 1)

A common strategy for avoiding elaboration and conversation was simply to repeat the statements to patients.

> 'He said that they had been told very, very clearly that they do not, or they must not, change the wording, try and explain them [the questions] in any way, all they can do is keep repeating them.' (Observation, site 1)

This strategy could have negative consequences, though, and could lead to a breakdown in communication, as not answering the patient's questions could appear unhelpful and even obstructive.

Even when administering the PAM by post, it could not be guaranteed that it had been completed in an independent and unmediated way, for example, because of language issues that required input from others.

> 'It would be potentially a problem for some patients and in quite a lot of households, there is somebody who speaks English and who can read correspondence because after all people get letters from you know, the Council and such like.' (Core team member 2, site 2)

With postal completion, some forms were returned on which patients had ticked more than one response to a question and/or had omitted a question. In some of these cases, we found that the person entering the data into the patient records sought to solve the problem of multiple responses by selecting which to enter or would fill in occasional gaps if they believed they could discern a pattern in the other responses. As far as we could tell, these interventions were minor. More significant interventions were recognised to be inappropriate such as in cases where some forms were observed to be discarded when only one side of a two-sided form had been filled in.

6.1.1 Implications of mediated completion

As stated, the current training and guidance for administering the PAM emphasises that it should be administered in a standardised way to generate good quality data. We found that the PAM was not always administered in this way. This has implications for logics of use (see table 2) that demand high-quality data fit for aggregation and fine-grained statistical analysis. It helps to, for example, detect significant changes in activation and commission services at a population level, not least because mediation is probably more likely to occur with certain demographic groups, or with people with particular conditions.

In this context, it may be of benefit to adhere to the standardised method of administering the PAM as it is known that a wide range of biases can arise at different levels from different modes of survey administration.[38] More research is needed to understand whether PAM scores arising from different projects and modes of administration can be aggregated.

It is not known how much mediation and elaboration will affect PAM scores. We are not aware of studies examining the relative quality of data produced by standardised versus more flexible approaches to administration. What constitutes 'quality' in data is a broad concept, and context and use are increasingly recognised as important

factors. In other words, the use that any data will be put to dictates the quality of data required and, conversely, the quality of any data will limit the range of uses to which it can be put.[39]

With this in mind, it may be that the concerns about bias which apply at the population level may not be as relevant when the PAM is used at the individual level. Therefore, it may be legitimate to take a less controlled approach to administering the PAM when the logic of use is for tailoring within or between interventions for the individual patient.

Mediated completion may not always be problematic. Professionals and relatives sometimes questioned patients' answers when they appeared to be inaccurate and revised answers were generated that seemed to present a more accurate picture of the patient's level of activation (although we acknowledge we were not able to assess this with any degree of certainty). Arguably, having an accurate assessment of where a patient is at in terms of managing their long-term condition, irrespective of how it is arrived at, is the most important issue prior to beginning to work with that patient. Activation is a novel construct for many stakeholders. It cannot be assumed that everybody, practitioner or patient, shares a similar understanding of what frame of reference to base their response to the PAM on, and it may be important to align understandings early on. It seems that attempting to administer the PAM in a standardised, neutral, scripted way may sometimes be unhelpful and counterproductive.

Further, mediated completion may be the only way some people can complete the PAM, and care should be taken not to exclude those who cannot complete it without help. Guidance suggests that the PAM can take less than five minutes to complete. However, when completion is mediated, it may take longer, especially when people have questions or have translation needs. It may be judicious to set aside extra time for completion, so that it does not encroach into the time available for an intervention. This was the case in some of the projects in Tower Hamlets, where extra time had not been allocated for completion of the PAM and other questionnaires.

It is not clear how many people will need extra time and support to fill in the PAM. Some groups are certainly more likely to require this than others. There is a suggestion that many among the general population might also need more than five minutes. This quote from a small-scale pain management project illustrates this point.

> 'I realise that some people might have needed help really, because some of them came back without...not completely filled in and not done right and maybe we could have offered more support, but we were two [intervention providers] and we had 17 [patients].' (Frontline staff member 12, site 3)

6.2 Language, literacy, and comprehension

Although the PAM has been translated into a range of languages, including Urdu, Gujarati, Hindi, Bengali, Punjabi, Polish, Slovak, Somali, Czech, and Romanian, it was not clear that these translations always worked well and PAM completion could still require mediation.

> '[What] they were finding was that for example the Bengali translation of the PAM questionnaire was very sort of, as they described it, archaic Bengali, it was very old and people weren't understanding the questions.' (Core team member 1, site 5)

It is known that translations that are rendered word for word, and strive to stay as close to the source text as possible, often result in language that becomes 'odd, unnatural, and cumbersome'.[40] Certain cultural and idiomatic concepts may not translate at all; for example, the original version of the PAM was developed in the US and many native UK English speakers struggled with some of the phrasing of the statements especially the first which began with the phrase 'when all is said and done'. After consultation, a new non-American version of the questionnaire in English has been developed which has been better received. This indicates how challenging it is to make a universally accessible instrument, as even closely related languages and cultures can have significant and important differences that affect acceptability, interpretation, and understanding.

It should also be noted that some languages are less commonly written than spoken, for example, Sylheti and Somali, and it was felt that having audio versions of the PAM could be a solution.

> '[We'd like to] explore locally having a Sylheti option of PAM, having a Somali option of PAM, but in audio, so that you don't rely on people to read.' (Core team member 1, site 5)

Moreover, many languages have sub-dialects; for instance, Sylheti is a dialect of Bengali and Hindi. In some cases, literal translation may simply not be possible. The problem of translation also links to the problem of fidelity as, clearly, cultural differences may mean that what can be asked in one language may not be as readily asked in another. Using translators is not a straightforward option as all sites reported that translation services are increasingly under pressure and costly. Using informal translators can pose problems as translational errors may go undetected and patient confidentiality might be compromised.[41]

6.3 Acceptability and perceived value of the PAM

In this section we consider acceptability and perceived value of the PAM to those asked to use it in practice: patients and healthcare professionals/service providers, and the impact this had on engagement of those involved in administering (and completing) the measure.

6.3.1 Patients' perspectives

Though we were unable to interview as many patients as we hoped to about their experiences of completing the PAM, we have been able to explore patients' perceptions to some extent through interviews, observed consultations, and annotated PAMs. The responses we did receive were mixed, and ranged from highly positive to negative. Some had little recollection of the tool, indicating that it did not stand out from the many other questionnaires that patients fill in. However it should be noted that there was a time lag between patients completing the PAM and being contacted for interview, which may have affected some patient's recall of the PAM.

> 'You seem to fill that many in at the doctors these days that one doesn't specifically spring out to mind.' (Patient 3, site 3)

We found some examples of highly-engaged patients, who have become advocates for person-centred care and involved in the sites' work. These people have suggested that ideally, their PAM score should be used routinely in consultations so that it could enable clinicians to engage with them in an appropriate way. The following is from a patient involved in the work of one of the sites who presented at a learning event we observed – although this was not a common response from patients.

> 'She would really like a sticker on her notes that says I am level 4, I am an activated patient, I know what I am doing, don't bloody tell me the same thing again, again and again. I know how to manage this.' (Observation, site 6)

We found that some features of the questionnaire itself, how patients interpreted the questionnaire in relation to their own context, and the very concept of activation, were potentially problematic for patient engagement. Some annotated PAM questionnaires from the postal survey completed in Islington gave an indication of which questions patients might wish to discuss before answering, and why. On these questionnaires, patients highlighted specific questions that had confused or troubled them. Arguably, these represent patients' more spontaneous and immediate responses to the questionnaire rather than the subsequent views expressed in interviews.

- In response to statement 4 (*I know what my medications do*) a patient reflected that they knew what their medications were for, but not how they acted on the body in the biological sense, and so was unclear about how to answer.
- Others with multiple conditions felt that how they answered the PAM would depend on what condition they were thinking about and which condition was most troubling at the time the questionnaire was filled in. For example, a patient with depression said that how they cared for themselves depended entirely on their depression. This resonates with a recent study which found a strong negative association between activation and depression. [42]

- Some patients with progressive conditions, for example, inoperable cancer and motor neurone disease, strongly felt that statement 11 (*I know how to prevent problems with my health*) was inappropriate to their situation.
- Another patient with chronic pain indicated that statement 10 (*I have been able to maintain [keep up with] lifestyle changes like eating right or exercising*) was problematic for them to answer as pain inhibited their activity.

Generally, patients seemed keen that their answers to the questionnaire should be seen in the context of their specific condition.

There was some debate within the Learning Set about whether the term 'activation' should be used explicitly with patients, and whether resulting scores should be shared with them. The guidance for using the PAM suggests not. However, some in the Learning Set felt that to avoid doing so is at odds with principles of transparency and that avoiding it may inhibit the normalisation of the concept amongst stakeholders.

Not unexpectedly, for many patients the concept of activation was unfamiliar - one patient annotated their postal questionnaire to demonstrate their confusion.

'Is it [activation] a shot in the arm or a kick up the backside – sounds painful.' (Document, site 2)

In interview, another patient reflected that they had had to guess what 'activation' meant and what, therefore, the questionnaire was asking of them.

'I didn't quite know what was fully intended by the word [activation]. I didn't know what they were getting at and some of the questions you could answer very differently according to the sense of...behind the questions, what people were seeking to know.' (Patient 2, site 2)

It is not clear how relevant the concept of activation might be to patients and how highly they value it. Patients may not regard the kinds of outcomes encompassed within something like patient activation to be as important as things like being able to maintain their social identity and social networks, be themselves, and gain support and knowledge from professionals so that they and their families can live well with their condition.[43-45]

6.3.2 Professionals' perspectives

For successful implementation of the PAM, the engagement of the health professionals tasked with getting patients to complete the questionnaire in their day-to-day practice is crucial. Professionals' views of the acceptability and value of the PAM, and the scores it generated varied. It ranged from highly negative to highly positive, and levels of enthusiasm and engagement were highly variable as well.

Some professionals were very negative and emphatic that the PAM offered little benefit because patients found it difficult to understand what they felt were

unnecessarily complex and lengthy statements. They said that greater benefit could be gained from having unstructured conversations with patients; some felt that their everyday conversations with patients covered the same ground. It should be noted that respondents expressing this view tended to be those who worked with fairly stable patient populations and had long-standing, well-established relationships with them.

'I think you're more or less asking the same questions, but I think you're getting the same answer just by you know, you're asking these questions in a different way around, aren't you really. They should have shorter ones. I mean who's got time to go through all that lot?' (Frontline staff member 9, site 3)

Others were more positive about the concept of activation but were ambivalent towards the PAM. They felt it could be improved, although they recognised it was the only tool currently available to measure activation.

'And I think the feedback on a lot of the PAM is that they sort of get the concept of activation, and people again, like me really, not going to be convinced the PAM measure is the perfect measure of it, but then when you ask them what else would you do, they are not sure.' (Core team member 1, site 3)

When asked about what an ideal tool might look like, professionals tended towards wanting a tool that was shorter and less wordy.

Some had become less negative after using the PAM in practice. In the early phases of the pilots, a number of frontline staff had expressed worries that the PAM would not be well received by patients and would not work, but some had since revised their opinion.

'I think having read it beforehand we were a bit dubious, but it seems to work better than we thought it would.' (Frontline staff member 4, site 1)

Nevertheless, professionals often reported that they believed the PAM was less acceptable to some patients than others, and that it could cause interactional difficulties that might be difficult to recover. In the example below, the PAM was being used with older and possibly frail patients by a third sector organisation. Age-related factors may be responsible for some of the difficulties reported.

'[Doing the PAM can] set things off really on the wrong foot, and turn what might have been quite a productive care planning consultation, into something that is potentially quite antagonistic.' (Observation, site 3)

Many felt that taking the score in isolation could be problematic and saw the value of the PAM as part of a broader conversational process. Speaking with reference to

patients with diabetes, the healthcare professional below felt that too great a focus on the number could distract some practitioners from delivering a holistic service and that it was key to make sure that any improvement in a PAM score was validated by other assessments.

'I mean I personally don't think we should get bogged down in trying to improve their PAM score which is the danger [...] I don't think we can take them in isolation really. It's only any use if you see it reflect upon their health I would say. That way you've got it from a PAM one to a PAM four and still be a poorly controlled diabetic, it's not the whole point of the PAM I would think really.' (Frontline staff member 8, site 3)

Others echoed this idea and reflected that it was important to limit the emphasis placed on measurement so that the true therapeutic or management value of the PAM process was not lost. It was recognised that there were incentives to collect scores and there were worries that some professionals were merely going through the motions.

'Yes, well it's the QOF points and money basically.' (Frontline staff member 6, site 3)

A number of practitioners expressed concerns about how stable PAM scores were, and the extent to which life changes and/or mental health issues could affect scores. It was unclear to many what a significant change might look like as, if scores fluctuated naturally, it could be difficult to get a sense of how an intervention was working.

'About using the PAM as an outcome rather than as a device to guide interventions and strategies, using it as an outcome. It's the lack of information about how frequently [to administer PAM], what counts as a clinically significant difference. How big a change is important, how frequently should you measure them? What credence, what weighting should you put on how much change? You know is a 2 point change enough worth investing x thousand pounds in?' (Core team member 4, site 4)

Debate continues about what scores mean, how they should be used and whether they should be fed back to patients. Some felt that not giving patients their scores was unethical, but this concern was tempered by the worry that patients might feel stigmatised or dispirited on receiving a low score. In practice, healthcare professionals reflected that during interventions, scores should be used carefully and sensitively, in accordance with the needs of the specific patient. Some thought that scores could have value as a motivational tool for a patient at the end of an intervention.

> "Well you started off at level one and you're actually up to a three now and that's really good news. That means you're much more in control" - so you can then use it as that kind of motivational speak with the patient. (Core team member, site 1)

Many felt the value of PAM was as a tool for ensuring that patients were seen by the most appropriate type of healthcare professional. Professionals often recognised that sometimes patients were not experiencing care that corresponded with their needs, for example seeing a GP when a practice nurse might be better. The activation score was seen as a way of identifying quickly which professional would be best placed to work with a particular patient, although how decisions about this would be made was not clear.

The PAM score was also seen as potentially useful when a professional was encountering a patient that they had not met before. They felt that the score could act as a proxy to some extent for the type of knowledge usually derived from a long-standing relationship. By using a PAM score, conversations and interventions could be 'kick-started', and it offered a way of ensuring that time could be used optimally. While many professionals maintained that they knew their patients well, some frontline staff reported that they had been surprised by a score and that this had enabled them to re-evaluate their approach to the patient. However, it should be said that if there was a discrepancy between a patient's PAM score and the professional's informal assessment, it was more common for professionals to prioritise their own assessment.

Staff also reported that the scores were useful for them as a marker of progress and that they could act to validate the professional's efforts and the worth of an intervention.

> 'And then if you see like a change in their PAM score, it's quite nice to know that actually the intervention on some level has worked, even if they might not necessarily have like changed their risk score or met goals or anything like that.' (Frontline staff member 4, site 1)

In common with those at the strategic level, some frontline staff welcomed the PAM as the missing item in the person-centred care tool box, as it gave staff a means of gauging how to pitch conversations before they began, and making them more productive for the patient. This was most commonly the case when professionals did not know the patient, or at least not very well.

In some cases, the PAM had become emblematic of person-centred care and the presence and use of the tool served as a continual reminder of what they should be aspiring to deliver.

> '[It's a] reminder for me of how to be doing it, how to be doing the sort of patient-centred care type of consultation, you know, that style of consultation.' (Frontline staff member 1, site 3)

Some reported that the PAM was easy to use as they felt that it aligned with their existing interactional approaches to person-centred care and covered similar topics.

> 'I feel, and the staff have felt that it's extremely easy to use and the reason why we are saying it's easy to use, it's because they are common sense questions. And those questions are what we usually ask anyway.' (Frontline staff member 4, site 3)

Often, frontline staff reported that patients' responses to specific statements were valuable, as these could enable them to understand where a patient's immediate problems might be and allowed them to prioritise those in the conversation.

> 'For example, if you ask "do you understand all your prescribed medication" and someone might say I don't understand and I have this many tablets. So straight away you are thinking okay perhaps maybe the medication they are taking or perhaps they are not even taking the medication and not understanding it so it kind of gives you a talking point and it kind of ties in.' (Frontline staff member 5, site 1)

The answers to the questions were also felt to be useful in legitimising attempts by professionals to explore in greater depth the psycho-social elements of a patient's activation profile, i.e. to talk specifically about knowledge, skills, confidence, and the individual's context. These subjects have traditionally featured less in paternalistic consultations.

For those positively disposed towards it the PAM was seen to be a tool that enabled conversations about behaviour change to happen around it and, as such, was instrumental in achieving engagement amongst professionals with new ways of working that prioritised such issues. It could be used to show the limitations of focusing only on biological markers and highlight the importance of understanding a patient's attitude to their own health. The tool was seen by some to be valuable because it gave a comparable output to a biomarker (i.e. a hard score) and enabled them to get a clearer sense of where the most gains might be made and where it would be best to direct their efforts and resources.

> 'Equal weighting to [activation], and equal weighting to an intervention that addresses it as much as prescribing or as much as doing other things like that that actually change somebody's health from a physiological point of view.' (Core team member 4, site 4)

6.4 Summary

- Training devised by the developers of the PAM encourages professionals to adhere closely to the wording of the questions, ask the questions in order, and not deviate from them or elaborate on them. An implicit message was that if the PAM was not administered in a consistent way, then the quality of the data derived from it could be compromised.

- The PAM is not always straightforward to administer. Mediated completion (by which we mean that the PAM was completed with input or assistance from others, or that those inputting data from completed PAMs made judgements about which answers to record) occurred for a range of reasons and might, in some cases, be beneficial.
- Efforts to avoid mediated completion may have negative unintended consequences.
- It is unclear to what extent fidelity to the tool should be prioritised.
- The need for fidelity may be related to the quality of data needed for the logic of use to which the PAM is put.
- With some logics of use, the need for valid metrics is subordinate to the PAM's role in shaping the therapeutic encounter or type of service in a more person-centred way.
- For the PAM to function effectively as a tailoring tool, the validated method of administration may have to be compromised.
- Research is needed to understand if, and how, more varied approaches to administering the PAM affect data quality.
- It is not always obvious who will need help with completing the PAM, nor how long it will take.
- Translation is challenging because of cross-cultural conceptual differences and the range of languages spoken in the UK.
- The views of patients towards the PAM varied:
    - Some had little recollection of filling out the PAM, indicating that it did not stand out from the many other questionnaires that patients fill in.
    - Some highly engaged patient advocates of the PAM felt the score should be routinely used to enable clinicians to engage with them in an appropriate way.
    - Specific questions could be problematic, for example some patients with progressive conditions felt that statement 11 (*I know how to prevent problems with my health)* was inappropriate.
    - Many wanted the concept of 'activation' to be explained.
    - Those with multiple conditions were sometimes not sure about answering with respect to which condition.
    - Some patients with depression were concerned that their condition would affect how they answered.
    - Patients seemed keen that their answers should be seen in the context of their particular condition/s and wider circumstances.
- Professionals' views of the acceptability and value of the PAM to them and to their patients also varied, for example:
    - Many felt the value of PAM was as a tool for ensuring that patients were seen by the most appropriate healthcare professional for their needs.
    - To some extent, the PAM score was seen to act as a proxy for the type of knowledge usually derived from a long standing relationship and it could be used to 'kick start' conversations when a professional encountered a patient they had not met before.
    - It was thought that the scores had a value as a marker of progress and that they could act to validate the professional's efforts as well as the intervention.

- Some reported that the PAM was easy to use and fitted well with their existing approaches to person-centred care.
- Responses to specific statements were valuable as these could reveal where a patient's immediate problems might be and enable their prioritisation.
- Responses to questions could make it appropriate for professionals to talk about knowledge, skills and confidence with patients - subjects that are not traditionally bio-medical.
- For those positively disposed towards it, the PAM was seen as a tool that enabled conversations about behaviour change.
- Some felt that the score could be considered equivalent to a biomarker, and could be used to get a sense of where to target effort and resources for the greatest gain.
- Some believed that the PAM offered little because it was overly complex and lengthy and patients found it difficult to understand. They said that having unstructured conversations with their patients would have more benefit.
- Others were positive about activation but less so about the PAM, but they recognised it was currently the only tool available.
- Professionals felt the tool was more acceptable to some patients than others.
- Many felt that taking the score in isolation could be problematic. They saw the value of the PAM as part of a broader conversational process. Some reflected that it was important to limit the emphasis placed on measurement, so that the true therapeutic or management value of the PAM process was not lost.
- Concerns were expressed about how stable PAM scores were and the extent to which they could be affected by mental health issues or life changes.
- Some felt the scores could make patients feel stigmatised, but others thought that scores could have value as a motivational tool.

7 Engaging stakeholders

7.1 Challenges to engagement

Many sites encountered challenges when trying to engage stakeholders with their person-centred care work and, consequently, with the PAM. This chapter reports some of these challenges and the most common strategies used to address them. It should be noted that many of these challenges could apply to the introduction of any new service or change to practice and, as such, are not necessarily specific to the PAM.

7.1.1 Missing the bigger picture

All strategic-level personnel in the sites shared a sense that the PAM was an element of a 'bigger picture' that was underpinned by a moral and ethical imperative, and they felt that the move towards person-centred care heralded a welcome and inevitable change to healthcare practices. For some the priority was realising that change, irrespective of whether it was accompanied by the hypothesised cost savings.

Over the course of the projects, core team members came to recognise that they needed to do more to put the PAM into context if they were to successfully engage frontline staff.

> 'So we clearly haven't succeeded in getting across that really the PAM is a tool in order to be the way that you treat patients. But I think that is really because it's new, and that once people get used to it I'm hoping that, you know, the understanding will develop.' (Core team member 3, site 3)

It was felt that the 'bigger picture' was not always widely understood. The rationale behind using the PAM and how it fitted in with the broader shift towards person-centred care was unclear to many frontline staff and stakeholders. It was also evident that, in practice, engagement with the broader principles varied greatly. For example, in Sheffield, it became clear that consistent and clear messages about the 'bigger picture' were required when engaging with practices, and that messages would have to be tailored to how well staff understood the broader context of the PAM within person-centred care.

> 'But there's huge variation with some people thinking that it's really useful and wanting to do the follow ups, and some people still not quite understanding how it fits in and almost seeing that doing a PAM is an end in itself.' (Core team member 3, site 3)

Ongoing pressures on time and resources in primary care meant that it was often difficult to engage general practices around initiatives like the PAM. This was not because they were inherently change averse but because they operated in a climate of increasing and sometimes, contradictory demands from both patients and policy

makers. Practices needed clarity about how participating in the projects would directly benefit their patients as they had little capacity to take on anything new that did not have a clear value.

> 'But there's a lot of resistance around […] and now we're at capacity, we can't take on doing anything new, there's a sort of slight tunnel vision around what can improve things for you and your patients when you're actually overstretched yourself. And so I think that has an impact, so that's going to be a harder sell than perhaps we anticipated I think.' (Core team member 3, site 5)

Some felt that they had underestimated the contextual challenges faced by practices and the importance of taking these into account when communicating the benefits of the PAM.

> 'So I think it's trying to package everything together, rather than going out to practices and saying can you do this, and then two months later can you do this, and two months later and can you do this. I think what we need to do is say look, you know, this PAM score could feed into whether or not the person is in the right place, and have they got the needs to do integrated personal commissioning. So it gives you something to bring it all together and see it all as one holistic process, as part of the personalised care planning, as opposed to another task on top of everything else.' (Core team member 3, site 5)

It was recognised that although the 'bigger picture' was understood by many at the strategic level, those on the ground could see PAM as being simply another drain on resources that offered little reward for the effort it took. For them, it was possibly just another data collection task with little relevance to the care they delivered day-to-day. This could easily set engagement with the PAM back, as initial discussions with frontline staff about using the PAM could get off on the wrong foot. Some felt that they had inadvertently pitched the PAM incorrectly at the outset by emphasising a particular logic of use for the PAM (high-level outcomes-based commissioning), rather than explicitly promoting the ways clinicians could use the tool to tailor the care they delivered. It was noted that it could not be assumed that the range of possibilities that the PAM offered would be obvious to frontline users or that they would invest time in experimenting with it.

> 'Again they saw it very much as an additional task, and I think that's probably an error on our part, in terms of how we went to them and said it in the first place, we almost made it a data collecting task, as opposed to saying do you know what, this is a tool you can use to actually work with individuals.' (Core team member 3, site 5)

7.1.2 Gatekeepers

We found that certain individuals could act as 'gatekeepers' and prevent engagement. Gatekeepers were usually individuals who were in positions of power

within practices, for example partners and practice managers, who could resist engaging for a range of reasons. More paternalistically-inclined practitioners simply felt no need to change as, from their frame of reference, they already practised in a person-centred way. Asking people to change, or at least do something additional, could be taken as an implicit critique of the way they were working.

> 'Some clinicians will argue that they are already doing this without necessarily understanding some of the unique differences that can be quite small, but to a patient, they are very big.' (Core team member 2, site 1)

Sometimes, GPs had been caring for the same patients for many years. They were reluctant to relinquish their involvement with their patients by referring them on to other externally-provided services. It was felt that the message about person-centred care and activation should feature more strongly in workforce training. Efforts are being made by some GPs, with links to the Royal College of General Practitioners, to progress this. The general sense was that paternalism was dying out, but had yet to do so entirely.

> 'I think a lot of them say that they do [practice person-centred care] but they don't practice it. When I say GPs, I don't just mean GPs. I mean clinicians in general. I mean consultants and nurses and the whole gambit.' (Core team member 3, site 1)

Practice managers could also play a gatekeeping role, and sometimes those who were running highly business-orientated practices could prove resistant if there was no obvious financial benefit to their participation.

7.1.3 Professional boundaries

Sometimes resistance to engagement reflected deeper issues associated with professional boundaries. Using the cases of care planning and occupational therapy as examples, a GP reflected that often self-management was not perceived as something 'medical' and was not, therefore, something that GPs would feel was part of their remit; rather it was something that should be done by nurses or other staff. The GP reflected that there was a tendency that things that could be delegated ended up 'out of sight and out of mind', and there was a danger that new approaches to patient care would pass them by.

> 'It's quite airy fairy, this is a different way of doing it, this is supporting self-management, this is a key part of medical care, but it can be delivered by a wide range of people, so I think it's really crucial that whatever you do, you keep the GPs engaged in some way. Otherwise, there's a real danger they just push it aside and go 'well the district nurses do that' or 'the practice nurse does that' and GPs are very good at doing that, that's what we have to do, we have to delegate stuff. But I think this is too important a paradigm shift to allow the GPs just to sideline it off, because if they don't buy into it and if they don't really support the value of it, they won't carry the patients along and it won't happen.' (Core team member 3, site 3)

Other factors associated with non-engagement included worries about being deskilled, Anglo-American cultural differences, and antipathy towards the term 'activation'. In Somerset, where GPs could potentially see their more complex patients transferred to a care hub, it was reported by some core staff that some GPs seemed particularly concerned about becoming deskilled and dealing with minor and routine care rather than complex care management.

> 'They worry about becoming deskilled and just getting all the boring bits.' (Core team member 3, site 4)

The initial version of the PAM, that used American phrasing, generated problems due to Anglo-American cultural differences. Following discussions with NHS England, a new English version of the PAM has been developed. However, some individuals continue to have concerns about the PAM's apparent links to the private healthcare system in America.

> 'They said it sounded more like a sales pitch and they disengaged with it completely. It was far too American for them and they just switched off and left early [from a training event].' (Observation, site 1)

Some disliked the term 'activation', feeling that it was overly biomedical and did not align well with their understanding of the person-centred care agenda.

7.1.4 Overload: the frontline context

Getting information about projects to the frontline was generally challenging and sites began to realise that they had to be more proactive about publicising their projects. They could not assume that their e-mails would be read.

> 'You know I anticipated, naively, if you sent information that people would read it.' (Core team member 4, site 4)

The reality was that often, frontline staff would receive several hundred emails a day and were operating in a culture of information overload. They simply did not have the

capacity to deal with anything that did not immediately appear to be important. Many sites found that they had to bolster their approaches to communication by investing more time and identifying which approaches would be best suited to reaching their target audience.

> 'I think the big things over the next few months, getting out, either doing Webexes with them or visiting them, producing information for the sites and engagement with the sites.' (Core team member 3, site 6)

Some reported that requesting space for brief presentations on the agendas of already scheduled meetings (for example, multidisciplinary team meetings in practices) was a useful strategy.

The PAM projects did not enter the healthcare context in isolation and in many sites there were other initiatives and services that competed for GPs' attention. For example, Horsham noted that the Better Care Fund's enhanced primary care service initiative went live at a similar time. Under this scheme practices could receive monies to deliver a care coordinator role. The project team thought that practices may have been reluctant to refer patients into health coaching in case this reduced the pool of patients that could be used to make a case for their eligibility for the enhanced primary care funding.

> 'There's a little bit of protection going on at the moment, because they don't quite understand the difference between the two.' (Core team member 1, site 1)

Generally, it was felt that professionals on the ground were often confused about who was offering what and, if two interventions appeared to offer equivalent patient benefit, then financial considerations would take precedence and that which appeared to be the most cost-effective would be preferred.

7.1.5 Evidence and engagement

In the context of engagement, the evidence base for the PAM seemed to act both as an enabler and a barrier, depending on how it was perceived. Some viewed it critically whilst others felt that it justified the use of the tool.

Some sites reported that scepticism towards the evidence base for the PAM had been cited as a reason for the frontline not engaging with the projects. There was also some scepticism amongst some core team members; for example, this team member reported that they felt that the evidence base might not be entirely objective as those who produced much of it were associated with the company that licensed the tool. Nevertheless, they felt that there was sufficient justification to follow through with implementing the PAM.

> 'I sort of have a worry in the back of my mind around the PAM that you know, this is a tool that's been developed in America. Most of the evidence base has been produced by the company that developed the tool and the university developed the tool, and I'm still slightly 'jury's out' as to how useful it is. I'm still very keen to follow it through, but I'm still not utterly convinced it's the right thing.' (Core team member 1, site 3)

Many felt that the limitations of the current evidence base meant that it was vulnerable to criticism by those who did not want to engage. There was the need to build a more credible UK evidence base, and this was sometimes cited as a reason for instituting and engaging with projects.

When people spoke about the evidence base, it became clear that many had not engaged with it in depth. Some reported that it was quite difficult to interpret, especially for those without statistical expertise. Some mentioned that they would like to be 'walked through it' by somebody neutral, so that they could be clear about what evidence supported the high-level messages they had been hearing.

> 'I mean, I've read lots of high-level blurb about how it's great and it's reliable and it's this, that and the next thing. But of course I haven't actually looked at published literature where people have tested it out and shown its reliability and shown that it meets all of the criteria and shown that it can be used as an outcome measure, I suppose I still have, not doubts in my mind, I just like to know, I'd just like that to be, I'd like somebody to show me it so I can go 'oh right, that's fine, I'm happy'.' (Core team member 4, site 3)

7.2 Addressing engagement challenges

7.2.1 Financial incentives

Financial incentives were used by some sites. Islington were interested in getting data for population-level analysis and were not, at that stage, focusing on getting the PAM used by practitioners as part of routine consultations, or driving a cultural shift in the way that staff delivered care. They took a pragmatic approach and paid practices for engaging in data collection, getting what they felt was a comparatively good response (25% overall, but with variation across practices) in terms of the number of PAMs completed.

> 'Well we haven't really engaged a great deal with staff. We've just told them this is what they have to do, and […] they get a payment for it.' (Core team member 2, site 2)

In Tower Hamlets, incentives were also used, and practices were offered around £5 per patient for completing and recording the PAM, but completion rates were low. When the project team investigated by speaking to frontline staff they found that they had not accessed the available on-line training on using the PAM and had not been

able to see the benefit of it. Financial incentivisation alone is not sufficient to drive engagement.

'The reason people aren't doing the PAM questionnaires in spite of incentivisation is because they haven't had the training. They don't really understand how it all fits in and how it can make their day job easier.' (Core team member 1, site 5)

In contrast, some sites such as Horsham did not begin by using incentives. However, they found that the number of patients referred into the health coaching service was lower than had been hoped. It was decided to offer GPs a payment for the time and resources needed to identify and refer patients, so that practices would not be 'out of pocket'. The CCG also felt that by investing resources, they were seen to endorse health coaching. The practices began to promote the service more actively and to emphasise the immediate gain of getting more patients referred on to other services.

'I think there was a payment term that was given to the doctors. I think a clear explanation and a willingness to see that this could work for their patients. I think GPs are really keen to see that there are other services out there that move the reliance on their service away from them.' (Frontline staff member 6, site 1)

Incentivising practices to participate in PAM-related work was treated with caution in Sheffield, as driving cultural change was one of their core project aims. It was felt that paying for compliance could be unhelpful and encourage a box-ticking approach. Sheffield were clear that the point of the scheme was to achieve culture change and were prepared to play a 'long game'. Having said that, incentivising care planning was part of their strategy and, in the pilot phase of their work, payments were made for nearing an agreed target of care plans. It was thought to be important to get practices used to care planning and to give them time to develop their own methods for doing so. With time, the quality of the care plans became more important to the project and, as part of the conditions of the second round of the scheme, practices were asked to produce detailed project plans and to develop case studies to illustrate their care planning work. In this way, the practices still enjoyed some flexibility around setting their own targets, but were also creating their own standard to which they could be held accountable. Sheffield's approach has enabled them to reward engagement and prioritise quality over quantity.

'If a practice is showing willing and making some progress then we're not going to withhold money.' (Core team member 5, site 3)

At the same time, Sheffield were equally clear that if practices committed to the project, but then refused offers of help and did not deliver on their plan, they would not be paid.

7.2.2 Mobilising stakeholders

Many strategic-level staff commented on the importance of identifying stakeholders early on, and getting information out to the broadest possible range of these. It was noted that the process of communication was not just about the dissemination of information about projects but also acted as a means by which people could be educated about, and recruited to, the broader ethos of person-centred care. Some made a distinction between immediate stakeholders, those directly relevant to the project, and those at a strategic level.

> 'You know we have been out and have spoken to them [professional peers] and have engaged with them and they said this would be amazing […] but actually it is not only those guys we have got to convince, it is the clinical leaders as well that also need convincing.' (Core team member 2, site 1)

Some felt that, in hindsight, they could have invested more effort in targeting strategic-level stakeholders and in generally giving more thought to stakeholder relationship management. It was felt that although those in influential positions were harder to reach, the effort would be worthwhile as top-down influence could help with the engagement process.

At the start of the projects, it was not clear what course engagement would take. It became clear that time was an important factor and gaining engagement could be a lengthy process that could slow the progress of projects.

> 'One has to absolutely recognise that this is a gradual process. You tend to get, as is always the case, the early adopters at the beginning and people come on board gradually.' (Core team member 1, site 2)

In Sheffield, it was felt that one of the distinctive features of their work was that it had a longer timescale than most primary care change projects. That gave their work greater legitimacy as general practices would not feel they were buying into something that would disappear.

> 'It's happened across two years in a row, which is quite important, because that's consistency for general practice that often these projects are 'one year ones' aren't they? And they give it one year then it's gone.' (Core team member 2, site 3)

Another version of the PAM, completed by clinicians, was used by one of the sites to engage stakeholders. The CS-PAM (Clinician Support for Patient Activation Measure) is a measure of healthcare professionals' awareness of and attitudes to patient activation.[46] The UK Renal Registry (UKRR) used it in their engagement work as a means of assessing and, if necessary, challenging clinicians' approaches to practicing person-centred care. They were clear that change is needed within the workforce if person-centred care is to become embedded, and have recognised that

many do not think that they need to change as they believe that they are already practicing person-centred care.

> 'So by using CS-PAM, we'll actually find out how engaged they really are in this, in patient participation, and hopefully again might look at ways of training them so that instead of talking at the patient and sort of although making… what shall I say... piecemeal offers of the patient having a choice, actually influencing them.' (Core team member 2, site 6)

7.2.3 Champions

Many participants spoke of the benefit of face-to-face communication and the value of individuals who could act as champions. In Horsham, for example, general practices were visited by members of the project team who explained what the health coaching service was, and how it would directly benefit the practice and their patients.

Any stakeholder could be a champion - those identified as champions in the projects have been nurses, healthcare assistants, and patients - and they often took on the role spontaneously. The key function of the champion was to act as an advocate, and often champions were spoken of as 'real enthusiasts' who were the glue that held a team together. The champion model is not without its problems though - in one project, the champion (a GP) went on a sabbatical and this had an impact on the practice's work in this area.

> 'There was a bit of a change in the practice, they didn't stop doing anything but they didn't make quite as much progress as when he was there so, no, it does make a difference even in the most forward of the practices.' (Core team member 3, site 3)

Sheffield's Locality Support Team (LST) has been key to driving engagement with the care planning work. The CCG directly funded the LST until the end of 2016. The LST is made up of a range of healthcare and other professionals (including GPs, practice nurses and practice managers) and met regularly. It was felt that one of the strengths of the team is that they are able to ensure visits to a practice from personnel who have experience of doing the same job as those they are engaging with. This facilitates an equable, peer-to-peer learning dynamic. It was felt that using peers was important as they were seen to be able to understand issues from a shared perspective. They also felt that the LST 'peers' acted as endorsements for the work amongst their colleagues. Practices could ask for support directly but the LST were also in regular contact with practices, including those from whom they would like to see improvement. As Sheffield have required practices to produce care plans and other documentary evidence of their approach to care planning work, the LST has been able to 'take the temperature' of engagement within practices and understand which practices might need additional support and encouragement.

Others within core teams also saw the value of using their professional status to reach peer audiences and made efforts to 'plug' their work when an opportunity arose. In effect, they acted as role models.

> '[Local] events, networking, so clinical-level networking events and plugs. I've stood up there and plugged the concept of activation and what we're doing with the tailored health coaching. And I think it just resonates with clinicians, it certainly did with me. (Core team member 1, site 1)

Other sites which had not used champions as much commented that with hindsight, they would have liked to identify champions earlier on in their work as this could have helped with the engagement process.

> 'I think finding local champions would be a big thing so actually engaging with people who are interested and then getting them to work.' (Core team member 3, site 5)

7.2.4 Patient involvement

One of the most powerful drivers for engagement was the clear alignment between what service users wanted and what the PAM could deliver. Many reported that emphatic messages about wanting to take control were coming from patients and this helped to make their case.[47]

> 'That what we were doing was as a result of, not only research, but feedback from your patients, so your patients with long-term conditions. This is what they want. Every meeting she [colleague] goes to, is kind of bashing on about patient activation and tailored health coaching and everything else that we're kind of doing.' (Core team member 1, site 1)

All sites involved patients in their work to some extent, but in keeping with their high-level commitment to co-production, the UK Renal Registry (UKRR) aspired to ensure that the work they did would involve patients at all stages and at all levels. A patient was co-chair of the broader programme and, on the ground, patients worked in the projects.

The UKRR did a great deal of scoping work to identify stakeholders early on to ensure that they could engage with the broadest possible range of interested individuals at all levels.

> 'I started to engage with the national clinical director for renal who was just appointed, the Renal Registry, but also more broadly the renal patient community. That was organisations and charities along with quite active patients in that area.' (Core team member 5, site 6).

It was thought that having such a wide mix of patient representatives and stakeholders was beneficial and fitted with the ethos of the programme. There was

some caution expressed about whether the same interest and expectations would be shared by everyone involved.

> 'I do think there is an issue like there is with anything that is a partnership and it has got lots of players involved at different levels. There is probably slightly different interpretation of what we are doing or emphasis on certain elements more than others I guess from the perspectives of partners involved but certainly so far I think in terms of getting engagement it has gone well.' (Core team member 5, site 6)

Each renal unit involved in the programme was asked to put together a multidisciplinary team of ten people - equal numbers of patients/carers and professionals. A project co-coordinator was put in place to facilitate this process and to ask what support each unit might need. The coordinator visited each unit and found considerable variation in the degree to which they had progressed. For the success of the collaborative element of the work, the UKRR had to ensure that patients and professionals would engage with the project to the same degree. Interestingly, they reflected that they perhaps had placed too much emphasis on reaching patients at the expense of reaching professionals.

> 'And the other thing that we clearly underestimated was actually the level of engagement that was required from staff. You know everybody thinks about - oh yes, we have to have the right wording, we have to have a leaflet that explains what happens to patient data, you know if they get involved in this programme and what it means to them and it has got to be written in a lay person's language and all of that but we haven't really given any thought to the fact that actually, this is a major undertaking for a renal unit. If you have not got the clinicians engaged it is going to fail.' (Core team member 1, site 6)

7.3 Summary

- All strategic-level personnel in the sites shared a sense that the PAM was an element of a 'bigger picture' that was underpinned by a moral and ethical imperative, and the move towards person-centred care heralded a welcome and inevitable change to healthcare practices. For some, the priority was realising that change, irrespective of whether it was accompanied by the hypothesised cost savings.
- Many sites encountered challenges when trying to engage stakeholders with their person-centred care work and, consequently, with the PAM. Some of these challenges might apply to the introduction of any new service or change to practice and, as such, are not all specific to the PAM.
- The rationale behind using the PAM and how it fitted in with a broader shift towards person-centred care was unclear to many frontline staff and stakeholders. It cannot be assumed that the range of possibilities the PAM offers will be obvious to frontline users.

- Ongoing pressures on time and resources in primary care meant that it was often difficult to engage general practices around initiatives like the PAM. This was not because they were inherently change averse but because they operated in a climate of increasing and sometimes, contradictory demands from both patients and policy makers. Practices needed clarity about how participating in the projects would directly benefit their patients as they had little capacity to take on anything new.
- Consistent and clear messages about the 'bigger picture' were required when engaging with practices, and that messages would have to be tailored to how well staff understood the broader context of the PAM within person-centred care.
- The rationale behind using the PAM and how it fitted in with the broader shift towards person-centred care was unclear to many frontline staff and stakeholders. Practices needed clarity about how participating in the projects would directly benefit their patients as they had little capacity to take on anything new that did not have a clear value.
- Certain individuals could act as 'gatekeepers' and prevent engagement; gatekeepers were usually individuals who were in positions of power and who might resist engaging for a range of reasons.
- Sometimes, resistance to engagement reflected deeper issues associated with professional boundaries. Often, self-management was not perceived as something 'medical' and was not, therefore, something that GPs felt was part of their remit.
- It was found that getting information about projects to the frontline was challenging and sites had to be more proactive about publicising their projects. Many sites found that they had to bolster their approaches to communication by investing more time and identifying which approaches would be best suited to reaching their target audience.
- On the ground, it was felt that professionals were sometimes confused about who was offering what. If two interventions appeared to offer equivalent patient benefit, then financial considerations would take precedence.
- Incentivising practices to participate in PAM-related work was treated with caution by some as it was felt that paying for compliance could be unhelpful and encourage a box ticking approach. It was believed that incentivisation paired with support could be most effective.
- Many strategic level staff commented on the importance of identifying stakeholders early on, and getting information out to the broadest possible range of these. Besides disseminating information regarding projects, it could be the means by which people could be educated about, and recruited to, the broader ethos of person-centred care.
- Many spoke of the benefit of face-to-face communication and the value of individuals who could act as champions.
- Any stakeholder could be a champion - those identified as champions in the projects have been nurses, healthcare assistants, and patients - and, often, they took on the role spontaneously.
- One of the most powerful drivers for engagement was the clear alignment between what service users wanted and what the PAM could deliver. Many reported that emphatic messages about wanting to take control were coming from patients and that it made a case for their work.

8 Impact: evaluations, next steps, and reflections

This chapter describes the impact of using PAM in the settings and contexts in which the sites have used it. It gives an overview of the evidence and learning that has been generated to date and from any evaluations commissioned by the sites externally (focusing in particular on our work package 2 case studies). It should be noted that we have not critically evaluated the statistical methods used by the sites. Therefore, we cannot comment in specific terms about the appropriateness of any techniques used or the robustness of any analysis.

Sites have taken different approaches to evaluating the effectiveness of the changes they have sought to make. Some sites have conducted their own evaluation work (e.g. Sheffield) and others have used independent evaluators (e.g. Tower Hamlets). Many evaluations have used changes in PAM scores as their main outcome measure, but sites have also drawn on qualitative data; for example, case studies, and information from patients and professionals.

All sites intend to press ahead with their work to embed person-centred care and to continue to refine their approaches to using the PAM. In general, sites believe that the work they are doing is paying off, and many have framed the impact of their work in terms of having made a contribution to the spread of person-centred care.

> 'That's been the biggest impact really. People can think differently about how to work with individuals to support them. It starts a whole conversation about health behaviour change.' (Core team member 4, site 4)

Some frontline professionals, including those also working in strategic roles, have cited examples of how 'changing the conversation' has directly benefited patients and also of how the new way of working has led them to re-evaluate the way they work.

> 'When we first asked the patients what do you think is really important to you?' [They say] 'Oh, I don't know. I've never been asked that before […] a patient, the other day said that having some hearing aids is the most important thing ever for her. […] and she had great-grandchildren and said I've never been able to hear their voice. [ ] You just learn so much more about people than 'well your bloods are high, right you've got to do this, this and this and we'll review you in six months'.' (Core team member 5, site 4)

It is still unclear how much contribution the Learning Set will make to a robust UK evidence base because many projects are still ongoing, and there is variability in the way that they have collected and analysed their data, and in the type of data they have collected.

8.1 Sites' progress, evaluations and next steps

8.1.1 Horsham

In Horsham, the PAM was used as part of a tailored health coaching pilot to tailor the approach taken to health coaching, and as an outcome measure to assess the impact of the intervention on patients' ability to manage their health.

The telephone health coaching service has now been in place for over a year and they report seeing evidence of immediate behaviour change amongst service users. However, they recognise that it is too early to determine whether the changes they have seen will be sustained and their ongoing aspiration is to explore that further.

Horsham measured PAM scores, individual risk scores, healthcare utilisation and costs, and patients' wellbeing (using the Warwick-Edinburgh Mental Wellbeing scale). In the evaluation of the service, they have compared those patients who went through the service (over 100) with those who had declined it. They have used this latter group as a 'natural control group', although its validity can be questioned as there may be significant differences between the two groups.

Their evaluation has found that the cohort who completed the coaching showed an increase of, on average, one PAM level. It was found that the increases in the PAM score correlated with increases in the Warwick-Edinburgh Mental Wellbeing scores. Risk scores, which had previously shown an upwards trend, have now shown a decrease and the team are keen to see if this effect continues over time.

Horsham also found some suggestion that healthcare utilisation, and therefore cost, has decreased for many patients. The team at Horsham recognise that there are challenges for quantifying the exact savings made, as variability exists in terms of the charges and tariffs attached to different services by different providers. Consequently, they have taken an average across the site and found an approximate saving of £450 per head. If the downward trend in utilisation and risk scores continues, the site will be in a position to make a case for further savings in the future.

Horsham's analysis showed an anomalous finding in that A&E attendance declined more in the control group than amongst those who had used the health coaching service. The team intend to explore this further. Horsham have a clear sense that their work will bolster their business case for health coaching.

'We can conclude very loosely that perhaps health coaching doesn't have an impact necessarily on A&E attendances, but it quite clearly has an impact on healthcare utilisation in terms of people taking more control and using the planned activities of follow-up appointments and seeking advice from their consultants in a planned way rather than relying on sort of, you know, emergency situations. And obviously that then has a knock-on effect with emergency bed days and the corresponding drop in cost for emergency bed days.' (Core team member 3, site 1)

Horsham are participating in the ongoing PAM testing and learning work. They plan to open up the health coaching service to different patient groups and will attempt to engage those at higher risk. They also plan to encourage referrals from a wider range of staff. Horsham are also hoping to target high users of 111 and 999, and they are developing a project with their local ambulance service. In order to enable paramedics to refer patients directly to the health coaches, a number of governance issues will have to be resolved. It is expected that frequent users of emergency services may have greater psychological needs and so, they have made links with the local mental health trust. The health coaches are being given additional training in techniques to engage people with personality disorders. Horsham are also seeking to work with people who are newly diagnosed with long-term conditions, as they feel that introducing coaching at a much earlier stage can benefit these patients.

The team in Horsham have noted that in the last two years, activation seems to have become more widely understood amongst professionals. As a result, they feel that it will be easier to get buy-in for new projects. The CQUIN is also seen as a driver for engagement with person-centred care.

8.1.2 Islington

Islington have used the PAM as a population-level outcome measure. They conducted a postal survey at two time points and the data analysis is being conducted by the Health Foundation's data analytics team (see Chapter 2).

It is not clear what degree of natural variation could be expected in PAM scores across a population without any intervention as in Islington. Though the results from the data analytics team are not yet available, the CCG believe that any increase in activation levels could be linked to the person-centred care work taking place across the borough.

Islington are committed to using the PAM as a population-level outcome measure, and feel that it should be administered once a year. They believe that doing it more often would be too burdensome for patients. They envisage continuing to use the PAM as 'a temperature check' that can show population-level changes associated with the shift to person-centred care in the borough.

> 'Over the course of five, 10, 15 years, and [if] the overall trend is upwards, then you know that you're on to a good thing, and that what you're doing, all your interventions, because obviously you can't attribute it to any particular intervention, but you can attribute it to your overall philosophy and commitment to patient-centred care.' (Core team member 2, site 2)

Islington are reviewing their next steps for embedding person-centred care and using the PAM with the new electronic person-held record that is to be introduced in 2017.

8.1.3 Sheffield

In Sheffield, the PAM has been used since April 2015 in the delivery of person-centred care planning. It is primarily being used as a tailoring tool, but there are aspirations to use it as an outcome measure.

This site has evaluated the care planning work on an ongoing basis and prioritised different measures at different stages. The first element of their work was intended to enable practices to become familiar with care planning and the PAM and to develop systems that could support that work. The second element was to implement care planning, and the third was to improve the quality of care planning. The outcomes for the first two elements were the number of care plans completed and the number of PAMs completed as a percentage of the eligible patient cohort. The data for 2015-16 showed that practices had a total starting cohort of 7750 eligible patients. By March 2016, 4195 patients had completed PAMs and 4715 had completed care plans.

In the latter element of their work, the team are prioritising quality and are now collecting case studies as well as quantitative data. The team will be encouraging practices to reflect on and document how using the PAM has made a difference to the way they work. Their intention is to ensure that practices are fully conversant with the implications of person-centred care in the way they work. The overarching aim is to make sure that any changes to working practices are sustainable as the team feel that the direction of travel within primary care is irreversibly towards person-centred care and supporting self-management.

One of their new strategies is to look beyond the remaining two years of funding for the Locality Support Team (LST). They aim to move to a patient champion model whereby each practice will have a trained patient champion who can help with the development of practice plans. The LST will remain but will be scaled down. Sheffield, like Horsham, have noticed knowledge of the PAM and the concept of activation seems to have increased amongst professionals and have attributed this to the inclusion of the terms in high-level strategic documents. Sheffield are participating in the ongoing PAM testing and learning work.

8.1.4 Somerset

The Complex Care Hub (Symphony project) continues to see a steady increase in referrals. The current focus is on ensuring the hub has the systems, process and resources in place to manage the increase in the number of patients. The hub recruited a large number of new staff, who are currently undergoing their induction and will be in place to cover the East and West of the county. Work is continuing to identify patients who would benefit from being under the care of the hub, for example patients with high admissions, those in nursing homes, as well as patients from the integrated practices. The team have sought and used feedback from primary care – as a result, it is felt that communication with practices is improving. Dedicated lines of communication include a GP direct phone line and an email for providing feedback.

On reviewing the PAM scores, the hub team found that approximately 70% of the patients were at level 1 or 2. It was felt that these patients were likely to benefit more from the level of services that the hub could provide, and so, they will continue to be targeted.

Efforts have been made to integrate patient information across agencies. There are some sources of information that are not accessible as yet, e.g. social care notes. It has been reported that PAM scores are not necessarily fed back to patients, but are being used to tailor consultations.

The Enhanced Primary Care work in South Somerset is intended to change the way general practice operates, ideally by allowing GPs to have more time to spend with those patients in most acute need. Enhanced practices offer other services, for example health coaching, to patients whose needs are less acute. It is still being decided on how the PAM should be used in this context - with specific patient cohorts or with whole practice populations.

The CCG has been encouraging practices to complete PAMs but so far the uptake seems to have been lower than expected. As the questionnaires were being sent to the commissioning support unit (CSU) for processing PAM scores, the scores could not be used immediately. An alternative electronic method is being sought as embedding the PAM into practice systems is considered to be key to increasing its use. Should it be successfully embedded, it is envisaged that that PAM might be used in a number of ways:

- As a tailoring tool to inform the approach clinicians might take with patients
- As a referral criterion into the complex care hubs
- As a higher-level outcome measure of the impact of the enhanced primary care service

It is recognised that work is needed to align the care planning process in enhanced primary care with the work around complex care done by the hubs. The aspiration is to broaden out care planning in enhanced primary care, but it is not felt that using the resource-intensive complex care model is viable. Questions remain about who should undertake care planning in practices and consequently, what level of investment in training might be needed.

Somerset is a rapidly evolving healthcare landscape. At a strategic level, work is underway to align with the new Sustainability and Transformation Plans (STP). A joint strategic commissioning board is in place, and it is anticipated that there will be two Accountable Care Organisations (ACOs) to deliver services and they will have some commissioning functions. Somerset are continuing to work towards an outcomes-based commissioning framework which will use a capitated (per head) budget allocated to a coordinated group of providers to cover the health and social care needs of defined populations, such as those with long term conditions. Somerset are participating in the ongoing PAM testing and learning work.

8.1.5 Tower Hamlets

In Tower Hamlets, the PAM was used as an outcome measure to evaluate a mix of clinical and voluntary sector provided projects.

The work in Tower Hamlets has undergone an independent local evaluation. However, low recruitment numbers and some projects over-running the completion date of the independent evaluation report have meant it has not been possible to realise statistically-robust evidence of long-term improvements arising from the pilot interventions. Despite this, there was some indication that the pilot projects had helped to increase activation scores, and on this basis, the procurement of some services will continue.

To support the roll-out of PAM in primary care for the financial year 2016-17, GP practices have received funding via the GP networks to implement PAM. This funding has been attached to the Integrated Care Network Incentive Scheme (NIS) in Tower Hamlets, whereby GP networks had to submit a plan that covered the following areas:

- How clinicians will be trained in use of the PAM
- How networks will complete a minimum of 100 PAM questionnaires
- How the effectiveness of the PAM will be evaluated

The CCG will be monitoring the delivery of the plans, and evaluation reports from each of the networks which should be available towards the end of the financial year. The team are also hoping to work more closely with other health and social care providers, including the local mental health trust and the local authority, but recognise that work needs to be done to design systems that will enable information to be shared.

Tower Hamlets are still seeking solutions to translation issues associated with the PAM. They have asked practices to explore and feedback any solutions that they develop. The team have continuing concerns about cultural bias in the PAM and feel that some questions overly reflect white Western health beliefs about what a clinician should do and the extent to which self-management is desirable or possible. Tower Hamlets are participating in the ongoing PAM testing and learning work.

8.1.6 The UK Renal Registry (UKRR)

The PAM is being used with patients with chronic kidney disease (CKD) (stage 3b and above) as an outcome measure as part of the 'Valuing Individuals: Transforming Participation in Chronic Kidney Disease' programme of work. Within the programme, as well as using the PAM, the UKRR are collecting other outcome and experience data, using the CS-PAM (Clinician Support for PAM) and collecting information on shared decision making along the pathway of care.

The UKRR carried out the CS-PAM with clinical staff in the units in cohort 1, and provided private and confidential feedback to individuals at a personal level, unit level and across the programme. The UKRR team feel that this has been valuable in

highlighting how levels vary and has provided something of a wake-up call for those who had assumed that they were already at a high level. It should be noted that much effort was made to ensure that the scores were not perceived as a criticism and that they would be taken as a light touch indication of an understanding of the novel concept of activation. It has also been thought that this process has introduced a soft element of inter-unit competition into the programme, and that units are keen to be seen to be making improvements. The CS-PAM will be repeated annually.

The UKRR do not have funding to develop and trial interventions themselves, but they have reported that they have made significant progress with the development of their intervention signposting guide. They aim to deliver workshops with some cohort 1 units, with more established projects to work through the intervention signposting guidance and to develop an appropriate plan to improve both CS-PAM scores and PAM scores. The UKRR will be looking for any changes in CS-PAM and PAM scores after the units begin to undertake interventions, which is likely to be in 2017.

In November 2016, the UKRR hosted a workshop designed to enable cohort 1 to share learning with cohort 2. Early findings from the UKRR's own evaluation of the project were fed back at this event including completion of 1053 surveys.[34] The UKRR is positive about the project as it was felt that their primary aim, i.e., co-production, is being achieved. Data is now being fed back to patients (via the 'Renal Patient View') and clinicians (using Excel spreadsheets). The UKRR has reported that they are beginning to see some instances of data being used in practice. Due to uncertainties about future funding, the UKRR has concerns about a formal project evaluation going ahead and the possibility of losing the impetus behind the project.

8.2 Reflections: hindsight, residual challenges and new opportunities

As part of our later interviews, we asked participants what they would have done differently with hindsight and about residual challenges and future opportunities.

On a practical level, Islington have reflected that the postal method used for their survey was prohibitively expensive having cost them £25,000 to send out. As they would be seeking to implement an integrated digital care record, they would not be using the postal method again.

The need to manage data efficiently was also cited by many as something that was key to the success of their work. They reflected that it was essential to have an efficient system for managing the PAM process and data so that it could be used as quickly as possible, especially when it was to be used to tailor interventions. The value of being able to use patients' responses to statements in conversations was reiterated.

In terms of what could have been done differently, many responses centred on the need to contextualise the PAM within the broader shift to person-centred care and the importance of ensuring that this was happening early in the pathway.

> 'I would have preferred to get patient activation in at the ground level in primary care, every patient has a patient activation level which is, you know, renewed annually, and that they're working with those patients, putting care plans together based on their level of activation.' (Core team member 3, site 1)

As an example, in Horsham's telephone health coaching project, the PAM was used exclusively by the health coaches and, therefore, practice staff were only indirectly exposed to the concept of activation. This meant that the concept could not gain ground 'organically' in practices as many were simply not aware of it. There were some exceptions, but these were usually linked to clinicians noticing obvious changes in certain patients.

Where the PAM had been introduced into practices early on, for example, in Sheffield, this was seen as positive because it meant that all professionals were at least aware of it, even if some were not overly positive about it.

> 'What we've achieved is that everybody now knows what a PAM is and they will have an opinion about it.' (Core team member 5, site 3)

Generally, it was felt that getting the message out could still be difficult. Some core team staff reflected that one of the biggest challenges they still faced was the entrenched attitudes of some professionals who, it was felt, would continue to resist change.

> 'They've been through ten years of training plus 20 years of doing it a certain way and then for somebody to come along and show them this kind of new-fangled way of doing stuff, is a really entrenched view and a lot of them don't want to change because it means changing the way they practice, essentially […] it's moving from a parent to a partner relationship and I don't know whether they'll ever get there to be honest until they become outnumbered by younger GPs…and the patients!'(Core team member 3, site 1)

Many felt that the concept of activation was gaining ground compared to when they had started their work and felt that this could provide greater opportunities for new projects. Some attributed it to a higher-level normalisation process driven by promotional campaigns focusing on self-management.

> 'Because at the same time that we've been doing this project, there's been a lot put out there nationally about the value of supporting people to self-manage and that whole side of things.' (Core team member 1, site 1)

It was also thought that work done by NHS England to introduce activation into the person-centred care CQUIN had provided the high-level endorsement needed to create the conditions for a national roll out of the PAM. Some thought that working

with independent/voluntary sector providers could be beneficial for the further development of activation-based initiatives, as they were seen to be less risk averse and more open to innovation than local authorities and the NHS.

> 'They're up for experimenting as much as we are and they're as passionate about the concept as we are. We've got a community interest company who's partnered with us. So their kind of raison d'être if you like is that they're interested in improving community assets so people doing it for themselves.' (Core team member 1, site 1)

It was notable that many felt that the principles of person-centred care could, and should, be made relevant more broadly. Some practices in Sheffield have decided to get all their patients to complete a PAM, not just those with long-term conditions. Others felt that the principles should be relevant to the general population, not just service users. As noted above, there is a synergy between the ethos behind many community-based interventions and person-centred care. These could encourage more joined up working between a greater and more varied range of partners, and potentially herald a re-shaping of health and social care. However, some were unsure whether the concept of activation, and consequently the PAM, would translate well into social care and other non-health contexts and could see challenges ahead.

8.3 Summary

- Sites believe that the work they are doing is paying off, and many have framed the impact of their work in terms of having made a contribution to the spread of person-centred care.
- It is unclear what contribution to the UK evidence base for the PAM will be made by the sites as many projects are still ongoing, and there is variability in the way that they have collected and analysed their data, and in the type of data they have collected.
- All sites intend to press ahead with their work to embed person-centred care into healthcare. For most sites, the next steps are to progress their work and to continue to refine their approaches to using the PAM.

9 Discussion

In this chapter we discuss our findings and, in particular, draw out a series of issues that have emerged. First, we reflect on why the construct of patient activation, and the PAM as a measure of it, has attracted attention and what its advocates hope it can deliver. Second, we reflect on some of the residual questions and areas of uncertainty related to using the PAM in practice that this evaluation has surfaced. This includes issues of fidelity for data validity versus flexibility for pragmatic use, difficulties with translation, uncertainty about what a significant change in score is, and how stable scores are over time. Third, we focus on staff and patients' views on the PAM and their experiences of using it in practice. Fourth, we reflect on practical issues that have arisen as the sites have implemented the PAM. Finally, we consider how the pilots have contributed to the current evidence base for the PAM.

9.1 The appeal of patient activation and the PAM

The construct of patient activation and the PAM as a measure of it have been welcomed by many. It was clear that many professionals felt some frustration at being encouraged to focus on what were often regarded as relatively 'soft', process-oriented, qualitative changes such as changes in the relationship between practitioners and patients, the ways that individuals lived with their condition and in individuals' attitudes and beliefs towards medicine. However, they did not consider that there was any very obvious way in which to assess or measure such changes. The PAM was welcomed as it seemed to offer a solution to this problem.

The construct of activation was seen to align well with the person-centred care agenda as it gave definition to the capacities that people have to self-manage and the PAM offered a means to measure those capacities.[36] Further, having a validated tool that produced metrics that could demonstrate the effectiveness of person-centred care was felt to be an essential requirement for the production of business cases that could convince decision-makers to invest in interventions such as health coaching, care planning, and peer-guided courses. As the PAM was made available by NHS England it was seen to have high-level endorsement. Also, as it was not disease-specific, it could be used with different patient groups and in social and public health initiatives.

Over the course of our evaluation, it has become evident that momentum is building within the Learning Set sites behind person-centred care and that, in their view, patient activation and the PAM have fulfilled some of their promise. However, some challenges and uncertainties remain.

9.2 Residual questions and areas of uncertainty

9.2.1 Logic of use - why the PAM is being used and for what purpose

The most fundamental issue, and one which underpins many of the others, is the need for clarity and shared understanding of why the tool is being used and what function it is serving, i.e. knowing what the underlying logic of use is. It is vital that

besides being clear at the strategic level, this understanding is shared by staff and patients at the frontline, as many people's perception of the PAM as just another burden of data collection was quite striking. This clarity of purpose is critical because many decisions about how the PAM can best be integrated into services, how it can be completed by patients, and how the resulting data be shared and used, come back to this key point.

For example, the use of either PAM score or level, and when each might be more or less appropriate, relates to the logic of use:

- As a means of tailoring the type of service provided or the approach taken in a consultation (where level might work well)
- As an indicator of initial activation to form the basis of efforts to improve activation (where level might not be sensitive enough)
- As an outcome measure (again, level is a less sensitive outcome)

We have noted a tension between using the PAM as a means to generate sensitive, robust comparative outcome data of the sort that can be used aggregately for commissioning purposes, and using the PAM more flexibly as a means to provide more immediate benefit to individual patients. We have characterised this tension as 'fidelity for data validity versus flexibility for pragmatic use' because if data validity is prioritised, fidelity to the questionnaire must also be prioritised.

There were some suggestions from our participants that fidelity did not necessarily equal validity as biased responding had been noticed. In addition, we have found that achieving fidelity in practice is challenging as mediated completion (by which we mean that the PAM was completed with input or assistance from others, or that those inputting data from completed PAMs made judgements about which answers to record) often occurs.

We have not found any studies that have explicitly compared data derived from a fidelity-oriented approach to administering the PAM with data derived from a more flexible, mediated approach. It is not known what, if any, differences there might be in terms of validity or data quality. Until this question is addressed, any users of the PAM must give careful consideration to the 'fidelity for data validity versus flexibility for pragmatic use' trade-off.

Having clarity about the PAM's logic of use is important. It should be noted that some stakeholders may have different priorities and consequently, different attitudes towards the issue of fidelity and flexibility. For example, policy makers and commissioners may set greater value on robust comparative outcome data from a fidelity-oriented approach; whereas frontline staff may prioritise using the PAM in a more flexible mediated way. Tensions between these priorities will need to be recognised and reconciled.

9.2.2 Translation and inequalities

We noted that mediated completion happened for a variety of reasons. It was often not easy to predict who, amongst the general population, might need help with

completing the PAM. Mediated completion often occurred when the PAM was translated. Some existing translations of the PAM have necessitated mediation because they are too 'literal' and do not seem to work well on a cross-cultural conceptual level. Further, a great variety of languages and dialects are spoken in Britain and some do not have a written tradition. Many sites are continuing to explore different ways of delivering the PAM, but time and resources will be needed to develop and validate any alternatives. Currently, mediated completion is difficult to avoid if the PAM is to be used in a truly inclusive way. If fidelity is prioritised, then there are concerning implications for how inclusive the PAM can realistically be. Furthermore, there could be a danger of creating new or re-enforcing existing health inequalities. Using PAM as a population-level measure may not be feasible in the short term as problems with translation, and including those who cannot complete it unaided, need to be remedied.

9.2.3 Understanding and interpreting PAM scores

A question that follows on from our discussion about fidelity for data validity versus flexibility for pragmatic use is to what extent, the PAM can effectively be positioned as an appropriate and effective measure of service effectiveness or impact. This comes back to the discussion we started in our interim report about what changes in score might reasonably be expected during or following any intervention and over what timescale. This is important if PAM scores are to be used to assess effectiveness. We have found that this issue remains largely unresolved. Although sites have conducted their own evaluations for the purpose of demonstrating the effectiveness of what they have done and have cited increases in PAM scores as evidence, it is still not known how stable PAM scores are or what a significant change looks like or means. Many professionals have reflected that clarity around score stability and what represents a significant change would be welcomed. If using PAM at a population level, a way to administer it in an unmediated way to a broad range of the population needs to be found, as well as having a clear understanding of what a significant change in score might be. Until then, the greatest current value in using the PAM may lie at the individual or service level.

9.2.4 Mediation may not always be negative

Although the PAM's developers advocate a particular form of unmediated completion, we have found that using the PAM in practice often seems to work better when patient and provider develop a little rapport as this seems to help patients answer the questions more insightfully. Many professionals believed that the responses to the PAM that they got from their patients were more accurate and useful when the PAM was mediated and used in a more flexible way.

As we have noted, using the PAM does seem to help providers identify possible 'quick wins' and patient concerns that they can deal with more easily, that would perhaps not otherwise become apparent. It seems that sometimes the activity of completing the PAM itself is of value as a conversation starter regardless of the final score. It makes it legitimate for patients to talk about what matters to them, and to be able to use patients' responses to prioritise issues. The PAM, therefore, may be able to function effectively as a process to support person-centredness, without

necessarily acting as a measure of it. It is possible its value may lie mainly in starting the conversation about person-centred care and exploring what changes to support may be offered. However, this will only work well if the provider is committed to person-centred care, has sufficient time available, and is enabled to deliver on this through wider supportive services and systems.

9.2.5 Use of PAM to tailor care

If the purpose of using the PAM is to help more effectively tailor services, there are important questions about how this can best be achieved. There is a significant distinction between:

i) the approach of using PAM scores to tailor the nature and means of providing care within a service, and
ii) using them as the basis of decisions about which service(s) will be offered to patients.

Although this latter approach is a possibility, there are some reservations about whether this could result in patients not being able to access services from which they may potentially benefit (i.e. that it becomes used as a gatekeeping or eligibility tool). If PAM is about person-centredness, then it has to be accompanied by approaches that emphasise shared-decision making and patient choice. However, some frontline staff have suggested it may be useful to use the PAM as part of the referral process into services to ensure that any patient being referred is sufficiently activated to be able to benefit from such services.

Staff have commented that those with higher levels of activation can often benefit from lighter-touch care and that this will release time and resources for those at lower levels. Although many believe the biggest gains might be made by targeting resources at those with lower levels of activation, there are concerns that they are also the hardest to reach and so may be less likely to engage with the PAM. Some concerns were expressed about how well patients with lower levels of activation are represented in the current evidence base.

9.3 Stakeholders' perspectives

9.3.1 Patients' perspectives on the PAM

Before the PAM was used in practice it was not known how well it would be received by patients. As we were not able to interview as many patients as we had hoped, our findings are limited, but we have been able to identify some key issues.

Our work suggests that the way patients engage with PAM, and the scores that are generated, may be influenced by context e.g. whether the tool is used as part of an ongoing relationship between a patient and known health professional or within a new service. The views of patients towards the PAM were varied. It seems that for many, it does not stand out from the other questionnaires that they routinely fill in. Others, however, found the tool problematic in some ways; e.g. patients with progressive conditions did not like being asked about knowing how to prevent

problems with their health. Those with multiple conditions felt it was difficult to know how to answer as they felt their answers would depend on which condition was most troubling at the time and how it affected them. Generally, we found that patients were keen to make sure that their responses to the PAM were seen by health professionals in the context of their specific condition(s) and wider circumstances.

We also found that activation is a novel construct for patients and many felt that having some clarification of what activation meant would be helpful when completing the PAM as they would be able to understand better what the questionnaire was asking of them and be able to relate their responses to their behaviours.

Given that activation is a novel construct, we need to know if it fits with patients' priorities and concerns. Patients may not regard the sort of outcomes encompassed within the construct to be as important as others, such as being able to maintain their identity within their social networks and being able to gain support from professionals so that they and their families can live well with their condition.[43] It should also be borne in mind that assumptions of individual agency (the means to make choices and the power to act on them) are embedded within the concept of activation and some individuals' social contexts and conditions constrain agency, making change difficult to achieve, irrespective of their level of activation.[44]

9.3.2 Professionals' perspectives on the PAM

Professionals' views on the acceptability and value of the PAM to them and to their patients varied. There seemed to be some confusion about what it could and could not do, suggesting that there is need for a clear narrative around the potential uses of the PAM. This resonates with other recent research which also shows that a lack of clarity can hamper engagement with, and the adoption of new tools or approaches to patient care by professionals.[45]

Those who were negative or ambivalent thought that the PAM offered little value as patients would not engage with it and felt the PAM could antagonise patients. Some felt that the PAM could encourage too great a focus on metrics at the expense of enacting care that was truly person-centred and that scores could be stigmatising. Professionals also expressed concerns about how mental health issues might affect scores. However, we found many who were positive and who thought that the PAM aligned well with their existing approaches to patients. They felt that the PAM had value as a tool that helps to ensure that patients see the most appropriate professional and that patients' responses to specific questions can help professionals identify where problems might lie. The PAM is thought to have value as a means of embedding person-centred care into practice. It makes it legitimate for patients to discuss psycho-social issues and further give legitimacy to the new ways of working amongst clinicians as the score it produces can stand alongside, and augment biomarkers. The PAM was also seen to have value as it could provide insight about where to target efforts to realise change and where cost savings might be made. The score had value as a marker of a patient's progress and, further, could serve as a shortcut to the kind of knowledge of a patient usually realised by professionals over time.

9.4 Implementation

Our evaluation sought to explore how the PAM was implemented. Some of the greatest challenges encountered arose from issues associated with governance and data management. Information governance arrangements took time to resolve especially when data was to be shared with third parties (for analysis or as part of an intervention). When consent was required from patients for their data to be shared, considerable time was needed to design appropriately informative letters. Information governance requirements sometimes made it difficult to enable some service providers to contact patients directly.

Data management continues to be problematic. The PAM and the information it generates is currently not integrated easily into electronic health records and many sites have spent time developing their own 'work arounds'. It was this kind of practical, 'how to' knowledge that many looked to the Learning Set to provide and suggested that an additional, online system for depositing and sharing information and resources would be desirable, especially if it could be freely accessible by all those who work with the PAM in the UK. It would be beneficial to explore ways in which data management can be made more efficient and streamlined so that PAM data is made more quickly and readily available to patients and professionals.

Generally, all sites found it challenging to secure stakeholder engagement with their work to some extent. In the context of engaging general practices, many found that practices did not always see the bigger picture and thus were unable to contextualise activation, and the PAM, into the broader person-centred care landscape. Because of this, it was sometimes unclear what the direct benefits to patients were and why the PAM should not be treated as another 'tick box' exercise in a frontline context characterised by information overload and competing initiatives.

Sites developed strategies to encourage engagement, including incentivisation. It was found that incentivisation alone was not sufficient to drive engagement and that it was more effective when paired with support. Sites reflected that it was worth investing time and effort early on in identifying and mobilising all potentially relevant stakeholders at all levels. It was felt that engagement was facilitated by getting both executive-level and frontline endorsement. It was reported that the investment made by NHS England in licences and the person-centred care CQUIN has encouraged engagement. Many reflected that gaining engagement had been a slow process, but some noted that activation is becoming more widely known, and thus new projects may struggle less than the pilot sites.

Other strategies for gaining engagement included tapping into existing professional networks, asking for time in already scheduled meetings or at events, and using champions. But many felt that the greatest driver for engagement was the clear alignment they perceived between what many service users wanted and what the PAM could deliver (although as we have mentioned above, it is not clear that the PAM as a measure of patient activation embodies outcomes that are valued by all patients).

9.5 Evidence base for the PAM

Throughout the evaluation concerns about the evidence base have been apparent, including how effectively it can be mobilised and the extent to which it is applicable in a UK context. It is not yet entirely clear what contribution the projects will make towards strengthening the evidence base. With some exceptions, many projects are small-scale pilots, and may not have generated the volume or type of data required for robust analysis. Further, there is variability in the way that projects have collected and analysed their data, and variability in the type of data they have amassed. Thus, the extent to which the current desire for a stronger evidence base can be met, at least in the shorter term, is perhaps not clear. The Learning Set may not be able to provide the robust evidence of change in outcomes over time that can be linked directly to patient activation and use of the PAM. Nevertheless, because of the growing momentum behind person-centred care, many feel that 'proof of concept' has been achieved, and that the potential utility of the construct of activation and the PAM should be pursued. Further evaluation work is planned for the ongoing PAM testing and learning work.

9.6 Summary

- Professionals leading the PAM work in the sites saw the construct of activation aligning well with the person-centred agenda, and the PAM as offering a means to measure impact and demonstrate effectiveness.
- Some frontline professionals, including those working in strategic roles, gave examples of how 'changing the conversation' had directly benefited patients and how the new way of working had led them to re-evaluate the way they work.
- In general, sites believe that the work they are doing is paying off, and many have framed the impact of their work in terms of having made a contribution to the spread of person-centred care.
- While activation and the PAM are believed to have fulfilled some of their promise, residual challenges and uncertainties remain.
- A tension arises between using the PAM as a means to generate robust comparative outcome data required for commissioning purposes and using the PAM as a less sensitive tool to provide more immediate benefit to individual patients. Any users of the PAM must give careful consideration to the 'fidelity for data validity versus flexibility for pragmatic use' trade-off.
- Policy makers and commissioners may set greater value on robust comparative outcome data, while frontline staff may prioritise using the PAM in a more flexible, mediated way.
- Mediated completion may be difficult to avoid if the PAM is to be used in a truly inclusive way. If fidelity is prioritised, then there are likely to be implications for how inclusive the PAM can realistically be and creating or re-enforcing health inequalities may be a risk.
- The views of patients toward the PAM were varied - many had paid it little attention, but others found at least some elements of it problematic, e.g. some patients found specific questions inappropriate for them and others were not sure which condition to base their answers on.

- Assumptions of individual agency (the means to make choices and the power to act on them) are embedded within the concept of activation and some individuals' social context and conditions constrain agency, making change difficult to achieve irrespective of their level of activation.
- Professionals' views of the acceptability and value of the PAM to them and to their patients also varied. Some, who were more negative, did not perceive it as offering anything new, and were concerned about quantification in this context.
- Some people, who were more positive, believed that the PAM aligned well with their existing approaches to patients and they could perceive clinical benefit to its use.
- The extent to which the current desire for a stronger evidence base can be met by the Learning Set's pilot work, at least in the shorter term, is not clear. Producing robust evidence of change in outcomes over time that can be linked directly to patient activation and use of the PAM may still be a way off.
- However, many feel that 'proof of concept' has been achieved and that the potential utility of the construct of activation and the PAM should be pursued.
- Further evaluation work is planned for the ongoing PAM testing and learning work.

10 Appendix 1: Site case studies, updated November 2016

The case studies in this appendix are narratives of each site's experience of using the PAM and include details of all the projects in each site.

NHS Horsham & Mid-Sussex and NHS Crawley CCGs

NHS Horsham and Mid-Sussex CCG comprises 23 GP practices and is responsible for the health and well-being of over 225,000 people. NHS Crawley CCG is made up of 13 GP practices and commissions healthcare services for more than 120,000 people. Both CCGs share a management team and the governing bodies of both CCGs share some members, demonstrating their integrated working relationship.

NHS Horsham and Mid-Sussex and NHS Crawley requested 5,000 PAM licenses. The team is using the PAM in three specialist services:

- Tailored Health Coaching Pilot, working with up to 2,000 patients and using the PAM to tailor the approach taken to health coaching, and as an outcome measure to assess the impact of the intervention on patients' ability to manage their health.
- Musculoskeletal (MSK) service, working with up to 2,600 patients with persistent pain and using the PAM as an outcome measure.
- Tier 3 Weight Management Service, working with up to 400 patients and using the PAM as an outcome measure.

The PAM is being used at an individual level with patients and, depending on the service, is delivered either over the telephone or as a face-to-face questionnaire. Each service has a different set of clinicians with different training and experience, and the central CCG team is interested in the impact of this training and experience on the potential increase in PAM scores. As well as the PAM, Horsham and Mid-Sussex and Crawley are collecting data including the risk stratification score which will provide information about predicted healthcare utilisation costs and activity. The project team are interested in exploring what skills and training a clinician needs to have to improve patient activation, and so plan to look across the projects to capture learning.

Project 1: Tailored Health Coaching pilot

Tailored Health Coaching was a new pilot service, jointly commissioned with West Sussex County Council from a local charity, Impact Initiatives, which launched in April 2015. Health coaching is targeted at those patients with a long-term condition at medium risk (45–65%) of increased health service utilisation (identified using their risk stratification tool). Lists of eligible patients are generated quarterly and practices filter out those who may not benefit from coaching (for example, patients with dementia and other vulnerable, highly dependent patients).

The health coach contacts the patient by telephone, explains the expected outcomes and, if the patient wishes to engage with the service, undertakes the PAM to ascertain the current level of activation. The PAM activation level is then used to tailor the approach and language, and utilised to identify goals as part of the 'Well-being Plan' formulated collaboratively between coach and patient. The goals and solutions are holistic and include health, social care, and third sector options, for example self-referral to psychological support, free weight management, low cost opportunities to exercise, financial and housing support, and e-learning opportunities about their conditions. If patients are at level 3 or 4 of activation support mainly consists of signposting to services. If patients are at levels 1 or 2, and so may not realise they play a part in their own conditions, more motivational interviewing and coaching is provided. Those delivering the intervention are not clinicians and have been trained in motivational interviewing and other coaching techniques tailored according to the PAM. NHS Horsham and Mid-Sussex initially hoped to run a randomised controlled trial of tailored health coaching, but were unable to secure funding; instead they are running this large-scale pilot project with a control group for comparison. Around 2,000 PAM licences will be used in this cohort. Outcomes measured before and after will be:

- PAM score
- Predicted risk score, including use of healthcare services and utilisation costs
- Warwick-Edinburgh Mental Well-Being Scale (WEMWBS)

By September 2015 four health coaches had been recruited and trained to deliver the Tailored Health Coaching service. Engagement with GP practices, which refer patients to the Tailored Health Coaching Service, had been slower than initially expected, with the first patients accessing the service in late May 2015. To encourage engagement, a locally commissioned service (LCS) had been put in place to compensate GP practices for the time needed to identify patients. Five practices signed up prior to the LCS, with a further ten interested in participating. Other referral methods, including self-referral and referral from other health and well-being partners such as social services, were also being considered following the pilot.

Additional outcomes being monitored in addition to those originally planned included the number of goals set and achieved by the patient being coached. The initial aim was to measure the PAM score at the beginning and end of the health coach's work, but the team found some benefit in conducting a 'middle' measure for some patients, to monitor progress. Some initial successes in improving PAM scores were reported by the team, which have also been reflected in some instances in other measures. The design of the service remained as originally planned, and as of September 2015 48 patients had enrolled into the service. As more practices came on board this was expected to rise rapidly.

By January 2016, referrals had increased as expected and the coaches were working with patients from 18 practices. The scheme had been formally promoted beforehand but the coaches had also visited practices and personally introduced the service, and it was felt that this had helped to increase practice engagement. Participation by practices was also financially incentivised in so far as the time spent filtering the lists generated by the health coaches was reimbursed. Contemporary figures showed 455 referrals, and an approximate 30% take-up rate (102

enrolments). Twenty-two people had completed their coaching and been discharged and a minority of PAM levels had been maintained and a majority had increased; a similar pattern was found in WEMWBS scores.

When the telephone health coaching service had been in place for over a year Horsham felt they had seen evidence of immediate behaviour change amongst service users but recognised that it was too early to determine whether the changes would be sustained.

In their 2016 evaluation of the service, Horsham compared those patients who went through the service (over 100) with those who had declined it. They used this latter group as a 'natural control group', although the validity of doing this is questionable as they may differ in important ways from those who participate in the service. Horsham measured PAM scores, individual risk scores, healthcare utilisation and costs, and patients' wellbeing (using the Warwick-Edinburgh Mental Wellbeing scale).

They have found that the cohort who completed the coaching showed an increase of, on average, one PAM level. It was found that the increases in the PAM score correlated with increases in the Warwick-Edinburgh Mental Wellbeing scores. Risk scores, which had previously shown an upwards trend, have now shown a small decrease and the team are keen to see if this effect continues over time.

Horsham also found some suggestion that healthcare utilisation, and therefore cost, has decreased for many. However the team have faced challenges in quantifying the exact saving made, as variability exists in terms of the charges and tariffs attached to different services by different providers and so they have taken an average across the patch and estimated a saving of £450 per head. If the downward trend in utilisation and risk scores can be confirmed and continues, then the site will be in a position to make a case for further savings.

Horsham's analysis showed an anomalous finding in that A&E attendance declined more in the control group than amongst those who had used the health coaching service, and the team intend to explore this further. Horsham have a clear sense that their work will bolster their business case for health coaching.

Horsham are participating in the next phase of the PAM testing and learning work. They plan to open up the health coaching service to different patient groups and to attempt to engage those who are at higher risk levels. They also plan to encourage referrals from a wider range of staff. Horsham are also hoping to target high users of 111 and 999 and they are developing a project with their local ambulance service to this end. In order to enable paramedics to refer patients directly to health coaches a number of governance issues will have to be resolved. It is expected that frequent users of emergency services may have greater psychological needs and so links have been made with the local mental health trust and the health coaches are being given additional training in techniques for engaging with those with personality disorders. Horsham are also seeking to work with those newly diagnosed with long-term conditions as they feel that benefit can be had from introducing coaching to patients at a much earlier stage.

The team in Horsham have noted that the idea of activation seems to have become more widely understood amongst professionals in the last two years and, because of this, feel it will be easier to get buy-in for new projects. The CQUIN is also seen as a driver for engagement with person-centred care.

Project 2: MSK service

The MSK service is a newly commissioned community-based service delivered by the Sussex MSK Partnership since October 2014. The Sussex MSK Partnership comprises the local NHS Mental Health Foundation Trust, NHS Community Trust, a charitable trust, and a not-for-profit organisation. Services offered range from short-term interventions (e.g. podiatry and orthopaedics) to longer-term therapies (e.g. pain management and rheumatology) but patients will be encouraged to self-manage their conditions as far as possible. Initial recruitment to the Mobilisation of the MSK Service has been slower than anticipated, in part because most patients access the service via an annual review process.

The PAM is being used with patients who have persistent pain who use the MSK service. It will be used as an outcome measure with up to 2,600 patients. Other outcome measures will also be collected, including a musculoskeletal patient-reported outcome measure (MSK-HQ) and a measure of shared-decision making (SURE). The PAM will be delivered as a face-to-face questionnaire in clinics by MSK clinicians with some training in motivational interviewing skills and shared decision making. Activation levels will be measured at initial referral to the service and then every six months. The team describe this as 'a less intensive collaborative care planning approach'.

Though the MSK Partnership service began to recruit patients in late 2014, they have not yet been able to implement the PAM due to logistical and contractual arrangements within the service. The Partnership delivers its services based on a programme budget approach, combining secondary, primary, and community care budgets, and it has taken longer than originally anticipated to finalise contractual arrangements.

The MSK service has resolved their contractual arrangements and, in early 2016, were about to introduce the PAM into the pain management clinic. The intention is that patients complete the PAM in their first clinical appointment; follow-up PAMs will be done at three and six months.

Project 3: Tier 3 Weight Management Service

The Tier 3 Weight Management Service has been commissioned from a not-for-profit organisation since April 2014. It caters for up to 400 patients per year. The service is designed to support patients with a Body Mass Index >40 (or >35 with co-morbidities) to manage their weight. It is provided by a multidisciplinary team including bariatric physicians, psychologists, dieticians, and physical trainers, who use cognitive behavioural therapeutic approaches to motivate and support patients. The PAM is used as an outcome measure, initially delivered over the telephone prior to attendance at the clinic. Activation levels will be measured at initial referral to the service and then every six months. Other outcome measures – including weight loss,

health-related quality of life, patient satisfaction, and bariatric surgery referrals – are also being collected. The Tier 3 Weight Management Service has been using the PAM since March 2015 as an outcome measure. PAM scores will be collected as a measure pre- and post- a 12-week intensive programme and at three month follow-up.

By October 2015 over 90 PAMs had been completed, but no data analysis looking at outcomes has been conducted at time of writing.

NHS Islington CCG

At the start of the project NHS Islington CCG comprised 36 GP practices and had responsibility for commissioning services for around a quarter of a million people living in an area of under six square miles. Islington is one of NHS England's 14 pioneer sites, developing a more integrated approach to care within the borough.

The aim was to use the PAM with patients with long-term conditions across the primary care setting and build on previous outcome measure work conducted in the area. In October 2013 the CCG sent out the LTC6 questionnaire, which asked ~40,000 people with a long-term condition about their healthcare over the previous 12 months, and a 25% response rate (~10,000 people) was achieved. The object was to provide evidence of the efficacy of new services being commissioned. It was felt that use of the PAM fitted with the broader direction of travel and work around embedding self-care and self-management support into clinical practice in Islington.

Islington decided to use the PAM as a means of measuring the effectiveness of a specific intervention, and the PAM has been used alongside care and support planning consultations in general practice with ~28,000 patients. The CS-PAM was also scoped by the site as a training tool to measure clinician activation as part of the Advanced Development Programme (a coaching-style training programme for clinicians). Islington CCG requested a total of 38,000 PAM licences and mainly distributed the questionnaires by post.

Project 1: Care and support planning in general practice

Islington CCG commissions GP practices to offer collaborative care and support planning consultations with their patients with a list of long-term conditions, historically agreed in collaboration with Islington Public Health department. These conditions include chronic obstructive pulmonary disease (COPD), diabetes, heart failure, atrial fibrillation, a cancer diagnosis, ischaemic heart disease, chronic kidney disease, dementia, hypertension, mental health problems (including depression), and liver disease.

GPs were initially commissioned (February 2013 to November 2014) to offer enhanced collaborative Year of Care support plans only to people with diabetes, and this was implemented via a locally commissioned service (LCS). From December 2014, this LCS was merged into an LCS which offered the enhanced care planning approach to all patients with a long-term condition.

As part of the 2014/15 GP contract, NHS England also commissioned GPs to develop a care plan with patients identified as being in the practice's top 2% of people who are deemed to be at risk of being admitted to hospital. The care planning commissioned by NHS England was not a collaborative enhanced care plan in the style of Year of Care, but the patients in this cohort often also included people with multiple long-term conditions who were receiving a Year of Care approach.

Commitment to engagement with the PAM project was embedded into the long-term condition LCS, which was initiated in October 2013. To ensure consistency across

each GP practice a search to identify patients who should complete the PAM was developed and uploaded onto each practice's clinical system. The team developed a template, enabling practices to code the patient activation score and free text space to record the level. The method of survey distribution (postal or face-to-face) could also be recorded. A pack detailing how to deliver the PAM tool was developed and sent out to each practice. The pack included:

- A letter to practices explaining patient activation, how this would be measured with the PAM tool, and what was expected of the practice.
- A step-by-step guide detailing how the CCG wanted practices to collect the PAM data.
- A letter to be sent to patients explaining why the tool was being sent to them and a copy of the questions.
- A letter including the PAM tool, to be sent to patients who had not responded to the initial mail out, with their invitation for their collaborative care and support planning appointment.
- A copy of a spreadsheet that would enable practices to calculate the PAM score and level.

Practices were paid £2.50 to calculate and register PAM scores to patient records. GP practices were also sent details of a retrospective review that they were expected to complete a year later, after a second PAM had been sent out to patients.

Although practices recorded the PAM score, Islington was keen to embrace the principles underpinning patient activation as a concept and not just focus on the number/score the tool produced. The score was not formally used by clinicians within the care and support planning process (as a tailoring tool), however it is visible in patients' electronic records. The team believed that there was a danger in focusing on the numbers in a superficial manner and limiting the depth of the ongoing relationship that clinicians were trying to develop; for example if a patient has a low activation score, the GP may decide it is not worth discussing the full range of support services available and thereby limit choice.

Initial data collection for 2014/15 finished in March 2015, with a response rate of 25%, providing baseline PAM scores for around 9,000 patients. This data was then shared (following appropriate NHS Information Governance procedures) with the Health Foundation Data Analytics team, who undertook a detailed analysis of this data.

The PAM was used for the second time from October 2015, and the deadline for completion was February 2016. These data were also passed to the Health Foundation Data Analytics team and analysis is ongoing. Of a population of 40,528, 7,000 scores were collected representing a completion rate of 17%.

It is intended that there will be a retrospective audit on 10% of patients with long-term conditions who have two PAM scores; this will explore how their activation levels may have changed and it is hoped that this work will enable the development of more targeted approaches to improving activation within practices. Relevant patients will be identified using EMIS, and a template has been designed that will enable other data to be recorded; for example, if a new long-term condition has been

diagnosed since the last PAM, number of care planning appointments carried out, and information on how the PAM survey was completed and returned. The audit is currently being piloted.

More broadly, in their integrated care work stream the CCG has started to test new models of multidisciplinary team working, introducing a new team to work with patients seen as at higher risk. As an informal part of this work the team has compared their referrals list with patient PAM scores where available. The aim of this very small-scale work is to start to look at whether the patients referred into the service also have low levels of activation.

An independent evaluation of the Year of Care diabetes care planning work was conducted in 2015, to ascertain if there are links between diabetic patients with care plans and improved clinical outcomes. The evaluation also assessed how engaged GP practices had been with this process. In summary the evaluation found:

- High performing practices (in terms of number of care plans completed) were achieving better patient outcomes.
- Practice staff were interviewed and it showed that there was good buy-in to the ethos of the new approaches, but that there were sometimes skills gaps in practices, in terms of delivery.
- The need for training in coaching and motivational interviewing has been recognised.

Work is currently underway to devise training, tailored to practice needs. The training will also serve to develop a greater understanding of the concept of activation and how patient activation scores/levels can be utilised in the delivery of collaborative care and support planning (CC&SP). It is expected that this approach will result in directly tailoring interventions to patients based on their levels of activation. The practices who have demonstrated the most commitment and enthusiasm for delivering CC&SP will be asked to trial this way of working and their learning will inform a wider implementation across the whole of Islington's primary care landscape later in the year. Islington are reviewing their next steps for embedding person-centred care and using the PAM with the new electronic person-held record that is to be introduced in 2017.

Project 2: Self-management commissioning contracts

This project involved embedding the PAM into the contracts for self-management support in three services, all commissioned from Whittington Health NHS Trust:

- Expert Patient Programme
- Diabetes Self-Management Programme
- Bariatric service weight regain intervention programme

Those administering the service were asked to record PAM scores at the start and end of each programme. The focus was on using the PAM as a measure of intervention effectiveness, rather than as a measure to shape how the support programme would be delivered. Work using the PAM started later than originally

planned, which was due to a number of issues including staffing changes which meant that early enthusiasm for using the PAM stalled.

After a slow start, the projects are now starting to generate data.

- Expert Patient Programme: For those who completed both pre- and end-course questionnaires the average Patient Activation score prior to participation in EPP was 50 and the average end-of-course score was 59, an average increase of 9 points (based on 17 completed pre- and end-course questionnaires).
- Diabetes Self-Management Programme: For those who completed both pre- and end-course questionnaires the average Patient Activation score prior to DSMP was 58 and the average end-of-course score was 70, an average increase of 12 points (based on 36 completed pre- and end-course questionnaires).
- Bariatric service weight regain intervention programme: 15 patients took part in the study which looked at post-bariatric surgery activation levels (measured at attendance in dietetic clinics). Although the study was small, there was some suggestion that low PAM levels might be associated with poor outcomes and it is hoped that this work can be pursued further.

NHS Sheffield CCG

NHS Sheffield CCG comprises 87 GP practices and has responsibility for commissioning services for approximately 580,000 people.

The PAM has been used in four project areas:

1. A pilot project with Sheffield Health and Social Care (SHSC) NHS Foundation Trust working with 14 patients with serious long-term mental health problems in the community.
2. A six week, peer-facilitated course focused on activation was run for patients with long-term conditions. The PAM was administered at the start and end of the course.
3. As part of diabetes self-management annual reviews in a large general practice. The project has been running for around a year and follow-up PAMs are beginning to be completed.
4. Citywide care planning, using the PAM as part of a locally commissioned service for long-term condition management. Citywide care planning is now in the third year of a five year programme.

Project 1: Mental health pilot

As part of a pilot project commissioned April 2013–March 2015, people with serious mental health problems and physical co-morbidities in three GP practices were provided with extra support to improve health outcomes with the long-term goal of reducing health inequalities. The project worked across primary and secondary care providers to develop an annual health check taking a holistic view of mental and physical health. A community development worker also worked with this patient group to introduce small interventions with the aim of reducing isolation. Between September 2014 and March 2015 the community development worker integrated the PAM into her work with 14 patients to measure activation levels. Activation levels were used to tailor these small interventions and to capture further information about the patient cohort and their needs compared with the general population. The EQ5D (a standardised instrument for use as a measure of health outcomes) was also administered for this purpose.

Although the initial mental health pilot work has finished, there are currently plans to use the PAM in a further SHSC NHS Foundation Trust project, measuring the improvement in self-management confidence following a six week course for people with long-term conditions developed with Sheffield Increasing Access to Psychological Therapies (IAPT).

Project 2: Peer facilitated course

The peer-facilitated course was a six week training course for people with long-term conditions; it was funded by the CCG. Of 17 patients who began, 12 finished the course. Participants had been signposted to the course by GPs and health trainers, and had self-referred into it. A paper version of the PAM was handed out to individuals who completed this on their own.

The course provided a forum where patients could talk through problems with their peers and jointly explore solutions. The course was facilitated by two people with a long-term condition, one of whom was an expert patient. When the PAM was re-administered, at the end of the course, it was found that all patients' scores had increased, and it was felt that the PAM could be a useful measure for similar assets-based interventions. The course has been internally reviewed and, at present, there are no plans to run it again.

Project 3: Diabetes self-management

The type 2 diabetes self-management project is based in the Sloan Medical Centre practice. The practice has ~12,000 patients and ten regular GPs. The PAM has been used for some time, and one GP and the practice nurses initially piloted its use for diabetes self-management, which was rolled out across the practice in early 2015. The practice had already bought PAM licences before joining the Learning Set.

Activation levels are fed back to patients as part of an intervention to improve self-management and tailor services at an individual level. As part of the Diabetes Year of Care pilot, all clinical and administrative staff (GPs, nurses, healthcare assistants, reception staff, admin and IT support team) at the practice received training about the PAM in late 2014. All diabetes patients have pre-testing (BMI, blood pressure, blood and urine testing, and foot check) with a HCA prior to their annual review appointment. The PAM is completed at this pre-testing appointment, and patients receive their results, including the PAM, from the administrator, both over the phone and via a letter, prior to their review appointment. At their 20-to-30 minute review appointment with a practice nurse patients have the opportunity to discuss the results of their tests and to be coached in a manner appropriate to their level of activation. Follow-up appointments are focused around person-centred care planning, as appropriate. Measures including changes in the PAM score, emergency admissions, prescriptions, and contacts with the GP will also be recorded as outcomes data as part of an evaluation being undertaken by the city council.

The practice staff are broadly positive about this new way of working, including the PAM which they say provides a more robust system for ensuring diabetes reviews are conducted. It is felt that getting the system right, including where and when the PAM was completed by the patient, was critical to ensuring its success. Since the initial phase of work one of the practice nurses who led the diabetes work has left to work at another practice. This has led to some small scale changes in how the appointments are organised, with a GP seeing the more complex diabetes patients and another practice nurse seeing the patients who have more stable HbA1c levels.

By 2016 the project had been running for around a year, and the practice was continuing to collect PAMs for all patients with type 2 diabetes; the practice reported that few patients have declined to participate and a broad range of activation scores have been found within the type 2 population.

Since some slowing of the project following staff changes, two nurses have been trained in care planning and the GP leading the project has become the practice lead

for diabetes; the project is regaining momentum and follow-up PAMs are starting to be done.

Feedback from those administering the PAM has indicated that sometimes the patient's score does not reflect the clinician's view of that patient's level of activation and, consequently, the PAM is increasingly viewed as an indicator or guidance tool, rather than as a hard outcome measure. The PAM is also thought to have value as a means by which the concept of activation can be introduced to patients and practitioners.

Although there are no plans to significantly change the diabetes programme, it is felt that care planning (with the PAM as a component) could be useful for all patients as a general marker of health because of concerns that focussing on a specific disease could mean that other problems were missed. There is some uncertainty as to how it might be feasible to administer the PAM to a general population (by post or at routine consultations). When reflecting on how the PAM could be used in a general population, ideally Sheffield would like to see scores rise, but recognise that preventing them from falling may also be valuable.

Project 4: Citywide care planning

Training for the citywide locally commissioned scheme for person-centred care planning in primary care started in the last quarter of 2014/15. The PAM has been used since April 2015 to help to deliver person-centred care planning. It is administered by practice staff (particularly healthcare assistants, administrative staff, and nurses), by community support workers employed by Sheffield City Council who are working closely with practices, and by community nurses for housebound patients. NHS Sheffield CCG is split into four localities (Central, North, West, and Hallam and South). Training for person-centred care planning and using the PAM was delivered in a group setting by a mix of internal and external experts, and supported by online training resources available from Insignia. Each GP practice was required to send at least one clinician and manager to one of 11 repeated standard training afternoons. Follow-up support was then available via multidisciplinary locality support teams (LSTs), who acted as champions and trouble-shooters. GP practices were incentivised between £2,500 and £10,000 per year depending on practice size to carry out the requirements of the locally commissioned service.

Use of the PAM builds on a previous year-long pilot of care planning, in which a lack of effective training was identified as a potential barrier to successful person-centred care planning. The PAM is seen as a tool to help clinicians to alter their approach to self-management and person-centred care, changing the manner of clinical consultation to ensure that the patient's goals are captured and inform their healthcare. The overall aims are for staff to develop skills in person-centred care, to increase work with the local authority and the third sector, and to build on the national Unplanned Admissions Enhanced Service to include patient views, goals, and self-support, with the aim of ensuring that patients feel empowered to self-manage.

Of the 87 practices across Sheffield, 80 have signed up to participate in the care planning work. Following feedback from the training sessions the CCG allowed

individual practices to make a case for using the care planning approach and the PAM with a different cohort of patients with long-term conditions, if they felt it would be more effective. Fourteen practices had taken this up for the purpose of the pilot work. The CCG started to receive completed PAM questionnaires in July 2015, at the end of the first quarter of the year's piloting implementation.

The total number of patients in the pilot projects was 7,550 and by the end of the last quarter in April 2016 4,915 PAMs had been returned, and 4,715 care plans (using the template) had been completed. It was hoped that, ideally, 2% of the population would have care plans, but a hard and fast quantity was not demanded and, in practice, a lower limit of around 1% of a practice's patients was set. It was felt that if a practice was making progress then money would not be withheld if they failed to meet the target. It was considered more important that practices became engaged with the underlying ethos of care planning.

Informed by learning from the second pilot phase, the next phase of the citywide care planning is underway. The CCG has successfully applied for 100,000 PAM licences. Practices have been invited to develop their own plans for 2016/2017 and to submit them for review. As of June 2016, 60 out of 69 plans have been returned and the review process is underway. Support will be offered by the LST if plans need to be refined. Practices are being encouraged to identify their own cohort of patients and give a rationale for why they have been chosen. No fixed number has been defined as a target and, again, it is hoped that this will enable practices to prioritise 'quality' over 'quantity' and use the process to embed person-centred care. The plans will be used as a benchmark or a 'soft contract' against which to evaluate a practice's performance over the year; in this way practices are able to participate in defining the measure of success to which they can be held accountable. As part of the accountability process practices will be required to produce 'case studies' that document their work.

In response to feedback from the pilot, which indicated the PAM was too American and too lengthy, an English language, 10 question version has been introduced. Practices have been assured that the score from the 10 question version aligns to the 13 question version, and so practices can move to the 10 question version and use it to re-test patients. Sheffield have noticed knowledge of the PAM and the concept of activation seems to have increased amongst professionals and have attributed this to the inclusion of the terms in high-level strategic documents. Sheffield will continue to participate in the ongoing PAM testing and learning work.

Locality Support Team (LST)

In the last two years the LST has grown, as has the range of support that they have been able to offer practices. The LST is made up of a range of health professionals including GPs, practice nurses, and practice managers. The team is funded until autumn 2016 and each member's time (generally 1-2 days a month) is bought out. The team have regular meetings. The practical remit of the team is to offer training, to support and disseminate learning around care planning, and to evaluate activity. At a strategic level the team are advocates for person-centred care and seek to drive engagement with new ways of working.

Amongst the LST care planning and the PAM are seen as an opportunity for services and staff to engage with the changes to practice envisioned in NHS Five Year Forward, particularly person-centred care, and 'get ahead of the curve'. The aim is to ensure that staff are skilled at allocating resources (clinical and social) to ensure that patients have the right support at the right time and to gain an understanding of how ready/receptive patients are to become more active participants in their care.

When visiting practices the team tries to include personnel who are doing the same jobs as those they are visiting; it is felt that this 'matched perspective' gives the advice of the LST greater legitimacy. The team intends to visit all 69 practices and will use the information generated from the 2016 practice plans to prioritise which practices might need the most help. The team have developed a system for documenting and tailoring their visits to practices, and recording and feeding back the issues that practices bring to them.

The LST have some limited resources available and organise events centred on person-centred care planning and they offer practical training (for example on motivational interviewing). Although the LST programme has been funded for another year in a difficult financial climate, it is not clear that the type of support offered by the LST will be available in the longer term and they are keen that practice plans show sustainable ways of working. Some LST members have reflected that achieving the desired cultural shift will be a long game, but they feel that getting a critical mass of practices on board will herald a 'tipping point', after which person-centred care will become normalised into routine practice. One of their new strategies is to look beyond the remaining two years of funding for the LST and to try to move towards a patient champion model whereby each practice will have a trained patient champion who can help with the development of practice plans. The LST will remain but be scaled down.

NHS Somerset CCG

NHS Somerset CCG comprises 400 GPs (310 whole time equivalents) based in 72 practices and has responsibility for commissioning services for a dispersed rural population of around 560,000 people. The design of the organisation is based on a locality model, with nine Commissioning Localities. In 2014 Somerset CCG introduced a local pilot of a GP quality scheme, known as the Somerset Practice Quality Scheme (SPQS), which replaces elements of the Quality and Outcomes Framework (QOF) for practices who sign up to it.

Building on this work, Somerset CCG is working with providers to develop a capitated budget, outcomes-based commissioning framework for all services for people living with long-term conditions in Somerset. In July 2015 the CCG published a comprehensive document which outlined the way in which outcomes-based commissioning would be implemented. The 'pay for performance' criteria to be used are currently under negotiation, but patient activation will be a core outcome measure.

The CCG's strategy was to encourage and support providers to consider using the PAM in their evolving work programmes (encouraging 'provider pull' rather than relying on 'commissioner push'), so that using the concept of activation became normalised.

Initially Somerset CCG requested 11,000 licences for the PAM. The PAM has mainly been used across primary care amongst patients with long-term conditions, but it has been trialled in a secondary care setting.

The following work programmes have been using the PAM:

- The House of Care focused on patients with long-term conditions. It used the PAM as part of the SPQS outcome framework with around 25 general practices, who have undergone training. Additionally, there are a number of smaller pilot projects, including:
    - Health Connections Mendip
    - Village Agents working with practices in North Sedgmoor
    - West Somerset Living Better project for people with long term conditions
    - Musgrove Park Hospital Patient Voices programme focused on care planning for hospital discharge
    - MCBT (mindfulness-based cognitive behavioural therapy) group for long-term conditions, with 100 patients completing the PAM as an outcome measure
- South Somerset, Taunton and Mendip Symphony schemes, as part of long-term condition management in primary and secondary care with people with long-term conditions.

Project 1: Outcomes based commissioning

As part of the Somerset Practice Quality Scheme (SPQS), 56 GP practices agreed to focus on the needs of people with long-term conditions. 18 organisations used the PAM with patients when making care plans. The initial focus was on GP practices that had been trained in the House of Care approach, but this was expanded to include other 'test and learn' sites in Somerset. Around 9,000 copies of the PAM were sent out to use with these patient cohorts. By the end of August 2015 18 organisations had returned 700 completed questionnaires.

The PAM was completed on paper by patients in the waiting room and both the activation level and the score could be added to the patient record in EMIS. GPs and other health professionals were encouraged to take a flexible approach when using the PAM, with the principle focus on using the results meaningfully with patients to effect positive change.

The 18 organisations who returned data included the West Somerset Living Better project, which aimed to help people with long term conditions to be less isolated by identifying the skills already in existence in the community that could be used to create a supportive community environment that will positively impact on healthcare service usage.

Similarly, the Musgrove Park Hospital Patient Voices project was a small-scale pilot delivered by the voluntary sector to provide personalised care planning and signposting to services at the point of hospital discharge, in order to ensure better liaison between primary and secondary care. However it was found that patients in hospital did not want a care and support planning conversation, including completing a PAM survey, when they were more concerned about when they would get home and about getting better. They were far more receptive when they had been settled at home for a few weeks.

The local mental health trust, Somerset Partnership Trust, delivered a group-based, six week MCBT (mindfulness-based cognitive behavioural therapy) course for people with mental health problems and long-term conditions: 'Reclaiming your Life'. The PAM was used with around 100 patients as an outcome measure. Again, those leading the programme were told to 'play with it' and use it as they saw fit; no training was given for fear of restricting how people viewed the PAM and how they thought about using it.

By 2016 a number of projects were using the PAM across Somerset, including an Age UK led programme using peer-guided conversations. Somerset is a rapidly evolving healthcare landscape; at a strategic level, work is underway to align with the new Sustainability and Transformation Plans (STP), a joint strategic commissioning board is in place, and it is anticipated that there will be two Accountable Care Organisations (ACOs) that will deliver services and have some commissioning functions within them.

Project 2: Symphony

The South Somerset Symphony programme provides additional services for patients with long-term conditions. The aim is to provide integrated care for these patients, using what are known as the 'complex care' and 'enhanced primary care' models.

The complex care model involves working with the four per cent of the population who generally have three or more co-morbidities (around 1,500 people), and who account for around 50% of health and social care costs. In parallel to the hubs, GP practices provide 'enhanced primary care', offering, for example, health coaching to patients with less complex conditions. Both the complex care hub and enhanced primary are using the PAM.

The South Somerset Complex Care Hub involves Yeovil District Hospital Foundation Trust, Somerset Partnership Foundation Trust, Somerset County Council, Somerset Clinical Commissioning Group, and the South West Commissioning Support Unit. It is one of NHS England's 'Vanguard sites', working to deliver an integrated primary and acute care system.

The model is a 'hub' system, with access to doctors, care coordinators, and key workers with health and social care backgrounds and skills in health coaching and motivating people to self-manage. Questions from the CS-PAM were included in the recruitment process, so that those who were focused on self-management were selected for the roles. The project aims to enable person-centred and empathetic care across health and social care providers that meets the needs of patients through integrated working. The PAM is an element of the baseline data collected when a patient accesses the service; it will be collected at six and twelve months. The hub team will use PAM scores to tailor their approaches and also to measure increases in the PAM score and other health service utilisation outcomes to understand the effect of the intervention on patients.

Symphony collect and analyse other sources of data in their work, including the 'Symphony score', a numerical representation of concern about the patient which is used as part of their information-gathering, to identify who is most appropriate to work with a patient and the kind of support they might need.

By June 2016, 198 patients had been through the hub service; the relatively low numbers were linked to implementation challenges, but it was felt that many of these have been resolved and that numbers will increase. Challenges included addressing information governance concerns about sharing patient data amongst GPs. Practice engagement with the new service had generally been patchy, and it was found that some practices were reluctant to hand patients over to the service. In response to concerns about losing contact with patients a new version of the model which will be more closely aligned to the ongoing enhanced primary care program will be tried in the East hub; this model emphasises supporting practices to manage complex patients within their practice.

The Complex Care Hub continues to see a steady increase in referrals. The current area of focus is on ensuring the hub has the systems, process, and resource in place to increase the number of patients in the hub, in line with the agreed trajectory for this increase in activity; this work is progressing well. The hub has seen a high number of new starters, who are currently undergoing their induction, including staff who will be covering the east and west of the county. Staff will begin working with practices in the east, from August. Work is ongoing to identify patients who would benefit from being under the care of the central hub, such as patients with high admissions, patients in nursing homes, as well as patients from three integrated

practices; this will be underpinned by a robust plan for on-boarding these patients. Using feedback from Primary Care practitioners, communication with practices is improving, with dedicated lines of communication for them to contact the hub now set up; this includes a GP direct phone line and an email for providing feedback.

On reviewing the PAM scores, the hub team found that approximately 70% of the patients were a level 1 or 2 and it was felt that these were the patients who would be most likely to benefit from the level of services that the hub could provide; these patients are therefore being targeted.

One of the key issues that Somerset faces arises from the geography of the county; Somerset is large and travel can be problematic for both patients and practitioners. The two hub models differ in that one emphasises seeing patients in their homes and the other (enhanced primary care model) is linked to GP practices where patients see members of the hub team. It is felt that visiting people in their homes offers the opportunity to better understand patients' needs, but at the cost of increased staff travel time. It is hoped that more hubs could go some way towards remedying the problem but, as yet, it is not clear which model, or what blend of the two models, will be used going forward.

Efforts have been made to integrate patient information across agencies, but there are some sources of information that are not, as yet, accessible. Some problems with electronic patient record systems are still in evidence; for example, the hub uses the EMIS community model (this is similar to the GP version of EMIS and can be linked to it) and it is thought that some are not familiar with it, and may not be using it optimally. The two versions of EMIS may impact on prescribing as it has been found that sometimes GPs are reluctant to fill prescribing requests from the hub if they are unable to see the patient's records. It has been reported that PAM scores are not necessarily fed back to patients, but are being used to tailor consultations.

Staffing levels in the current hub have been increased. A team member commented that there had been a good deal of interest in the posts, especially amongst younger members of the workforce, and speculated that that was because many valued the opportunity to spend more time with patients afforded by the new ways of working. In parallel with increasing staffing levels, focus is also on developing systems to support information sharing. Work is ongoing to create an easily accessible database of local services (for example, befriending services) that can be used by GPs and social services.

Project 3: Enhanced primary care

The Enhanced Primary Care work in South Somerset is intended to change the way general practice operates, ideally by allowing GPs to have more time to spend with those patients in most acute need. Enhanced practices offer other services, for example health coaching, to patients whose needs are less acute. How the PAM should be used in this context is still a source of debate; it has not yet been decided whether it should be used with specific patient cohorts or whether it should be used with whole practice populations.

The CCG have been encouraging practices to complete PAMs but, so far, the uptake seems to have been lower than expected. It was reflected that the system for processing the PAM scores - the questionnaires were sent to the clinical support unit (CSU) for processing - had meant that scores could not be used immediately. An alternative electronic method is being sought, as normalising the PAM into practice systems is considered to be key to increasing its use. Should normalisation be successful, it is envisaged that that PAM might be used in a number of ways:

- As a tailoring tool to inform the approach clinicians might take with patients
- As a referral criterion into the complex care hubs
- As a higher level outcome measure

It is recognised that work is needed to align the care planning process in enhanced primary care with the work around complex care done by the hubs; the aspiration is to broaden out care planning in enhanced primary care, but it is not felt that using the resource-intensive complex care model is viable. Further, questions remain concerning who, in practices, should undertake care planning and, consequently, what level of investment in training might be needed.

NHS Tower Hamlets CCG

NHS Tower Hamlets CCG comprises 36 GP practices in eight commissioning networks and has responsibility for commissioning services for around 254,000 people. They are one of NHS England's 14 pioneer sites, and one of their priorities is developing a more integrated approach to care within the borough.

Initially Tower Hamlets envisaged using the PAM for long-term conditions like COPD, cardiovascular disease (CVD), and diabetes, forming part of the care planning process for long-term condition care packages. However, as there was a plan to reconfigure care packages more widely in 2015-16, this was put on hold and the PAM was used in three pilot projects and to contribute to one commissioning initiative. All pilot projects were run with the Integrated Care team and delivered with the voluntary sector. The CCG is interested in ensuring sustainability at scale based on the pilot work conducted and commissioned an independent organisation to evaluate the pilot projects. The projects were:

- Esteem Self-management, led by Community Options with healthcare service provider partners, working with ~220 people with long-term conditions and mental health conditions.
- Your Move, led by Green Candle Dance Company with healthcare service provider partners, working with ~55 older adults, some with long-term conditions, to improve exercise levels.
- Managing your health and well-being, led by Ability Bow with healthcare service provider partners, working with ~75 people with long-term conditions or uncontrolled symptoms (e.g. high blood pressure) to improve self-management.
- Commissioning for diabetes education, integrating the PAM into current education programmes with the aim of helping to tailor and structure educational interventions.
- Care planning.

The PAM was used as an outcome measure (used at the start and end, and possibly also in the middle) and as a tailoring tool, helping service providers to meet the needs of individuals. The majority of projects were provider-referral (activation scores were not used as a referral criterion, although once referred to a pilot an initial PAM score could be used to tailor support to individuals). As the projects were diverse a mix of clinical and voluntary sector providers were involved in delivering the interventions and administering and interpreting the PAM. The majority of questionnaires were delivered face-to-face, using patient advocates to translate if needed and to access the questionnaire in community languages. Throughout the process there have been concerns about the impact of this mediated completion on validity.

Projects 1-3: Self-management pilots

Using the PAM as an outcome measure in the self-management pilots (projects 1-3) encountered initial teething problems, but is considered to have proceeded relatively smoothly from the CCG perspective. The pilots were slow to get going because of

problems recruiting staff and patients. Many services had to undertake extra outreach work into communities to recruit relevant cohorts as recruitment via general practices was challenging. One of the reasons cited for recruitment problems was that practices were generally inundated with information and, therefore, tended to refer to the services that they were familiar with and so it took time for new services to raise their profiles. As a result of the delays it was decided to extend the pilots by three months.

Relevant personnel in each pilot were given training in how to administer the PAM. A spreadsheet was provided to collate individual scores collected by the independent local evaluation team. In total, the projects used 693 PAM licences. Data collected as part of the evaluation of these, including the PAM scores, will be used to inform commissioning decisions.

In keeping with the findings of the independent local evaluation, our data shows that administering the PAM was often problematic, particularly amongst groups with learning difficulties and amongst non-native English speaking groups. Further, administering the PAM was felt, by some service providers, to be too time consuming and could eat further into intervention time already eroded by the need to complete other paperwork and questionnaires.

Recruitment numbers and some projects over-running the due date of the independent evaluation report have impacted on the evaluation and it has not been possible to realise statistically robust evidence of long-term improvements arising from the pilot interventions. Despite this, there was some indication that the pilot projects had given rise to increases in activation scores and the procurement of some services is expected to go ahead.

Project 4: Commissioning for diabetes education

Discussions did initially take place to introduce the PAM within the service, but it was decided to continue using the existing questionnaire from the X-pert patient programme.

Project 5: Care planning

NHS Tower Hamlets CCG, in collaboration with Barts Health NHS Trust, East London NHS Foundation Trust' and London Borough of Tower Hamlets, has been awarded vanguard site status by NHS England, focused on providing integrated care. Within this integrated care work, the CCG plans to deliver the PAM from October 2015 with around 1,000 patients in general practice as part of their person-centred care planning work. The aim is to tailor care and support based on PAM level. This work has been running since April 2015, but implementation of the PAM has been slow to start, with some concerns from GPs about capacity to complete the PAM coupled with a lack of awareness about the potential benefits of doing so. There are no plans to use the Carer-PAM as yet, but doing so may be explored in the future. Discussions about how to engage diverse populations, including those who do not speak English, patients with learning difficulties, patients with serious mental health problems, and children, are also on-going.

The use of the PAM in care planning in general practice was incentivised and around £5 was offered for a PAM and a one year follow-up PAM, administered to patients with complex needs. Despite the financial incentives uptake was low and it was discovered that completing the PAM required a GP to log out of EMIS and into another system, thus putting pressure on consultation times. Further, it had been noted that clinicians did not necessarily understand the rationale for using the PAM and its potential to tailor consultations and streamline service delivery. It has been recognised that increased training in the use of, and rationale for, the PAM could improve the uptake of it, although no firm plans are in place for this at the moment.

Mediated completion (by, for example, translators, carers, and administrators) remains an unresolved problem, although attempts have been made to find solutions; for example, the PAM was translated into Bengali but, in that instance, attempting a literal translation resulted in an overly formal and stilted questionnaire that was not well received. In the short term it was suggested that GPs should try to target those who can complete the English version of the PAM.

To support the roll out of the PAM in primary care for the financial year 2016-17 GP practices have received funding via the GP networks to implement the PAM. This funding has been attached to the Integrated Care Network Incentive Scheme (NIS) in Tower Hamlets, whereby GP networks had to submit a plan that covered the following areas:

- How clinicians will be trained in the use of the PAM
- How networks will complete a minimum of 100 PAM questionnaires
- How the effectiveness of the PAM will be evaluated

The CCG will be monitoring the delivery of the plans, and evaluation reports from each of the networks should be available towards the end of the financial year 2016-17.

Tower Hamlets are still seeking solutions to translation issues associated with the PAM and have asked practices to explore and feedback any solutions that they develop. The team have continuing concerns about cultural bias in the PAM and feel that some of the questions overly reflect white Western health beliefs about what a clinician should do and the extent to which self-management is desirable or possible. Tower Hamlets will participate in the ongoing PAM testing and learning work.

The UK Renal Registry

The UK Renal Registry (UKRR) is part of the Renal Association, a not-for-profit organisation registered with the Charity Commission. It collects, analyses, and reports on data from 71 adult and 13 paediatric renal centres in the UK, as mandated by the NHS National Service Specification, and provides access to a clinical database that can be used in research. UKRR holds extensive data on renal patients: this is mainly clinical information but they are interested in extending this to include patient-reported outcomes. Within the renal community there is growing interest in shared decision making and patient-reported outcomes.

The PAM is being used with patients with chronic kidney disease (CKD) (stage 3b and above) as an outcome measure as part of the 'Valuing Individuals: Transforming Participation in Chronic Kidney Disease' programme of work. This work commenced in March 2015, following a launch event in February 2015, and will run until March 2017. The aim of using the PAM is to measure activation levels as part of wider work on person-centred care, building towards a better understanding of care pathways for long-term conditions.

The Valuing Individuals programme has a programme board, co-chaired by clinicians and patients. Three work streams within the programme are linked to patient-reported outcome measures (PROMs) and the PAM: measurement; intervention (guiding decisions about what interventions to put into different environments); and commissioning (what services get commissioned, what should be written into service specifications). A communications sub-group has also been put in place to develop an inclusive communication strategy, and they have been undertaking stakeholder analysis, brand identity work, and media planning incorporating a wide range of traditional and social media.

Within the programme, as well as the PAM the UKRR are collecting outcome data including PROMs (patient-reported outcome measures), PREMs (patient-reported experience measures), the CS-PAM (Clinician Support for PAM), and information on shared decision making along the pathway of care.

As PROMs, the measurement work stream have chosen the EQ-5D-5L (which records health-related quality of life states across five dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/depression at five levels of severity) and the POS-S Renal.

Work on measurement is grounded in testing hypotheses agreed with the programme board. Their objectives are to gather evidence about whether it is feasible and useful to collect PAM data routinely for the renal population:

- Can PAM data, along with other PROM and PREM data, be collected on a national basis – what is the feasibility, cost-effectiveness, and robustness of the data gathered?
- Are PAM levels associated with other patient-reported outcome measures (PROMs, PREMs, symptom burden)?
- Are PAM levels associated with clinical outcomes?

The UKRR is able to link its data to HES data and so, within the work on measurement, it could also examine levels of service use, and include indicators such as blood pressure management, blood sugar control, lower medication costs, likelihood of acute kidney injury (AKI), and survival. UKRR is also interested in whether the PAM is an indicator of other clinical and non-clinical outcomes, what interventions are effective in increasing activation, how long these interventions might be effective for, and whether this leads to improvements in other outcomes. As the programme progresses the programme board will establish how the PAM score or activation level will feed into the wider body of work on commissioning.

Because the focus of the programme is to test feasibility and consider sustainability in the longer term, questions about practicability are being prioritised going forward. This has led to extensive and detailed project planning, particularly considering the scale of the project. Initial plans outlined the involvement of ten renal units, with two more receiving detailed support as part of the programme, but interest in the programme has grown and at least 23 units are expected to participate in the project. It had been proposed that some CCGs could participate in the programme so the possibility of identifying CKD patients at an earlier stage in their disease progression pathway could be explored, but CCG partners have yet to be identified. To manage capacity, renal units were split into two cohorts, with cohort 1 (ten units) commencing work in winter 2015.

Patients who are at stages 3b-5 on the CKD scale (with moderate or severe decrease in glomerular filtration rate (GFR) or established renal failure) are most likely to be under the care of renal units, and these patients will be asked to complete the PAM. The project aims to achieve a response rate of 60–70% for each participating unit. As UKRR has access to patient identifiable data, it will also be investigating what types of patient do or do not complete the PAM.

As each renal unit will administer the PAM independently, UKRR is interested in looking at the implications of each approach to completing the questionnaire. The longer term aspiration is to upgrade the Renal Patient View electronic system (where patients can see their own health records) to enable patients to complete and upload measures online; this will include PROMs, PREMs, and the PAM. A paper-based system is used to complete the questionnaires, and data is returned to the UKRR for analysis. Depending on the renal unit, peer-assisted or healthcare professional-assisted methods are being used to administer the PAM.

The UKRR have worked hard to optimise collection of the PAM and other measures to balance the need for high quality data with the potential burden of data collection on renal units. PAM and the selected PROMs will be measured quarterly. A suitable, validated PREM could not be found and so the measurement work stream, in collaboration with the BKPA and NKF, have developed a renal specific PREM.

The intervention work stream team was keen to design and test a series of evidence-based interventions to see if these can increase activation scores, and consequently improve outcomes. In May 2016 a toolkit of interventions was being drafted.

The UKRR is also interested in exploring whether feedback of PAM scores to clinicians at an individual level has an impact on outcomes, testing the hypothesis that feedback of data alone may drive improvement. Again, this may be tested using randomisation of sites to feedback or no feedback conditions. The UKRR has been using CS-PAM and has a good response rate from renal clinicians. The intervention work stream have been reviewing the data from the CS PAM and designing interventions to improve and support clinician activation.

As part of the broader work, a Person-Centred Care Facilitator was appointed (in June 2015) who supports the individual renal units and provides a link to the central programme board.

As of early 2016, each participating renal unit now has a project team. Ideally, each team was to have been made up of equal numbers of clinicians and patients although this has not been possible in all cases. Each team has been matched with a 'buddy' team from another unit so that learning and resources can be shared. It was hoped that each unit would have had their team in place before the launch event for cohort 1 in November 2015 but, in practice, a number of teams met there, as a team, for the first time. It was noted that, although guidance has been developed for the data collection element of the project, a need existed for a broader 'getting started' guide for the next cohort which should include advice on configuring a team, and how to use 'learning means' analyses to audit a team's skills.

The teams were tasked with writing a 30-, 60-, and 90-day plan for their projects and, by January 2016, seven out of ten plans had been returned. It was intended that the plans would help to indicate if a team lacked any significant skills that might inhibit their ability to complete their work; if skills gaps were identified, then the Person-Centred Care Facilitator would provide teams with, or signpost them to, training and/or expertise.

The guidance and materials for collecting the PAM and the PROM were finalised and sent to the units and data collection began in early 2016. It was expected that completed PAMs and PROMs would start to come in from mid-February and the co-ordinating team had plans in place to road-test their systems to ensure an efficient process of data entry and export to CBS file. Also under review was how best to feed data back to the teams and patients. The communications sub-group were especially concerned with getting data into the right format on 'patient view' (originally a portal where patients could go onto to see their latest blood results, but now used beyond renal medicine) so that it would be most meaningful to patients. It was realised that many would want to access information about what their scores meant, and so work is underway to resolve that. The communications sub-group also recognised that it was important that patients should receive feedback about to what work, or benefit, their scores were contributing. Work was also ongoing with an interface for clinical staff; again, a web-based portal (Sonar) showed PAM and PROM data.

It was envisaged that the first six months of 2016 would be a period in which data collection and processing systems would be refined, and possible improvement interventions would be explored; it was not intended that any patient interventions should be started.

A second Learning and Sharing Peer Review Event took place in May 2016. This event provided an opportunity for the unit teams in cohort 1 to meet to share their successes and challenges and to capture and translate their experiences into learning for cohort 2. It was reported at this event that 467 PAMS and 324 CS-PAMs had been returned.

A third event was held in November 2016 for cohort 1 to share learning with cohort 2. Early findings from the UKRR's own evaluation of the project were fed back.[37] In summary, it was reported that 1,053 surveys had been completed. The UKRR are positive about the project as it was felt that their primary aim, co-production, is being achieved. Data is now being fed back to patients (via 'patient view') and clinicians (using Excel spreadsheets) and the UKRR report that they are beginning to see some instances of data being used in practice. Because there are uncertainties about future funding, the UKRR have concerns that they may not be able to fund a formal evaluation and there are worries that the impetus behind the project may be lost.

11 Appendix 2: Interview topic guides

11.1 Work package 1

11.1.1 Interview Schedule for Patient Activation Measure evaluation: project staff

Welcome and introduction - Seek consent to continue and to audio-record the interview.

Re-cap of project and plan for interview
The interview will explore current and on-going work using the PAM in practice. The aim is to understand what activities and actions are being planned and undertaken and how the PAM is being implemented. We are interested in your perceptions, on the basis of your knowledge and experience. If you do not feel you are able to comment on any area please say so.

Do you have any questions before we start?

If this is the initial interview with a team member, the following should be covered:
– What is your present job title?
– Could you explain how you are involved (your role) in the PAM project within your organisation?
– Could you explain what you understand to be the aims of your organisation's use of the PAM?
– How does this fit in with the strategic aims of the organisation?
– What do you understand to be the main strategies for achieving these aims?
  - Who was involved in developing and/or consulted about your organisation's use of the PAM?
  - How appropriate do you think these strategies are for achieving these aims?
  - Why do you think these strategies will lead to the desired outcomes? (or not)
  - Do you think there are better alternative strategies? What? Why?
  - Do you anticipate any challenges implementing the strategies/activities? Could you tell me about these?

Updates on current action
– Could you update me on what has been happening with the PAM project [since our last interview in [month]]?
  - What activities/events have taken place (planned/unplanned)?
  - Have there been any changes in the local context which have been important? What? Why?

– Can you tell me more about what happened when you did [X activity]?
  - Did it go as planned? (If not, in what ways)
  - Did it/In what ways did it achieve the intended outcomes/or appropriate?

- Could you tell me about any (expected/unexpected) difficulties in implementing/conducting this activity?
- How did you deal with these?
- What factors do you think were important in contributing to its success/failure (as appropriate)?
- Have you made any changes to the planned [activities/strategy]?
- Can you tell me about these changes?
- What prompted this alteration?

- How are you finding the task of co-ordinating the inputs of different partners?
- Have you any tips you would like to share on this?
- In what ways is your organisation currently using the PAM, and the results from it?
- Is this in line with the original plans? If not, can you say why your use has evolved this way?

Update on perceptions of progress
- Overall – which aspects of the project have gone well [since you started/since our last interview]?
    - Did you expect these to go well, or have you been pleasantly surprised? Why?
    - What factors do you think were important in contributing to this?

- What kinds of difficulties or issues have you encountered [since you started/since our last interview]?
    - Did you expect this to be challenging? Why or why not?
    - What factors do you think were important in contributing to this issue?
    - How have you sought to overcome/resolve this issue? How successful has that been?

- Have there been any changes to the project plan/design?
    If yes:
    - Can you tell me about these changes?
    - What has prompted this alteration?

- Have you found the data from the PAM to be useful?
    If yes:
    - What kind of knowledge/ insight has it given you?
    - Was this what you expected?
    If no:
    - What did you expect to get from the data?

Future plans
- What activities/other are planned for the next month?
    - How (& why) are these important to the intervention?
    - What do you expect to achieve from these?
- Can you see any potential opportunities or challenges on the horizon? Why might these be important?

Anything not covered?

Is there anything that we haven't covered in the interview that you think we should know or think about?

Closing and thanks

Check that the participant is still happy for us to use all the information provided and offer the possibility to erase sections of the recording. Thank for their time and contribution.

11.2 Work package 2

11.2.1 Interview Schedule for Patient Activation Measure evaluation: patients

Welcome and introduction - Seek consent to continue and to audio-record the interview
Reassure: confidentiality and anonymity.
- Confirm that the interview is solely for the use of the researchers and any discussions will not be communicated in any way to any service provider
- The report will pull together findings from all participants in the study and no individual will be identified.

N.B. indicative topic guide only. Interviewers are to use this guide as a starting point, and to explore related issues of interest as they arise.

Aim of interview
To understand current acceptability and usage of the PAM among people with long term conditions.

We are interested in your perceptions, on the basis of your knowledge and experience. If you do not feel you are able to comment on any area please say so. Do you have any questions before we start?

Background to participant
- Please could you tell me a little bit about yourself (age, long-term condition)?
- Would you say you were good at managing your health? Why/why not?

Communication/ introduction to the PAM
- Who told you about the Patient Activation Measure? (prompts: how did you hear? who told you/asked you to fill it in?)
- What did they tell you about it?
- Why do you think you were asked to fill it in?
- What did you think when you were asked to fill it in?
- Was it helpful for you to think about your health like that? Why/why not?
- Do you think the answers you gave will be helpful to the healthcare team/people looking after you? Why/why not?

Acceptability of the PAM
- Did you understand all the questions?
- Did the questions seem relevant/important to you?
- How easy did you find the PAM to fill in? Why was that?
- Did you ask for any more information/support about filling it in? If so, was that helpful?

Impact of using the PAM
- Have you noticed any changes in your care since you completed the PAM?

- Did you feel that you had sufficient information and knew what was going on when you wanted to?
- How far did you feel that you were involved in decision making about the care you received?
- Were there any points where you felt you would have liked a greater say in the care you received?

Anything not covered?

Is there anything that we haven't covered in the interview that you think we should know or think about?

Closing and thanks

Check that the participant is still happy for us to use all the information provided and offer the possibility to erase sections of the recording. Thank for their time and contribution.

11.2.2 Interview Schedule for Patient Activation Measure evaluation: frontline staff

Welcome and introduction - Seek consent to continue and to audio-record the interview.

Re-cap of project and plan for interview
The interview will explore current and on-going work using the PAM in practice. The aim is to understand what activities and actions are being undertaken and how the PAM is being implemented. We are interested in your perceptions, on the basis of your knowledge and experience. If you do not feel you are able to comment on any area please say so.

Do you have any questions before we start?

Background details of participant
– Organisation name and type of organisation (if not previously established)
– What is your present job title?
– How long have you been in this position?

Working with the PAM
– Could you explain how you are involved (your role) in the PAM project within your organisation?
– Could you explain what you understand to be the aims of your organisation's use of the PAM?
– What do you understand the purpose of the PAM to be?
– What training did you have prior to being involved with the PAM work? Was that enough/ too much training?
– Who needs to be involved when it's implemented to make it work in practice?
– Do you find it useful to your [clinical] practice? Why/why not?
– What changes (if any) have you made to your clinical practice due partly or solely to what you've discovered from using the PAM?
– What do your colleagues think about it?

Patient views
– What patient group are you using the PAM with, and why was that group chosen?
– How long have you been using the PAM (and with how many patients so far)?
– What do you think patients think about the PAM? How have they received it?

Challenges and successes
– Have you faced any challenges or difficulties in using the PAM?
– How could the process be improved?
– How have you sought to overcome/resolve any challenges? How successful has that been?
– Which aspects of the project have gone well in your view?
– Did you expect these to go well, or have you been pleasantly surprised? Why?

– What helped to make this successful? Prompts: time taken to implement, training, support, structural, cultural, who involved, cost.

– Can you tell me more about what happened when you did [X activity]?
- Did it go as planned? (If not, in what ways)
- Did it/in what ways did it achieve the intended outcomes/or appropriate?
- Could you tell me about any (expected/unexpected) difficulties in implementing/conducting this activity?
- How did you deal with these?

Practicalities of data collection [if appropriate]
– Can you talk me through the process of collecting the PAM data?
– Who is involved? Just you? A team of people?
– How is the data collected? (on paper/ online/ over phone/ mediated)
– How long does it take per patient?
– How do you record the data?
– Who uploads the data to the Insignia spreadsheet (if recorded on paper first)?
– Have you any tips you would like to share on this?

Data analysis
– What happens to the results of the PAM (how are they stored/used)?
– What kinds of thing does the CCG [or other organisation] use the results for? [Prompt as appropriate regarding: individual patient management; population planning and risk stratification; commissioning decisions; managing performance of providers]
– Who looks at the results? Do you share them with patients?

Patient-centred care
– Has using the PAM changed your organisation's approach to patient-centred care?

If yes:
- In what ways?
- How have these changes been achieved?
- Has this been easy or difficult?
- What has enabled or hindered this?
- How sustainable do you think these changes will be? Why?

If no:
- Why not? (Pin down whether they want to make changes and haven't been able to or whether they don't perceive change as necessary)
- If they don't perceive change as necessary, why not?
- If they would like to make changes but haven't managed this, why not? (e.g. wider structural/organisational/management context, resources, skills etc.)

What have you learned from using the PAM?

Future plans
– What activities/other are planned for the few months?

– Can you see any potential opportunities or challenges on the horizon? Why might these be important?

Anything not covered?
Is there anything that we haven't covered in the interview that you think we should know or think about?

Closing and thanks
Check that the participant is still happy for us to use all the information provided and offer the possibility to erase sections of the recording. Thank for their time and contribution.

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