

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

Early Findings

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1 Introduction

Engaging patients in taking a greater role in managing their health is a core element of current health and public health agendas. But what does it mean to be engaged?

Patient activation describes the knowledge, skills and confidence a person has in managing their own health and healthcare. Individuals with long-term conditions with higher levels of knowledge, skills and confidence understand their role in the care process and feel capable of fulfilling that role. They are also more likely to engage in positive health behaviours and to manage their health conditions more effectively. Measuring knowledge, skills and confidence gives health service information it can use to re-shape its services to support people where they are.

This report presents the early findings from the qualitative evaluation of a range of projects that are testing different approaches to using the Patient Activation Measure (the PAM). The projects are being run by five clinical commissioning groups (CCGs) and the UK Renal Registry. All of them aim to use the PAM as a tool to support people getting more involved in their health and care, and/or as a way of measuring patient involvement in their healthcare. The projects are being implemented (to varying timescales) over the course of 2014-16.

The PAM is a well-researched and validated questionnaire used to understand an individual's attitude to their own health care. NHS England has funded the projects' PAM licenses and is supporting shared learning, in order to understand how the PAM can help in realising the national aspirations for person-centred and personalised care in the NHS. Project leaders and commissioners from the six organisations meet regularly as a learning set, so that experiences, challenges, encouragement and solutions can be shared as the projects are implemented.

The Health Foundation is helping to facilitate the learning set and has joined with NHS England to fund an independent qualitative evaluation of the experience of using the PAM. A team from the University of Leicester has been commissioned to undertake the evaluation and this report presents the initial findings from their study. The evaluation aims to:

- Understand how the PAM is being used, and how this develops over time
- Explore the impact of using the PAM in participating organisations at a range of organisational and individual levels, including perceptions and experiences of people with long term conditions
- Explicate the mechanisms of change and contextual influences on the use of the PAM
- Provide formative feedback to the learning set
- Produce generalizable, practical evidence for the future, share knowledge and learning, and disseminate findings.

We have taken the unusual step of publishing these early stage findings due to the level of interest in the work from across the health sector. Many other organisations; commissioners, providers and public health services are looking to use the PAM or other approaches to understand patients' knowledge, skills and confidence with

regard to their health and care. It is important to share what we are learning about ways to approach this; how to engage health professionals and service users; the expected and unexpected challenges faced, how to overcome these and what helps to make implementation run smoothly.

To complement this qualitative evaluation, the Health Foundation's data analytics team are carrying out a quantitative evaluation of the work. This will link pseudonymised data from routinely collected datasets in primary and secondary care with the results of the PAM questionnaires, to understand the links between patient knowledge, skills and confidence and how people use health care.

We hope that you find this report interesting and informative. We hope it will support whatever work you are involved in to help provide care and support that is person-centred and responsive to what matters to the individual. The PAM projects discussed are at the early stages of implementation and we will be working with the project teams to continue to share their experiences, learn from these and adapt the approaches used as necessary. The evaluation studies are ongoing: we are gathering qualitative data through interviews, observation and documentary analysis, while we are in the early stages of collecting quantitative data for analysis and interpretation. Future reports will provide updates about the experiences, findings and outcomes from the PAM projects.

2 Background

Over recent years, the push for the NHS to become more person-centred has been mounting, with increasing attention being paid both to the importance of patients' experiences of care and to supporting them to manage their own health. This emphasis is made clear both in the direction of travel laid down in the *Five Year Forward View*¹ and by the continued inclusion within successive NHS Outcomes Frameworks of indicators relating to supporting self-management and ensuring people have a positive experience of care.² However, despite these policy drivers and good intentions, truly person-centred care remains elusive.

There is no single definition of what is meant by person-centred care, and a recent review identified 160 different tools all trying to measure the concept.³ This suggests both a welcome interest in this topic but also perhaps a lack of clarity about what exactly constitutes person-centred care and how to assess the extent to which it is being delivered. In order to try and move forwards, the Health Foundation has developed a framework that sets out four principles of person-centred care:⁴

- affording people dignity, compassion and respect
- offering coordinated 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 skills, confidence and knowledge a person has in managing their own health and healthcare, maps clearly onto these person-centred care principles. Patient activation is closely linked to other concepts such as 'self-efficacy' and 'readiness to change', but patient activation 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. 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 to supporting people to recognise and develop their own strengths and abilities.

The Patient Activation Measure (PAM) is a measurement scale of patient activation based on patients' responses to questions which include measures of an individual's knowledge, beliefs, confidence and self-efficacy. The resulting score 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:

- Level 1: disengaged and overwhelmed
- Level 2: becoming aware, but still struggling
- Level 3: taking action
- Level 4: maintaining behaviours and pushing further.

While early versions of the PAM comprised 22 questions,⁵ shortened 13-item (PAM-13)⁶ and 6-item (PAM-6)⁷ versions have since been developed, with the 13-item version appearing to be the most commonly used. Additional tools developed to

meet the needs of particular groups include the Clinician Support Patient Activation Measure (CS-PAM),⁸ the Caregiver Activation Measure (CAM),⁹ Patient Activation Measure for Mental Health (PAM-MH)¹⁰ and Parent-Patient Activation Measure (P-PAM).¹¹ The PAM has been translated into over 20 languages and validated in a number of them, including German,¹² Dutch,¹³ Spanish¹⁴ and Danish.¹⁵

There is a significant and growing volume 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.¹⁶ Recent research has demonstrated that improvements in patient activation levels can be maintained over time and are associated with better self-management and lower healthcare service use.¹⁷

The PAM has been used most extensively in the USA to support the management of patients with long-term conditions. A recent review identified three distinct approaches to using the PAM. These are:¹⁸

- 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,¹⁹ little is known about how the PAM could best be implemented and used in the NHS context. To try to answer this question, NHS England is working with six healthcare organisations (five CCGs and one disease registry) to pilot the PAM, and has supplied them with licences to use the PAM-13 tool. These six organisations form the PAM learning set and are using the PAM in different ways, across a range of approaches to improving care and supporting self-management. Support for the PAM learning set is provided via quarterly meetings in which progress, ideas and learning are shared. There has also been some support provided by an independent consultant.

In order to maximise the learning from the experiences of the six organisations involved in the PAM learning set, the Health Foundation and NHS England together commissioned a team from the University of Leicester to undertake an independent qualitative evaluation of the feasibility of using the PAM in the English healthcare context. This report presents the team's early findings from the qualitative evaluation.

In addition, the Health Foundation's in-house data analytics team will conduct a quantitative study of PAM use and outcomes across the six organisations. Combining the findings of these qualitative and quantitative pieces of work will deliver a sound evaluation of this test phase that has the potential to make a substantial contribution to informing any future attempts to implement the PAM more widely.

3 Evaluation methodology and progress to date

3.1 Aims and approach

Our qualitative evaluation of the feasibility of using the PAM is designed to be in-depth, multi-method, and theory-oriented. It seeks to:

- understand how the PAM is being used in practice and how its use develops over time
- determine the impact of using the PAM in participating organisations at a range of organisational and individual levels
- explain the mechanisms of change and contextual influences on the use of the PAM, using a programme-theory guided approach
- provide formative feedback to the PAM learning set and the Health Foundation while the programme is running, providing information that may be of value in 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, we are drawing on diverse forms of evidence and using multiple stages of data collection. Analysis involves moving between different viewpoints, data sources and theoretical perspectives in order to ensure comprehensive understanding of why and how processes give rise to different consequences. The approach permits flexibility, to ensure that the evaluation is responsive to changing experiences in each of the six organisations and remains fit for purpose as the project and the organisations evolve over time.

Our fieldwork takes an ethnographic approach that explicitly seeks to be pragmatic in ensuring that all relevant data sources are accessed and thus uses a flexible and iterative approach to question specification and data collection. This approach recognises the need for a nuanced understanding of the role of local-level contextual factors in determining what happens to the PAM implementation being undertaken, and what consequences and outcomes ensue from those interventions (both intended and unintended).

3.2 Work packages

Our evaluation is broadly split into two work packages:

3.2.1 Work package 1: Surfacing programme theory and understanding the logic of change as this evolves through time

This work package focuses on the 'core teams' involved in designing and running the PAM pilot work at each organisation. We will be:

- interviewing key members of each project team at regular intervals throughout the project's lifespan (provisionally 3-4 times a year)

- conducting ethnographic observations at appropriate events, such as training sessions and consultation events
- collecting relevant documents, such as project plans, meeting agendas and minutes, reports, training materials and other outputs
- conducting ethnographic observations of the experiences and learning of all participants by attending learning set events and other relevant meetings where appropriate.

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

Based on initial findings from work package 1 we are currently finalising our plans for work package 2. Work package 2 aims to examine implementation and experience at the front line, e.g within care planning consultations in general practices, self-management training programmes, or other interventions. Our aims here will be to explore the understanding of the PAM in practice, its use and function for different groups of staff and patients, and wider conceptualisations of the relevance of patient activation for both those living with long-term conditions and those involved in supporting self-management. This work will employ similar methods to work package 1, namely interviews, observations and documentary analysis.

3.3 Progress to date

The evaluation commenced in November 2014; at the time of writing this report we have done the following.

- Gained ethical approval from the University of Leicester Research Ethics Committee for work package 1 and secured appropriate permissions from the participating sites.
- Reviewed the sites' initial theories of change generated from work conducted by the independent consultant to inform our interviews with the sites and our observations.
- Conducted 19 first-round interviews for work package 1, with representatives from the project teams at all six sites. All interviews have been recorded and transcribed verbatim.
- Conducted 26 hours of observations at both learning set and project-specific events. All observations have been 'debriefed' by the researchers (discussed within the team to record data, relate insights to existing knowledge, and develop further research questions); these debriefs have been recorded and transcribed verbatim.
- Generated a description of all projects currently underway at participating sites.
- Selected a purposive sample of six projects to be studied in depth as part of work package 2.
- Conducted an initial analysis of the data from early work package 1 interviews and observations in order to generate early findings, which are presented in this report.

4 Early findings

4.1 Overview of sites' work

All six sites are measuring patient activation in multiple projects (these are briefly summarised in table 1, and presented in more detail in appendix 1). The diversity of these 20 projects provides an opportunity to explore the potential of patient activation across different care settings and long-term conditions, and within different interventions and approaches. Most projects began collecting and using data from the PAM in April 2015, with some sites starting to collect baseline data prior to this.

Across these different projects there is a wide variety in terms of:

- type of condition/patient group involved
- type of intervention
- type of health professional or other service provider involved
- scale of project (in terms of number of PAM licences requested).

At this stage it is important to reiterate that the findings presented here reflect the sites' work in progress. Projects will evolve and be refined in line with changing objectives, contexts, and learning, and the evaluation focus will be reviewed in light of this development process. All the sites were aware that they were still quite early on in their work. The next steps for the sites over the coming months include: managing and monitoring progress; ensuring staff are trained to administer the PAM and have adequate support to do so; actively recruiting patients to complete the PAM and participate in interventions; analysing initial baseline data; and working to collect data. All sites were positive at this stage that the implementation of measuring activation would make due progress and that any issues encountered could be overcome.

Emerging themes about early progress, successes and challenges are presented in the remainder of this report. Initial analysis has focused on: the decision to measure patient activation and how this fits within the context of the wider work and strategic aims of each organisation; lessons from the planning and early implementation process; and engagement with stakeholders.

All those interviewed to date form the 'core teams' associated with planning, designing and leading the introduction of the PAM in their organisation. The core teams are varied, with some sites' activity led by GPs, and others by those with dedicated roles for commissioning services. Some projects have dedicated project or programme managers, while others are working on patient activation as part of a wider remit of person-centred care. Some projects have commissioned internal or external evaluation of their activities, and we also interviewed individuals involved with evaluating the project

Classification: Official

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 licences	Patient populations	PAM function	Providers
NHS Horsham and Mid-Sussex CCG and NHS Crawley CCG	Tailored Health Coaching Pilot	2,000	Long-term conditions/medium risk of increased health service use	Tailoring and outcome	Trained health coaches
	Musculoskeletal (MSK) service Tier 3 Weight Management Service	2,600 400	Rheumatoid arthritis Obesity	Outcome Outcome	Sussex MSK partnership A multidisciplinary team including bariatric physicians
NHS Islington CCG	Care planning in General Practice Diabetes Self-Management Programme The Expert Patient Programme Bariatric Service: weight regain intervention programme	28,000 10,000 patients across three services	Long-term conditions Diabetes Long-term conditions Obesity	Outcome Outcome, with the potential for tailoring	GPs NHS Whittington Health Trust
NHS Sheffield CCG	Citywide long-term condition management	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 CCG	House of Care and SQPS outcome framework – including several smaller pilots	10,000	LTCs	Outcome	GPs, community providers and Symphony Consortia
	DAFNE diabetes self-management	100	Diabetes	Outcome	Community providers
	Mindfulness-based cognitive behavioural therapy groups	100	Mental health and long-term conditions	Outcome	Community providers
NHS Tower Hamlets CCG	Commissioning diabetes educational self-management	Not known	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 wellbeing	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	Valuing Individuals: Transforming Participation in Chronic Kidney Disease	30,000	Chronic kidney disease	Outcome, possibly tailoring	Renal units

4.2 Different approaches to using the PAM as a tool

Our initial work with the sites has shown that, across the wide variety of projects, there are three broad approaches to how the PAM is being used:

- As an outcome measure, typically for some form of intervention. In these cases, the PAM is being used as a measure of the effectiveness of an intervention in supporting patient activation.

The whole concept of activation – an individual’s knowledge, skills and confidence – seemed like a really useful measure to enable us to understand where people are on that trajectory. That in turn would enable us to understand whether interventions are working or whether they would benefit from other specific interventions. (Core team member 1, Islington CCG)

- As a tailoring tool, either at the individual patient level or at a higher population level. In these cases, the PAM is being used as a means of ensuring patients are receiving the most appropriate types of support for their level of activation.

It would include what services patients get signposted to as a result of having this score rather than that score. And the nature of the consultation itself would be different according to what score they get, and that is a massive culture change from a patient having a seven-minute consultation with the GP which results in a prescription being given. (Core team member 1, Sheffield CCG)

- As a combination of both an outcome measure and a tailoring tool. Here the tool is being used in both of the above ways within the same project.

For me the tailoring is the really critical part of this... but also using it as an evaluation tool, to say: ‘Okay. This person started at this level of activation... Where have they got to by the end of six months, by the end of a year and what impact has that therefore had on their health?’ (Core team member 1, Horsham and Mid-Sussex CCG and Crawley CCG)

4.3 How the PAM might contribute to delivering person-centred care

While the measurement of patient activation may be undertaken in a standalone way, it is much more common for it to be integrated into a larger programme of work and used to support delivery of what sites hoped would be a truly person-centred approach to care.

Many members of core project teams discussed the way in which their organisation had previously considered or tried to implement a new model of care, moving towards a personalised and person-centred service model often integrated with social care. However, in previous work they had encountered staff concerns and resistance, systemic barriers and in some cases identified a lack of service provision. They saw measuring patient activation as a means to support effective realisation of the wider service changes they were seeking to achieve.

This is the step we are missing, that we should be doing before care planning. If we understand where our patients are at in terms of the activation level, we can have a much more meaningful care planning discussion around their [long-term] condition. (Core team member 1, Tower Hamlets CCG)

What was missing from our service offering was something that looked at patients in a much more holistic way, looked at a less medicalised model for delivering care for particularly those with one or more long-term conditions. (Core team member 2, Horsham and Mid-Sussex CCG and Crawley CCG)

These planned changes to service provision are often intended to have a vast and profound impact on the delivery of care. The predominant view is that the PAM represents a tool that can be used to help move from a healthcare-provider focused, paternalistic model of service delivery to a more personalised, holistic, multi-provider model in which the patient is given the most appropriate support to self-manage.

[We're using it] to help practitioners understand that that's what we're asking them to do. The PAM is a tool to enable that completely different approach to consultation, as well as perhaps being an outcome measure and all the rest of it as well. (Core team member 4, Sheffield CCG)

Those interviewed often used the phrase 'culture change' or 'system change' to refer to the intended effect. Learning set members do not underestimate the challenges in changing ways of working and delivering services, both for patients and clinicians, but are still positive about being able to improve healthcare systems. In one case concerns about the extent to which these changes could be achieved quickly, and the PAM become properly understood and embedded, have led to a more cautious initial approach being adopted for fear of unintended consequences.

By attaching a figure to a person's level – a score – it might actually limit the effectiveness of conversations that a health professional is having with a person and actually kind of prevent those good discussions. I think a lot of people when they are stretched for time would look at the route of least resistance, and so: 'I can see you are a level 2 or a level 1, so there is no point in me even having a conversation with you today about maybe referring you to a health management programme because you are not even ready.' And actually potentially preventing those sorts of helpful conversations that happen to move people on. (Core team member 1, Islington CCG)

For all sites, establishing the link between the strategic aims of the organisation and the concept of patient activation was crucial to the planning process. The PAM played a central role as a tool that could connect overall aims with the on-the-ground reality of delivering care.

The strategic aim is very much around the prevention agenda. Making sure that we are keeping people well and keeping people out of costly acute care... understanding their condition and... understanding what it is that makes people anxious about their condition. And I think the Patient Activation Measure fits into that in terms of our marker and gives us a structure by which we can uniformly measure. (Core team member 2, Horsham and Mid-Sussex CCG and Crawley CCG)

From the CCG perspective there's a big push around increasing self-management and supporting people to be able to do that, as there is nationally, and so the PAM's right in the middle of that as an enabler or as a tool to help us do that. (Core team member 4, Sheffield CCG)

4.4 The changes sought, and how to measure success

Clarity on what outcomes are being sought, and how to measure success, are both crucial. While PAM scores will of course be measured, other outcomes are also being recorded in order to ensure the impacts of any interventions are fully captured. Across the projects a wide range of outcomes are being considered. Typically, increased activation is seen as something that could have a positive impact on health care service utilisation, patients' clinical outcomes, patient engagement, and patient experiences of care.

Once we have got health care professionals behaving differently we can then look at some outcomes. So they would be things like... fewer emergency admissions and fewer prescriptions and fewer contacts with the GP, the change in nature of the person's relationship with the GP... and being more engaged in their health care, so in this sense [the] PAM itself becomes an outcome measure. (Core team member 1, Sheffield CCG)

If you have got patients that are much more engaged in their own care, does it lead to better patient and clinical outcomes? So, do patients feel a lot more in control, because they feel like they are being consulted? (Core team member 1, UK Renal Registry)

How data on patient activation is positioned relative to other data also being collected, such as that about patient experience and clinical outcomes, needs to be carefully considered. In some cases, exploring the relationships between PAM scores and other types of data is an explicit part of teams' work, while in others several different forms of data are being collected but there is less clarity on the rationale for doing so.

Clarity about what success will look like is particularly important in those cases in which the PAM score itself is being used as an outcome measure to assess the effectiveness of an intervention. In these cases, teams have to think carefully about what change in patient activation score they might reasonably expect to see following any particular intervention, and over what period of time this might be achieved. It is likely that there will not be any standard answer to this question, and the following factors are likely to be important:

- The type of intervention, in particular its intensity and frequency of contact.
- The patient's starting point, as it is generally accepted that increases in activation score are more easily achieved by patients who are starting from a low score rather than those already at higher levels.²⁰
- How frequently the PAM score is taken.

Going forward, the potential for tensions to arise when the PAM score is being used to assess 'success' or 'failure' of an intervention is likely to require careful handling and skilful negotiation, especially in the case of third-party service providers for which there may be financial implications.

4.5 Planning to use the PAM

All sites in the learning set have conducted a significant amount of planning to design their projects, including thinking about how best to integrate the PAM with what currently exists in their context. Several sites have also conducted small-scale pilot work to inform this process. One key learning point from the work conducted so far is the amount of planning required to implement a new tool like the PAM into existing care arrangements.

The sites initially joined the learning set in December 2013 and by April 2015 most were using the PAM, with the majority of sites starting to collect data or conduct training from around the end of 2014 or start of 2015. Some sites had started planning the work prior to joining the learning set, building on previous data collection work to inform commissioning. Because – for some sites – using the PAM represented a significant shift in service design and approach, this needed to be carefully designed to secure engagement and ensure that provision was joined up. Several teams commented on how they have found it valuable to undertake piloting work before moving to full implementation of their plans, while at the same time accepting that it is not possible to plan forever.

It's taken a couple of rounds of reviewing what's going on... whenever you change a system there's always things that happen and it's only when you interrogate what's going on... I think it does take two or three just checks of the system. (Core team member 2, Sheffield CCG)

I often think the planning is quite important to get it right in the first stages... in some ways I feel the pre-planning before we actually start recruiting wasn't really big enough. But... it's like [the] devil and the deep blue sea, you can't plan forever, you've got to start the work. (Core team member 2, UK Renal Registry)

4.6 Practicalities of using the PAM

The practical implementation of the PAM was one aspect of the planning process that proved to require further thought and decision-making than initially anticipated. Project teams have had to tackle several important issues.

4.6.1 When?

When to record a patient's activation score must be carefully considered: for example, whether this is best linked to a particular event (such as an annual review or in relation to a change in treatment or health state) or determined by time since commencement and/or completion of an intervention. Each site has responded to this question based on the needs of their patient cohort and the intervention chosen. For example, Sheffield CCG are measuring the activation levels of diabetes patients in one GP practice as part of their annual review, and Tower Hamlets CCG are measuring activation as patients begin a self-management intervention as a baseline, then re-measuring after the intervention, and at six month follow-up.

4.6.2 How?

How the PAM questionnaire will be delivered also needs to be thought through carefully: for example, whether it will be completed independently by the patient on paper or electronically, with the support of a healthcare professional or patient peer/advocate, over the telephone or in person. While the literature suggests that mode of completion does not influence the scores recorded and that multi-mode completion is the best way to secure higher response rates,²¹ the particular features of any instance of PAM use are likely to play an important role in how decisions about administration are made. For example, when the PAM score is required will be important – if the PAM score is being used as a tailoring tool within an intervention like care planning, then reliable completion ahead of that consultation is required. Mediated completion has emerged as a particularly challenging issue to manage, and there are some concerns about the extent to which this may impact on the validity of the data collected. Again, each site has tailored their delivery method based on their use of the PAM. Islington CCG have opted for a large-scale postal delivery of the PAM with supplementary face-to-face administration for those not responding, while Horsham and Mid-Sussex and Crawley CCG are administering the PAM over the telephone as part of their Tailored Health Coaching.

4.6.3 Who?

Which healthcare professionals or other service providers will be responsible for administering the PAM and processing the data also needs thinking about. This is related both to which organisation (e.g. general practice or some other specialist care provider of an intervention), and which particular professional group (e.g. if administered within general practice then this may be best done by a GP, practice nurse, or healthcare assistant). Again, there is unlikely to be one right answer here – the specifics of the way in which the PAM is being used in each case should drive these decisions. As examples, the UK Renal Registry plans to use patients as peer

support to aid completion of the PAM, while Sheffield CCG are using healthcare assistants to administer the PAM with diabetes patients.

A further point to consider is how PAM data collection can best be positioned relative to any intervention to which it is linked. In cases where the PAM is being used solely as an outcome measure of the effectiveness of an intervention, and not actively within the intervention itself, it is debatable whether those delivering that intervention should also be responsible for collecting PAM data, or whether the two should be separated. In cases where the PAM data is being used as a tailoring tool, there may be pros and cons to the person delivering the intervention also collecting the PAM data themselves as a first step. For example, there is some early suggestion that when this has been attempted within health coaching it causes interactional difficulties within the coach/patient encounter.

No matter who administers the PAM and processes the resulting data, care must be taken to ensure they are suitably knowledgeable about the tool and the data it will produce. For example, it is highly likely that some completion styles indicate that the data produced will be invalid, such as in cases where a patient has indicated 'strongly agree' in all cases, and those involved must be able to spot these and take appropriate steps (e.g. discarding that data and arranging for re-completion, possibly by another means, at a later date).

4.6.4 Where?

Where the results of the PAM will be stored and who will have access to these must also be considered, and this will need to be thought through in advance of data collection if patients are to be fully informed about what will happen to their data at the time they are asked to complete the PAM. Whether patients themselves will be provided with information on their activation level should also be considered, and how this can best be communicated.

4.6.5 Other issues

How to deal with language issues and literacy was a common concern among the teams. Questions about the suitability of any available versions of the PAM for some community languages were discussed in all sites, with some sites considering how to ensure it could be used with the whole of their patient population, or if this was even feasible. The issue of mediated completion as outlined above was particularly pertinent here.

And some of the people are not even literate in their own languages so having something in Swahili, leaflets in other languages are helpful but they're not the whole answer because really you need somebody to talk to the patient as well. (Core team member 3, Sheffield CCG)

For our population particularly we have an issue around the Sylheti language which is the dialect of the vast majority of our local ethnic minority population. [It] is not a written language. So, even providing it translated into Bengali wouldn't work for our population... we are going to have to look at how it works for those people and whether or not using the advocacy model of translating for people actually would be a bias. (Core team member 2, Tower Hamlets CCG)

Capacity for data analysis was also a concern for some sites, which were aware that they may not have enough support to maximise the learning from the data produced about activation.

So that will be interesting, to know how we go about doing that and when, and who's going to analyse it... my concern is capacity here to do all the analysis. (Core team member 2, Islington CCG)

There's so much more we could learn because we're rich with information. It's just we haven't got the capacity to give it, to analyse that data and draw conclusions from it. (Core team member 1, Horsham and Mid-Sussex CCG and Crawley CCG)

4.7 Engaging stakeholders

Engagement with stakeholders has two stages. First, there may be a wish to consult with healthcare staff and patients in project design, to think about the needs of the local population, how these needs could be met, and what role measuring patient activation might play within this. Second, once projects have been designed, there is a need to spread awareness and use of the concept of patient activation and the PAM to a wider group of staff and patients, including training healthcare staff in how and why to use it.

On the first point, some sites have involved front-line clinical staff and patients in project design. This has had benefits and drawbacks. Although engagement was broadly seen as a worthwhile process that could ultimately lend credibility to implementing new interventions, it could also be time-consuming.

What we're doing is just lots of talking. Lots of engagement with practices. All of the patient engagement that we've done, we've included the practices in on. So they've been able to hear first-hand from their patient sitting in front of them what they want. We've also fed back the comments that have come through from that patient engagement to the patients, included it in the business case. (Core team member 3, Horsham and Mid-Sussex CCG and Crawley CCG)

[It's] not quite gone according to plan, in terms of timescales, just because the length of time it's taken for us to do some of the sign-up work. Because we're doing the programme in co-production with patients, they don't necessarily work in the same speed and way that we do. (Core team member 2, UK Renal Registry)

On the second point, effectively communicating what is required to those being asked to use the PAM, as well as ensuring that this is achieved, needs careful management. In one project, the locally commissioned service contract includes an incentive dependent on staff attendance at training events as well as proportion of questionnaires completed, to ensure that GP practice staff fully understand the wider

context of the introduction of the changes to services. The aim here is to move away from questionnaire completion as a 'tick box' exercise to greater engagement with concepts underpinning person-centred care. Much of the planning in this case has involved attempting to win the 'hearts and minds' of staff. While incentivisation has played a role in securing engagement, it was recognised that on its own this would not provide the desired genuine engagement with the process.

GPs are being asked to carry out one administration of PAM but they are getting paid to do that. It is not the same as saying their hearts and minds are in person-centred care planning through administering PAM. Some will be, some won't... How that connects with the wider processes in which it is embedded, then the wider person-centred care planning approach is to try and bring about a culture change within primary care where ideally, maybe idealistically, GPs are enthusiastic about implementing PAM in the total spirit of it rather than just getting a PAM score. (Core team member 1, Sheffield CCG)

In cases where practices do not deliver on what is expected of them, this project has plans to offer further help and support, rather than focusing on withholding incentives.

The approach we're going to use is not just stopping the money. We're going to say [to GP practices]: it looks as if you're having a few difficulties. Would you like somebody from the locality support team to come and talk to you about it? So that's how we're aiming to work. (Core team member 3, Sheffield CCG)

In those cases where PAM data will be used only as an outcome measure, less extensive engagement at the level of 'hearts and minds' may be required. One project using the PAM as an outcome measure for care planning has adopted the approach of asking general practices to record PAM data but explicitly not to use it as a tailoring tool within consultations, meaning they have not focused so much attention on this aspect of engaging stakeholders.

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. So it's incentivised. If GPs actually want to do something about [understanding and using activation levels] then that's fair enough. But it's not what we were planning. (Core team member 2, Islington CCG)

Some sites considered how the rollout of the programme to a wider group of stakeholders could have been managed differently, even from an early stage of data collection. The role of champions was considered, with the recognition that not all healthcare staff would see the need to change practice and encourage greater self-management.

But in hindsight I think probably to have selected a few practices who are keen to do it, and then started from there, and then encourage the others. (Core team member 1, Somerset)

I think finding local champions would be a big thing so actually engaging with people who are interested and then getting them to work and making sure that the people that are involved in any plans for how you are going to implement it are actually people who are working on the ground. (Core team member 2, Tower Hamlets CCG)

When being used as an outcome measure of an externally commissioned service, building the use of the PAM into service specifications was a commonly used step to ensuring its use. New or existing self-management services could be commissioned specifically mandating use of the PAM as an outcome measure with all patients in the programme.

4.8 Early challenges

Clinical buy-in was mentioned by five sites as a big challenge, both in relation to getting clinical staff to engage with the wider project or intervention, and getting them to accept the need for more person-centred care.

Some clinicians are really clued up and forward thinking, want the patients to be involved and believe in educating the patients. But you will get a few that just don't want to engage. They think they are but they're not. (Core team member 2, UK Renal Registry)

If we were going to do this again and do it differently, I think we would engage our membership much earlier... I think our lining up our allies, so to speak, would have been a much chunkier piece of work. So the stakeholder engagement element of it, I think would have been a little bit more robust. (Core team member 2, Horsham and Mid-Sussex CCG and Crawley CCG)

In some sites, the challenges were not to the concept of person-centred care, but to the validity of measuring activation as a concept. Some challenges to the validity of the PAM centred on its prior use in an American context, with perceptions of the differing needs and characteristics of a UK population in comparison with a US one.

It is more the fact that it has come from America and it is like an: 'America sneezes and we catch a cold' kind of attitude. (Core team member 2, Tower Hamlets CCG)

Ensuring that information technology systems supported the implementation of the PAM and person-centred care quickly emerged as a challenge in many sites. The use of different IT service providers between and across primary care and secondary care meant that 'joining up' data could be complicated and undermine approaches to encourage patients to self-manage. This was reported as a source of frustration among front-line staff and as affecting their wider engagement with the concept of increasing patients' ability for self-management.

Systematic change has been quite difficult – we can't share information between one provider and another provider. So I might develop a care and support plan for a patient but then that patient might go and see a secondary care provider and they might make complete changes which aren't then communicated back to me for a while because I am waiting for a letter, so fragmentation in the IT system. (Core team member 1, Islington CCG)

Another question that came up a lot was about information technology... the problem for years has been interoperability... There were real concerns about how they're actually going to share information. (Training event observation debrief, Sheffield)

4.9 Early successes

Although still at an early stage in measuring patient activation, sites were able to identify some initial successes in the implementation process. For sites that had sent out large numbers of questionnaires to patients, response rates to the initial baseline survey appeared to have been good, and there was a desire to learn from this.

I haven't really spoken to many practices, but there was one practice who seemed to think she'd got almost 70 per cent of the questionnaires that had gone out returned. (Core team member 2, Islington CCG)

The next steps will be to visit the five practices [with a high response rate] to understand how they found it in terms of approaching people to do it, how they did actually give them out, or send them out. (Core team member 1, Somerset CCG)

Getting stakeholders engaged was also seen as something that was challenging, but that some sites had started to achieve.

The co-design event I felt went really, really well... it was incredibly positive. It was incredibly respectful between patients and the professionals that were there... There was a real appetite for the programme so for me that is our biggest success to date. And our biggest challenge is patient [and] carer involvement. (Core team member 1, UK Renal Registry)

Other sites were pleased with the learning they had gathered so far and anticipated further learning about the best ways to implement the tool.

[We've] learned a lot about the operational side of it, how do you actually do it, when do you do it, do you send it out in advance, does the patient do it in the waiting room, how do you get it into the notes. You know, all these kind of really practical things. And I think they've got it sorted in [the pilot] practice but every practice is a bit different, so one of the things we'll hopefully learn from our evaluation is what are the different ways of doing it. (Core team member 4, Sheffield CCG)

The enthusiasm encountered among clinical communities and the awareness of the potential uses of the PAM were seen as positives in some sites, though there was recognition that it was still early in the implementation process.

I think we've all very much been focused on the same goals and aims of what we're trying to achieve and built it up very much as a collaborative approach to it. (Core team member 1, Horsham and Mid-Sussex CCG)

So there was this sort of scepticism a little bit about it, but actually when practices had had a look at it they like it and it's been quite interesting, because initially we sent it out for the two per cent frail elderly... But actually people have come back and said... we'd like to do it on those [patients]... and some even have said we want to do it for this particular intervention [as well]. (Core team member 1, Somerset CCG)

5 Summary points

5.1 Role of the PAM

The approaches and projects, led by the CCGs and the Renal Registry, primarily focus on one of three ways of using the PAM:

- as an outcome measure
- as a tailoring tool
- as a combination of both an outcome measure and a tailoring tool.

We have identified four different hypotheses about the role of the PAM that underpin the diverse projects being conducted across the six sites. Projects may be underpinned by more than one of these hypotheses.

- PAM scores can be used to tailor healthcare interventions at an individual level to ensure that they are appropriate, given patients' baseline levels of activation. This will result in improved intervention effectiveness, improved clinical and patient outcomes and will have a positive impact on patients' utilisation of health services.
- PAM scores can be used to tailor the provision of services in a locality based on population levels of activation. This will result in improved efficiency, cost-effectiveness, and individual and population outcomes.
- PAM scores can be used as outcome measures for interventions which are targeted at improving health outcomes, or at increasing patient self-management/self-efficacy. There is an implicit assumption that 'success' will be reflected in increased PAM scores.
- The PAM tool can be used as part of the consultation to change health professional behaviour, to change the nature of consultations, and to increase patient involvement and engagement in their care. This may link in with wider aims of generating cultural change towards more person-centred care, among professionals as much as among patients. This will result in improved clinical and patient outcomes, have a positive impact on healthcare utilisation, and will lead to increased patient activation (increased PAM scores).

We will use these hypotheses to characterise the six projects we are focusing on in work package 2, to explore decision making around the role of the PAM, and to assess the effectiveness and challenges of using the PAM in different roles and to different ends.

5.2 How the PAM is delivered

Across the projects there are differences in how the PAM is being delivered. Key distinctions include:

- the extent of stakeholder involvement and engagement with the administration of the measure and the use of PAM scores
- how the PAM is introduced to the patient, whether its purpose is clearly explained etc

- whether the PAM is administered by post or is completed by the patient when attending the service (and, if completed at attendance, whether the patient completes it themselves or in collaboration with a health professional)
- whether the PAM score is shared/discussed with the patient, and if so how the score is explained
- whether repeated measures are taken and if so, how often and at what points.

How the PAM is delivered will potentially have implications for response rate and for the validity of the scores, but also, importantly, will impact on the extent to which it can be effective as a tool to change health professional behaviour, to change the nature of consultations, and to increase patient involvement and engagement in their care.

5.3 Issues and challenges

One key issue, particularly in relation to the use of PAM scores as outcome measures, relates to the risk of implicit assumptions that PAM scores would be expected to increase in a linear fashion as a result of interventions. There is a need for recognition that increases in activation are likely to be greater and easier to achieve for patients who are starting from a low score.²² There is also a possibility that patients may shift between PAM levels as their condition changes – for example, moving from a higher to a lower level of activation as their condition worsens. For some patients, maintaining their PAM score at their current level, rather than increasing it, may be a positive outcome.

A second issue relates to the risk that when patients achieve low PAM scores this may deter health professionals from investing time in attempting to engage these patients in self-management or preventative activities.

It is unclear how these issues will impact on, or be taken into account by, the proposed projects, and we will remain sensitive to exploring these issues as the projects progress.

5.4 Planning to use the PAM

A key learning point from the work to date is the amount of time and planning required to implement the PAM in the context of existing care arrangements. Significant challenges faced by sites have included: mediated completion of PAM; working with patients whose first language is not English; gaining clinical buy-in and overcoming perceptions of PAM as a ‘tick-box exercise’; barriers arising from IT systems; and finding the time and expertise to analyse the data.

Sites have highlighted the need for piloting where possible, and have also highlighted the potential value of an approach based on staged roll out of the project with early sites acting as ‘champions’. Sites using the PAM at commissioner level have suggested that the inclusion of the PAM into service specifications can be a helpful approach.

5.5 The PAM and outcomes

Evidence suggests that PAM scores are predictors of health outcomes, improved service utilisation, and reduced cost.²³ The four hypotheses we identified suggest different and complex possible relationships between PAM score and other outcomes: tailoring care based on the PAM improves efficiency and outcomes; the PAM can be seen as an outcome in itself alongside other outcomes; use of the PAM in itself improves outcomes through promoting patient-centredness and involvement.

6 Appendix 1: Individual site plans (at April 2015)

6.1 NHS Horsham and Mid-Sussex and NHS Crawley CCGs

6.1.1 Overview of site and work

NHS Horsham and Mid-Sussex CCG comprises 23 GP practices and is responsible for the health and wellbeing of over 225,000 people.²⁴ NHS Crawley CCG is made up of 13 GP practices and commissions healthcare services for more than 120,000 people.²⁵ 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:

1. Tailored Health Coaching Pilot, working with up to 2,000 patients to tailor the approach taken to health coaching, and as an outcome measure to improve self-management
2. Musculoskeletal (MSK) service, working with up to 2,600 patients with rheumatoid arthritis and using the PAM as an outcome measure
3. Tier 3 Weight Management Service, working with up to 400 patients and using the PAM as an outcome measure.

The PAM will be used at an individual level with patients and will be delivered either over the telephone or as a face-to-face questionnaire. Each service will have a different set of clinicians with different training and experience, and the team is interested in the impact of this training and experience on the increase in PAM scores. As well as the PAM, Horsham and Mid-Sussex and Crawley are collecting data including the risk stratification score, HES data, GP data, healthcare utilisation costs and patient satisfaction. The project team is also interested in thinking about what skills and training a clinician needs to have to improve patient activation, and so will look across the projects to capture learning.

6.1.2 Project 1 – Tailored Health Coaching pilot

Tailored Health Coaching is a new service, jointly commissioned with West Sussex County Council from a local charity, which launched in April 2015. Health coaching is targeted at those with a long-term condition at medium risk (45–65 percent) of increased health service utilisation (identified using their risk stratification tool). The health coach will contact the patient by telephone, explain the expected outcomes and undertake the PAM to ascertain the current level of activation. The PAM activation level will then be used to tailor the service provided, identify goals, formulate a 'Well-being Plan', and then use a web-based 'Menu of Care' to choose appropriate support options for the patient. Service delivery will be holistic and include all health and social care services. If patients are at level 3 or 4 of activation, support will mainly consist of signposting to services. If patients are at levels 1 or 2, more motivational interviewing and greater support will be provided. Those delivering the intervention have been trained in motivational interviewing. 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. Around 2,000 PAM licences will be used in this cohort. Outcomes measured before and after will be:

- use of healthcare services and utilisation costs
- PAM score
- risk score
- the Warwick-Edinburgh Mental Well-Being Scale.

6.1.3 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. physiotherapy) to longer-term therapies (e.g. pain management) but patients will be encouraged to self-manage their conditions as far as possible. Initial recruitment to the MSK service was slower than anticipated, at least in part because most patients access the service via an annual review process.

The PAM is being used with patients who have rheumatoid arthritis 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 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’.

6.1.4 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, 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.

6.2 NHS Islington CCG

6.2.1 Overview of site and work

NHS Islington CCG comprises 36 GP practices and has responsibility for commissioning services for around a quarter of a million people living in an area under six square miles.²⁶ It is one of England's 14 pioneer sites,²⁷ developing a more integrated approach to care within the borough. Islington was planning to use the PAM as part of its work before joining the learning set.

The PAM is being used across the primary care setting with patients with long-term conditions. Its use builds on previous work conducted in the area: in October 2013 the CCG sent out the LTC6 questionnaire (which asks patients with a long-term condition about their healthcare over the last 12 months) to ~40,000 people with a long-term condition. The aim was to provide evidence of the efficacy of new services being commissioned and a 25 per cent response rate (~10,000 people) was achieved. Islington's PAM use fits in with the broader direction of travel and work around embedding self-care and self-management support into clinical practice.

Islington is focusing on the PAM as a means of measuring the effectiveness of any intervention. There are two main pieces of work:

1. alongside care and support planning consultations in general practice, with ~28,000 patients
2. embedding into contracts for self-management support commissioning.

Two other pieces of work with the CS-PAM are also being 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) and the 'Year of Care' trainers. Islington CCG requested 38,000 PAM licences and mainly distributes questionnaires by post.

6.2.2 Project 1: Care and support planning in general practice

Islington CCG has commissioned 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); liver disease.

GPs were initially commissioned (February 2013 to November 2014) to offer enhanced collaborative Year of Care care and 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 offers 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 who are identified as being in the practice's top 2

per cent of people who are at risk of being admitted to hospital. The care planning commissioned by NHS England is not a collaborative enhanced care plan in the style of Year of Care, but the patients in this cohort will also include people with multiple long-term conditions who will receive a Year of Care care plan.

Commitment to engagement with the PAM project is embedded into the long-term condition LCS, which was initiated in October 2013. In order 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. Method of survey distribution (postal or face-to-face) could also be recorded. Instructions detailing how to deliver the PAM tool were developed and sent out to each practice, including:

- a letter to practices explaining patient activation, how this could be measured with the PAM tool, and what was expected of the practice
- a step-by-step guide to how the CCG wanted them to collect and use 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 they would need to answer
- a letter including the PAM tool, to be sent to patients 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 to calculate and add PAM scores to patient records, with payment of £2.50 for each score recorded. GP practices have also been sent details of a retrospective review that they will need to complete a year later, after a second PAM has been sent out to patients. The review will look to see if there has been a change in an individual's PAM score and if they have taken part in the collaborative care and support planning process. While acknowledging that a lot is likely to occur in the intervening year, the project team hope to be able to comment on the effectiveness of care and support planning consultations based on this data. They will also be asking GPs to pull relevant information from a sample of patient records retrospectively to review what else occurred with those patients.

Although practices record the PAM score, Islington is keen to embrace principles underpinning patient activation as a concept and not just focus on the number/score the tool produces. The score will not formally be used by clinicians within the care and support planning process, though it will be visible in patients' electronic records. The team believes that there is a danger in focusing on the numbers in a superficial manner and limiting the depth of the ongoing relationship that clinicians may try to develop: eg if a patient has a low activation score, the GP may think it is not worth discussing the full range of support services available and so limit choice.

6.2.3 Project 2: Self-management commissioning contracts

This project involves 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 are being asked to record PAM scores at the start and end of each programme. The focus is on using the PAM as a measure of intervention effectiveness, rather than as a measure to shape how the support programme is being delivered.

6.3 NHS Sheffield CCG

6.3.1 Overview of site and work

NHS Sheffield CCG comprises 87 GP practices and has responsibility for commissioning services for approximately 580,000 people.²⁸ It is using the PAM in three projects:

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. As part of diabetes self-management annual reviews in primary care. Based in one GP practice, around 300-400 patients will complete the PAM.
3. Citywide care planning, using the PAM with around 5,000 patients as part of a locally commissioned service for long-term condition management with the aim of addressing unplanned hospital admissions in the cohort at highest risk of exacerbation.

Initially, NHS Sheffield CCG requested 1,000 PAM licences from NHS England, but this is to be expanded in line with plans for the citywide rollout. Using the PAM is seen as a development opportunity for services and staff. The aim is to ensure that staff are skilled at allocating resources to ensure that patients have the right support at the right time.

The team hopes to gain evidence from the evaluation about the PAM's application to the UK health system and wants to know if it is valid and reliable in this context, and whether it can be used as an outcome measure. It is hoping for a true critical appraisal, in the context of ascertaining which outcome measures are actually useful for commissioning, and has commissioned an internal team to evaluate the citywide care planning commissioned service.

6.3.2 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 among this

patient group. 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.

6.3.3 Project 2: Diabetes self-management

The type II diabetes self-management project is based in the Sloan Medical Centre practice. The practice has ~12,000 patients and 10 regular GPs (six partners and four salaried). The PAM has been used for around 15 months, 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 initial implementation of the PAM was thus piloted at a local level and was service provider-led. The practice had already bought the 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, reception staff, admin and IT support team, HCAs) 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) prior to their annual review appointment. The PAM is collected at this pre-testing appointment and the appointment system is administered by an office junior. Patients will receive their results and an explanation prior to their review appointment. At their 20-to-30 minute review appointment, all patients will have the opportunity to discuss the results of their pre-tests and be coached in a manner appropriate to their level of activation. Follow-up appointments will then be 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.

6.3.4 Project 3: 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 will be used from April 2015 to help to deliver person-centred care planning. It will be administered by practice staff (particularly healthcare assistants, admin staff and nurses), and also 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, Hallam and South Localities (HASL), North, and West). Training for person-centred care planning and using the PAM is being 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 will then be available via multidisciplinary locality support teams, who act as champions and trouble shooters. GP practices are 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 in this project 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 goal of ensuring patients feel empowered to self-manage.

6.4 NHS Somerset CCG

6.4.1 Overview of site and work

NHS Somerset CCG comprises 400 GPs based in 75 practices and has responsibility for commissioning services for a dispersed rural population of around 540,000 people.²⁹ The design of the organisation is based on a federation model, with nine federations. 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 QOF. Somerset is working on integrated service provision via the Symphony organisation, involving Yeovil District Hospital Foundation Trust, Somerset Partnership Foundation Trust, Somerset County Council, Somerset Clinical Commissioning Group and the South West Commissioning Support Unit.³⁰

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. Patient activation is a core outcome measure in that framework which will begin operation in April 2016. The 'pay for performance' criteria to be used are currently under negotiation, with the expectation that this will be implemented in April 2017.

The strategic intention of the CCG is 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 becomes normalised within provider behaviour prior to specific payment mechanisms being evoked.

With this background, the following work programmes have identified themselves as early adopters:

1. Using the PAM as a proxy outcome measure within the SPQS outcome framework, with around 25 GP practices who have undergone the House of Care training focused on patients with long-term conditions. Within this, there are a number of smaller pilot projects, including:
 - West Somerset Living Better project for older adults
 - Musgrove Park Hospital Patient Voices programme focused on care planning for hospital discharge
 - DESMOND diabetes management in the community, with 100 patients completing the PAM as an outcome measure

- MCBT (mindfulness-based cognitive behavioural therapy) group for long-term conditions, with 100 patients completing the PAM as an outcome measure.
2. Symphony, as part of long-term condition management in primary and secondary care with people with three or more long-term conditions.

Somerset CCG has requested 11,000 licences for the PAM. The PAM will mainly be used across the primary care setting with patients with long-term conditions, but is also being used in some secondary care settings to examine the effectiveness of specific interventions.

6.4.2 Project 1: SPQS outcomes framework

As part of the SPQS, 56 GP practices have agreed to focus on the needs of people with long-term conditions. Somerset CCG is also encouraging GP practices to undertake House of Care training, and estimates suggest that 25 practices will be trained in the House of Care approach by May 2015. The bulk of work using the PAM will be with these 25 practices. It will be used as an outcome measure, administered before and after House of Care training. Around 9,000 copies of the PAM were sent out for practices to use with this patient cohort. By the end of March 2015, 10 practices had returned 430 completed questionnaires.

The PAM is not being marketed locally as a separate initiative, but as integrated within the House of Care approach. The Local Medical Committee and CCG have sent a letter out to GP practices asking them to get patients to fill in the PAM and this commenced in November/December 2014. The PAM is completed on paper while patients are in the waiting room and either the activation level or the score can be added to the patient record in EMIS. GPs are not being told how to use the PAM or House of Care approach, though it has been suggested that House of Care might be useful to use with the top 2 per cent of healthcare service users or with people with three or more long-term conditions. The PAM is being used as an outcome measure and not for tailoring, although the feeling is that individual GP practices may start to use it proactively if they feel it will be useful.

The West Somerset Living Better project, based on an approach established by Age UK, uses a guided conversation between patients and healthcare staff to inform personalised care planning which can be shared among all practitioners (including social care) responsible for that patient's care. The PAM will be used as an outcome measure from April 2015 with around 100 patients. The aim of the project is to help older adults to be less isolated, identifying the skills already in existence in the community that can be used to create a supportive environment which will then have an impact on healthcare service usage.

The Musgrove Park Hospital Patient Voices project is a small-scale pilot delivered by the voluntary sector to provide personalised care planning and signposting to services at the point of hospital discharge, to ensure better liaison between primary and secondary care.

DESMOND is a diabetes self-management training programme, delivered in groups based in the community. PAM will be used as an outcome measure with around 100

patients in the programme. The aim is to encourage local use and adaptation based on need, so its use will evolve as programme managers decide where and when it should be used.

The local mental health trust, Somerset Partnership Trust, delivers a group-based MCBT course for people with mental health problems and long-term conditions. The course is called 'Reclaiming your Life' and runs over six weeks. The PAM will be used with around 100 patients as an outcome measure. Again, those leading the programme have been told to 'play with it' and use it as they will. No training has been given on using the PAM in either self-management programme, as it is felt that this will restrict how people view the PAM and how they think about using it.

6.4.3 Project 2: Symphony

The Symphony project in South Somerset is one of NHS England's 'Vanguard sites', working to deliver an integrated primary and acute care system. They are using the PAM as an outcome measure in several projects, including in Yeovil Hospital's cancer unit to review activation levels to inform treatment after diagnosis and in the complex care model. The complex care model involves working with the four per cent of the population who have three or more co-morbidities (around 1,500 people) who account for around 50 per cent of health and social care costs. 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 aim is to enable person-centred and empathetic care that works across health and social care to meet the needs of patients and ensure integrated working. The hub team will measure increases in the PAM score and other health service utilisation outcomes to understand the effect of the intervention on patients.

6.5 NHS Tower Hamlets CCG

6.5.1 Overview of site and work

NHS Tower Hamlets CCG comprises 36 GP practices in eight commissioning networks and has responsibility for commissioning services for around 254,000 people.³¹ They are one of England's 14 pioneer sites, and one of their priorities is developing a more integrated approach to care within the borough. They are the only site to join the PAM learning set following the invitation to tender from NHS England.

Initially Tower Hamlets envisaged the PAM being used on the care pathway for long-term conditions like COPD, cardiovascular disease (CVD) and diabetes – forming part of the care planning process for long-term condition care packages. In line with this aim, 60,000 licences were requested for the PAM. However, as there is a plan to reconfigure care packages more widely in the next year or so, this is on hold.

Instead, the PAM is being used in three pilot projects and to contribute to one commissioning initiative. All pilot projects will be run with the Integrated Care team and delivered with the voluntary sector. The projects are:

1. Esteem Self-management, led by Community Options with healthcare service provider partners, working with ~220 people with long-term conditions and mental health conditions
2. 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
3. Managing your health and wellbeing, 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
4. Commissioning for diabetes education, integrating the PAM into current education programmes with the aim of helping to tailor and structure educational interventions.

The PAM is seen as an outcome measure (used at the start and end, and possibly also in the middle) but also as a tailoring tool, helping service providers to meet individual needs. The majority of projects will be provider-referral but the activation score as measured by the PAM is not being used as a referral criterion; although once referred to a pilot, an initial PAM score may be used to tailor exactly how an individual is treated. As the projects are diverse, a mix of clinical and voluntary sector providers will be involved in delivering the interventions and thus administering and interpreting the PAM. The majority of questionnaires will be delivered face-to-face, using patient advocates to translate if there is a need to access the questionnaire in community languages. There are some concerns about the impact of this mediated completion on validity.

The CCG is interested in ensuring sustainability at scale based on the pilot work conducted and has commissioned an independent organisation to evaluate the pilot projects.

6.5.2 Project 1: Esteem self-management

A multi-intervention package of support for people with long-term conditions and mental health problems, services include:

- weekly community choir
- Coping Options for long-term conditions course
- diabetes and mental health course, with 80 hours one-to-one support
- specialist intensive one-to-one support to help people who hoard
- holistic alcohol management support, with 40 hours of one-to-one intensive support.

The aim is to help people to manage when their psychological symptoms may also affect their physical health and people who are supported by multiple services but often end up accessing hospital/emergency services inappropriately. They have identified five 'cohorts' of potential service users, totalling 219 people, and plan to look holistically at their health and social care needs. The PAM will help to tailor interventions to the needs of the cohort. Services will be provided by Community Options (lead), Poplar and Limehouse Health Networks, Barts Health Diabetes Care

Centre, Barts Health Adult Community Respiratory and Rehabilitation Service and East London NHS Foundation Trust.

6.5.3 Project 2: Your Move

A programme of exercise and dance for older adults (55+) aiming to increase exercise and decrease social isolation. Two dance class groups will be run – one targeted at the older adult with specific long-term conditions (examples given include stroke and Parkinson's) and one for older men with mixed conditions (CVD, COPD etc). Each group will have 25 participants. There will also be five patients with dementia in the classes, who have extra barriers to access (like transport), testing the impact of removing these barriers on participation. The interventions will be provided by Green Candle Dance Company (lead), East London NHS Foundation Trust, Poplar and Limehouse Health Network, Neighbours in Poplar and the SE Locality Integrated Care Team.

6.5.4 Project 3: Managing your health and wellbeing

A holistic health service intervention supporting people to improve their self-management for ~75 people with diagnosed long-term conditions or with uncontrolled symptoms that may contribute to long-term conditions (eg being overweight, high blood pressure) and frequent use of services. The cohorts include people with long-term physical conditions, severe mental illness and learning disability. The PAM will be used to help to tailor support to patient need. Interventions include coaching and support interventions and group and one-to-one exercise programmes. Services will be provided by Ability Bow (lead), Primary Care Network 8, Healthy Island Partnership, Community Options and Health Trainers.

6.5.5 Project 4: Diabetes education

Diabetes education is currently delivered by acute services and by two voluntary sector organisations. All contracts were about to end, but have been extended for 12 months as a pilot to integrate the PAM into all three services. The aim is to look at PAM scores, review how providers are using the PAM to improve activation and structure educational interventions, and review the core educational components. The CCG will then use this review to inform procurement of services going forward. The particular service that any individual accesses will be dependent on their preferred option and their PAM score.

6.6 The UK Renal Registry

6.6.1 Overview of site and work

The UK Renal Registry (UKRR) is part of the Renal Association, a not-for-profit organisation registered with the Charity Commission.³² 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 currently 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.

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. Following an event with stakeholders across Europe to agree consensus on PROMs and PREMs to be collected for renal work, they included the SF-12 (a 12-item health survey) and POS-S renal (Palliative care Outcome Scale-Symptoms) to record symptom burden score. The UKRR requested 30,000 licences for the PAM.

The Valuing Individuals programme has a programme board, co-chaired by clinicians and patients. Three work streams within the programme are linked to PROMs and PAM: measurement; intervention (guiding decisions about what interventions to put into different environments); commissioning (what services get commissioned, what should be written into service specifications).

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.

1. 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?
2. Are PAM levels associated with other patient-reported outcome measures (PROMs, PREMs, symptom burden)?
3. 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.

Initial plans outlined involving 10 renal units, with two more receiving detailed support as part of the programme. Due to a high level of interest (with 25 expressions of interest from renal units and two from CCGs in the first week of inviting organisations

to be involved) work will now involve a larger sample of sites than originally planned (with 23 renal units and one CCG currently signed up to participate). As the 'principle of a registry is that it includes everyone' UKRR is aiming to encourage as many units as possible to participate.

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 per cent 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 Renal Patient View electronic system (where patients can see their own health records) is being upgraded to enable patients to complete and upload measures online; this will include PROMs, PREMs and the PAM. This will be used in some sites to collect data, but other sites may use paper, other electronic, peer-assisted, or healthcare professional-assisted methods. A facilitator is being appointed to work with each of the sites to establish the most effective methods in each location.

The UKRR is still discussing how often to collect the PAM and other measures within its work stream, to balance the need for high quality data with the potential burden of data collection on renal units. Current thinking is that PROMs may be collected twice a year and PREMS data collection may be split into sections (eg transport and facilities, teamwork, communication) to be administered quarterly through the year. The team is keen to design and test a series of evidence-based interventions to see if these can increase activation scores, and see if this in turn improves outcomes; they are currently looking at the literature to inform this. Interventions may include coaching developed by the PAM team, coaching developed by Coventry University and peer support. Each project would be run as a QI project, trialling interventions across different units and assessing improvement; they may be able to randomise units to interventions.

UKRR is also interested in exploring whether feedback of PAM scores to clinicians at 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. Testing interventions to improve clinician activation is also being considered.

7 References

- ¹ NHS England (2015) *NHS Five Year Forward View*. London. Available via: [Copy of NHS England's Five Year Forward View](#)
- ² [Department of Health \(2014\) NHS Outcomes Framework 2015 to 2016](#). London: Department of Health.
- ³ [The Health Foundation \(2014\) Helping measure person-centred care](#). London: The Health Foundation.
- ⁴ [The Health Foundation \(2014\) Person-centred care made simple](#). London: The Health Foundation.
- ⁵ Hibbard JH, Stockard J, Mahoney ER, Tusler M (2004) *Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers*. *Health Services Research*, 39(4):1005–26.
- ⁶ Hibbard JH, Mahoney ER, Stockard J, Tusler M (2005) *Development and testing of a short form of the Patient Activation Measure*. *Health Services Research*, 40(6):1918–30.
- ⁷ Adams SR, Goler NC, Sanna RS, Boccio M, Bellamy DJ, Brown SD, et al. (2013) *Patient Satisfaction and Perceived Success with a Telephonic Health Coaching Program: The Natural Experiments for Translation in Diabetes (NEXT-D) Study, Northern California, 2011*. *Preventing Chronic Disease*, 10:1301–16.
- ⁸ Hibbard JH, Collins PA, Mahoney E, Baker LH. (2010) *The development and testing of a measure assessing clinician beliefs about patient self-management*, *Health Expectations* 13(1):65-72. doi: 10.1111/j.1369-7625.2009.00571.x
- ⁹ [Centers for Medicare and Medicaid Services \(2013\) Exploring Medicaid Health Homes Leveraging Care Coordination Organizations in Medicaid Health Homes: The Washington Way](#).
- ¹⁰ Green CA, Perrin NA, Polen MR, Leo MC, Hibbard JH, and Tusler M. (2010) *Development of the Patient Activation Measure for Mental Health (PAM-MH)*. *Administration & Policy in Mental Health and Mental Health Services Research*, 37(4):327–333.
- ¹¹ Pennarola BW, Rodday AM, Mayer DK, Ratichek SJ, Davies SM, Syrjala KL, et al. and HSCT-CHESS Study (2012) *Factors associated with parental activation in pediatric hematopoietic stem cell transplant*. *Medical Care Research and Review*, 69(2):194–214.
- ¹² Brenk-Franz K, Hibbard JH, Herrmann WJ, Freund T, Szecsenyi J, Djalali S, et al. (2013) *Validation of the German version of the Patient Activation Measure 13 (PAM13-D) in an international multicentre study of primary care patients*. *PLoS One*, 8(9) e74786.
- ¹³ Rademakers J, Nijman J, van der Hoek L, Heijmans M, Rijken M. (2012) *Patient activation in the Netherlands: translation and validation of the American short form Patient Activation Measure (PAM13)*. *BMC Public Health*, 12:577.
- ¹⁴ Alegría M, Sribney W, Perez D, Laderman M, Keefe K. (2009) *The Role of Patient Activation on Patient–Provider Communication and Quality of Care for US and Foreign Born Latino Patients*. *Journal of General Internal Medicine*, 24(Suppl 3):534–541.
- ¹⁵ Maindal HT, Sokolowski I, Vedsted P. (2009) *Translation, adaptation and validation of the American short form Patient Activation Measure (PAM13) in a Danish version*. *BMC Public Health*, 9:209.
- ¹⁶ Hibbard JH, Gilbert H. (2014) *Supporting people to manage their health: An introduction to patient activation*. London: The King's Fund.

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- ¹⁷ Hibbard, JH, Greene, J, Shi, Y, Mittler, J and Scanlon D. (2015) *Taking the Long View: How Well Do Patient Activation Scores Predict Outcomes Four Years Later?* Medical Care Research and Review. doi:10.1177/1077558715573871.
- ¹⁸ Hibbard JH, Gilbert H. (2014) *Supporting people to manage their health: An introduction to patient activation*. London: The King's Fund.
- ¹⁹ Ellins J, Coulter A (2005) *How engaged are people in their healthcare? Findings of a national telephone patient survey*. London: Picker Institute.
- ²⁰ Hibbard, JH, Greene, J, Shi, Y, Mittler, J and Scanlon D. (2015) *Taking the Long View: How Well Do Patient Activation Scores Predict Outcomes Four Years Later?* Medical Care Research and Review. doi:10.1177/1077558715573871.
- ²¹ Greene J, Speizer H, Wiitala W. (2008) *Telephone and web: Mixed-mode challenge*. Health Services Research, 43(1):230–248.
- ²² Hibbard, JH, Greene, J, Shi, Y, Mittler, J and Scanlon D (2015) *Taking the Long View: How Well Do Patient Activation Scores Predict Outcomes Four Years Later?* Medical Care Research and Review. doi:10.1177/1077558715573871.
- ²³ Hibbard JH, Gilbert H (2014) *Supporting people to manage their health: An introduction to patient activation*. London: The King's Fund.
- ²⁴ [NHS Horsham and Mid Sussex Clinical Commissioning Group \(2015\)](#) *About us*.
- ²⁵ [NHS Crawley Clinical Commissioning Group \(2015\)](#) *About us*.
- ²⁶ [NHS Islington Clinical Commissioning Group \(2015\)](#) *About us*.
- ²⁷ [Department of Health \(2013\) Integration pioneers leading the way for health and care reform.](#)
- ²⁸ [NHS Sheffield Clinical Commissioning Group \(2015\)](#) *About us*.
- ²⁹ [NHS Somerset Clinical Commissioning Group \(2015\)](#) *About us*.
- ³⁰ Calkin, S. (2013) [South Somerset Local Integration Plan](#). HJS Local Briefing.
- ³¹ [NHS Tower Hamlets Clinical Commissioning Group \(2015\)](#) *The Tower Hamlets Population*.
- ³² [The UK Renal Registry \(2015\) Welcome to the UK Renal Registry.](#)