

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

Summary Interim Report

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

Subtitle: Summary Interim Report

NHS England Gateway Publications Reference 04985

First published: 25 April 2016

Prepared by: University of Leicester, Department of Health Sciences

- Natalie Armstrong, Senior Lecturer in Social Science Applied to Health
- Carolyn Tarrant, Senior Lecturer in Health Psychology
- Graham Martin , Professor of Health Organisation and Policy
- Bradley Manktelow, Senior Research Fellow in Medical Statistics
- Liz Brewster, Research and Teaching Fellow
- Sarah Chew, Research Associate

Classification: OFFICIAL

Other formats of this document are available on request. Get in touch at england.contactus@nhs.net or 0300 311 22 33.

Contents

Foreword by NHS England	5
Patient Activation: At the heart of self-care support.....	5
1 Introduction	6
1.1 Scope of this summary document	6
1.2 Background	6
1.3 Feasibility of using the PAM in the NHS in England	8
2 Interim learning	9
2.1 Overview of PAM usage	9
2.1.1 PAM as an outcome measure	9
2.1.2 PAM as a tailoring tool.....	9
2.1.3 PAM as both outcome measure and tailoring tool	11
2.2 Using the PAM in practice	11
2.2.1 Planning and adapting.....	11
2.2.2 Designing and introducing new services or interventions	12
2.2.3 When to use the PAM, and for what purpose	12
2.2.4 Mediated completion	13
2.2.5 How PAM might contribute to delivering person-centred care	13
2.2.6 Evidence, data collection and analysis	14
2.2.7 Engaging stakeholders.....	16
2.2.8 Engaging patients.....	17
2.2.9 Effective sharing of PAM data	17
2.2.10 Challenges of using PAM data as an outcome measure	17
2.2.11 Using PAM with other measures	18
3 Key points for consideration	19
3.1.1 Clarity of purpose	19
3.1.2 Acknowledgment of uncertainties and possible limitations	19
3.1.3 Value in the PAM completion process	19
3.1.4 Thinking about when best to use it	20
3.1.5 Responsible usage	20
3.1.6 Fidelity versus validity.....	20
3.1.7 Context.....	21
4 Case studies: Using the PAM in practice	22
4.1 Case study 1: Using the PAM in telephone tailored health coaching	22
4.1.1 How is the PAM contributing in this context?.....	22
4.1.2 How is the PAM used in practice?	23
4.1.3 Using PAM as a tailoring tool	23
4.1.4 Using PAM as an outcome measure	24
4.1.5 Successes in using the PAM.....	25
4.1.6 Challenges in using the PAM	25
4.1.7 Challenges to the wider service.....	26

4.2	Case study 2: Using the PAM in diabetes care	27
4.2.1	How is the PAM contributing in this context?.....	27
4.2.2	How is the PAM used in practice?.....	27
4.2.3	Using PAM as a tailoring tool	28
4.2.4	Using PAM as an outcome measure	29
4.2.5	Successes in using the PAM.....	29
4.2.6	Challenges in using the PAM	30
4.2.7	Challenges to the wider service.....	31
5	Appendix 1: Individual site plans, updated September 2015	32
5.1	NHS Horsham and Mid-Sussex and NHS Crawley CCGs	32
5.1.1	Project 1 – Tailored Health Coaching pilot	32
5.1.2	Project 2 – MSK service	33
5.1.3	Project 3 – Tier 3 Weight Management Service	34
5.2	NHS Islington CCG	35
5.2.1	Project 1: Care and support planning in general practice	35
5.2.2	Project 2: Self-management commissioning contracts	37
5.3	NHS Sheffield CCG	38
5.3.1	Project 1: Mental health pilot	38
5.3.2	Project 2: Diabetes self-management	39
5.3.3	Project 3: Citywide care planning	39
5.4	NHS Somerset CCG	41
5.4.1	Project 1: Outcomes based commissioning.....	42
5.4.2	Project 2: Symphony	43
5.5	NHS Tower Hamlets CCG.....	45
5.5.1	Project 1: Esteem self-management	46
5.5.2	Project 2: Your Move	46
5.5.3	Project 3: Managing your health and well-being.....	46
5.5.4	Project 4: Diabetes education.....	47
5.5.5	Further information	47
5.6	The UK Renal Registry.....	48
6	References.....	51

Foreword by NHS England

Patient Activation: At the heart of self-care support

The NHS Five Year Forward View set out a central ambition for the NHS to become better at helping people to manage their own health: 'staying healthy, making informed choices of treatment, managing conditions and avoiding complications'. To meet this commitment, NHS England has established a 'Self-Care programme' to scale-up support for people living with long-term conditions (LTCs) to manage their own health and wellbeing, empower them to make decisions about their health and care whilst delivering financial benefit to the wider healthcare system as part of the £22bn efficiency challenge.

Patient Activation is a measure of patients' knowledge, skills and confidence to manage their own health and is a core enabler for the Self-Care programme. Health and care systems that know the activation level of their population can begin to tailor their services in order to support people on a 'journey of activation', thus helping them lead better lives at a lower cost to the system.

NHS England has agreed a five-year licence to use the Patient Activation Measure (PAM) tool with up to 1.8 million people through key NHS change programmes, including the new care model vanguards and integrated personal commissioning demonstrator sites. These programmes will have a major impact on how national policy develops, and so have significant implications for enabling person-centred care for people living with long-term conditions.

In addition to these national programmes, around 40 clinical commissioning groups and other primary care organisations will be granted access to PAM licences subject to an application process in 2016-17. These sites will use the PAM to understand the activation level of their local population, ready to become key partners in the national Self-Care programme which will begin to deliver further support later in the year. Locally, it is expected that measuring and supporting improvements in patient activation will lead to patients having better outcomes, improved patient experience, increased engagement in healthier behaviour (such as those linked to smoking and obesity), and fewer episodes of unplanned and emergency care.

This interim report from the independent evaluation of the PAM learning set by the University of Leicester, focuses on practical lessons and points to consider for those who wish to use the PAM and learn from the experiences of those who have been using it in different projects in their local areas. NHS England will use the emerging learning from the PAM learning set to develop practical toolkits to support the wider roll-out of patient activation measurement.

By making patient activation central to the Self-Care programme, NHS England is sending a clear signal to the wider health and care system that it is important to focus on people having the knowledge, skills and confidence to self-manage. Understanding and responding appropriately to an individual's level of activation is a key skill for clinicians and a key priority in realising the national aspiration for person-centred and personalised care in the NHS.

1 Introduction

1.1 Scope of this summary document

This report has been prepared by the University of Leicester as an interim learning document for use by those, either using the Patient Activation Measure (PAM) at the moment or planning to in the future. The intention is to offer some practical insights related to using the PAM, and to highlight issues which may be relevant to new users. The report also serves to signpost potential PAM users to current patient activation delivery so that they may draw on others' experiences and learning.

This document is a summary version of an interim report of the 'Independent evaluation of the feasibility of using the Patient Activation Measure in the NHS in England', which was shared with the PAM learning set in December 2015. In that report, we focused on the different ways the PAM is being used by the learning set. We highlighted key learning from this early implementation and also reflected on how the PAM relates to broader aims to change the way care is delivered towards providing person-centred care and support for self-management.

This report includes an overview of the PAM-related work being undertaken by all six organisations with whom we are working, and two case studies focused on using the PAM in frontline healthcare service delivery. The first of these case studies looks at integrating the PAM into routine diabetes care in general practice and the second examines the use of the PAM within a new health coaching service for those people identified as at risk of use of healthcare services more frequently. In both of these case studies, the PAM is being used for tailoring care and as an outcome measure.

It should be noted that the material presented here draws upon the interim findings of an evaluation that is still on-going and should, as such, be read with that in mind. Nonetheless, the process of embedding the PAM in the NHS in England offers the potential for wide ranging learning, and may contribute to encouraging broader engagement with the agenda of person-centred care and support for self-management amongst healthcare professionals and other service providers.

The University of Leicester team would like to extend our sincere thanks to the project teams and organisations with whom we are working for their participation in, and support for, this evaluation.

1.2 Background

Person-centred care remains central to NHS priorities, building on the strategy laid out in the NHS Five Year Forward View.¹ There is, as yet, no single definition of what is meant by person-centred care.² In order to try and move forward, the Health Foundation has developed a framework that sets out four principles of person-centred care³:

- Affording people dignity, compassion and respect.
- Offering co-ordinated care, support or treatment.
- Offering personalised care, support or treatment.

- Supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life.

'Patient activation', which describes the skills, confidence and knowledge a person has in managing her/his own health and healthcare, maps clearly onto these person-centred care principles. While relevant to the principles of person-centred care across the board, the concept of patient activation is potentially most applicable to the need to offer care that is suitably personalised, and that supports 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 that interrogate an individual's knowledge, beliefs, confidence and self-efficacy.⁴ The resulting score places a patient at one of four levels of activation; 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

Recent research has suggested that improvements in patient activation levels can be maintained over time and are associated with better self-management and lower use of healthcare services.⁵

A recent systematic review⁶ concluded that patients at a higher level of activation had a lower usage of emergency services and their rate of hospitalisation was lower. No evidence was found of a relationship between activation and medication adherence. However, the review urged caution as patients in the studies included in the review appeared to be more highly activated than those in previous studies. The review concluded that whilst clinical outcomes were better for patients with higher levels of activation, further evidence is needed to fully understand the relationship between a patient's activation level and their health outcomes.

To date, 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 PAM⁷:

- 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

1.3 Feasibility of using the PAM in the NHS in England

While the PAM has been validated for use in the UK⁸, little is known about how to best use and implement it in England. NHS England is working with six healthcare organisations (five Clinical Commissioning Groups and one disease registry) to pilot the PAM and has supplied them with licences to use the PAM-13 tool. Together, these six organisations form the 'PAM learning set' and are using the PAM in different ways across a variety of healthcare settings. Table 1 gives a summary of the organisations and the projects. The projects are described in more depth in Appendix 1.

The Health Foundation and NHS England have co-commissioned an independent qualitative evaluation of the learning set's work in order to explore the feasibility of using the PAM in England. Alongside this, the Health Foundation's data analytics team is conducting a quantitative study of PAM use and outcomes across a number of selected organisations from within the learning set. Combining the findings of these qualitative and quantitative pieces of work will deliver a sound evaluation of this test phase which has the potential to inform plans to implement the PAM more widely.

Our qualitative evaluation of the feasibility of using the PAM uses a combination of interviews, observations and documentary analysis and 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 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 practical evidence for the future; share knowledge and learning; and disseminate research findings

2 Interim learning

The organisations within the learning set are working across multiple projects to measure patient activation in different contexts, with different patient groups and with different aims, broadly centred on the aim of improving person-centred care and patient self-management. An overview of sites' projects is provided in Table 1, while full details and updates on progress for all projects are presented in Appendix 1.

2.1 Overview of PAM usage

Across the different projects there is 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)

There are different approaches to using the PAM in practice, and sites are often employing one or more of these across their work. We have characterised the uses of the PAM as:

- An outcome measure
- A tailoring tool
- A combined outcome measure and tailoring tool

2.1.1 PAM as an outcome measure

In some cases, PAM is being used as an outcome measure, typically for a distinct intervention or service that a patient has received, either as part of their existing care or offered as an additional service. In these instances, the data the PAM generates is intended to be used to measure the effectiveness of an intervention for supporting patient activation.

Further, the potential of the PAM as a higher system-level outcome is also being explored in NHS Somerset Clinical Commissioning Group (CCG) as part of wider attempts to ensure more person-centred care across the board at a system-wide level. The potential for the PAM to be used more broadly to evaluate and assess care provision at this level is attracting interest.

2.1.2 PAM as a tailoring tool

While there are some instances in which an organisational unit or the population level is the focus for tailoring, the PAM is more commonly being used by learning set organisations as a tailoring tool at individual patient 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.

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 licenses#	Patient populations	PAM function	Providers
NHS Horsham and Mid-Sussex and NHS Crawley	Tailored Health Coaching Pilot	2,000	Long-term conditions/ medium risk of increased health service utilisation	Tailoring and outcome	Trained health coaches
	Musculoskeletal (MSK) service	2,600	Rheumatoid arthritis	Outcome	Sussex MSK partnership
	Tier 3 Weight Management Service	400	Obesity	Outcome	Multi-disciplinary team including bariatric physicians
NHS Islington	Care planning in General Practice	28,000	Long-term conditions	Outcome	GPs
	Diabetes Self-Management Programme	10,000	Diabetes	Outcome, with the potential for tailoring	NHS Whittington Health Trust
	The Expert Patient Programme	patients	Long-term conditions		
	Bariatric Service: weight regain intervention programme	across 3 services	Obesity		
NHS Sheffield	City-wide long-term condition management care planning	5,000	Long-term conditions / those at risk of unplanned hospital admissions	Tailoring	GP practices and community nursing staff
	Diabetes self-management in primary care	400	Diabetes	Tailoring and outcome	GPs
	Community mental health management	40	Mental health	Tailoring	Community mental health teams
NHS Somerset	Outcomes based commissioning, starting with the Somerset Practice Quality Scheme (SPQS) outcome framework – including several smaller pilots	Whole population	Long-term conditions, including COPD, Chronic Heart Failure, diabetes, mental health conditions	Outcome	Two accountable care organisations
	Symphony complex care model work		Patients with three or more long-term conditions	Outcome	Symphony consortia
NHS Tower Hamlets	Commissioning diabetes educational self-management	To be confirmed	Diabetes	Tailoring and outcome	NHS and two voluntary sector organisations
	Esteem self-management	220	Long-term conditions and mental health conditions	Tailoring and outcome	NHS and voluntary sector organisations
	Managing your health and well-being	75	Long-term conditions and those with uncontrolled symptoms	Tailoring and outcome	NHS and voluntary sector organisations
	Your Move	55	Older adults with long-term conditions including dementia	Tailoring and outcome	NHS and voluntary sector organisations
UK Renal Registry	Valuing Individuals: Transforming Participation in Chronic Kidney Disease	30,000	Chronic Kidney Disease	Tailoring and outcome	Renal units

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

2.1.3 PAM as both outcome measure and tailoring tool

The potential for the PAM to be used as a combination of both an outcome measure and a tailoring tool within the same service or intervention appears to be growing. Sites that were previously more focused on one of the two uses are becoming interested in the other use as well.

2.2 Using the PAM in practice

It is important to reiterate that this summary reflects the organisations' 'works in progress' as of Autumn 2015. The projects will continue to evolve and develop as sites learn more about how to implement and use the PAM.

Consequently, the projects' contexts and objectives may change and be refined. For many sites, it is still quite early on in a process that many are framing as the beginning of a major system change towards enabling and accommodating person-centred care.

The PAM is one of the tools which sites hope will enable them to work towards these goals. However, there is still a lot of learning to be done about the feasibility of implementing and integrating the measurement of activation into routine care, in particular where, how, for what purpose, and by whom this might most usefully be done.

However, we can start to identify some important learning for others wishing to use the PAM in their work. Introducing a new tool into existing service provision or into new services requires a significant amount of planning, and the sites have generated valuable learning about some of the challenges faced and possible solutions. We share some interim learning below.

2.2.1 Planning and adapting

Many sites found that they had to adapt their work plans according to the demands of the practical challenges of implementing large-scale system change. For example, the UK Renal Registry (UKRR) had originally hoped to start to capture data from the PAM, along with Patient Reported Outcome Measure (PROM) and Patient Reported Experience Measure (PREM) data following their programme launch event in early 2015. Because of the interest in their work on person-centred care, which attracted more attention than originally anticipated, collecting data had to be delayed until the feasibility of supporting renal units on a wider scale could be scoped out. In other cases, in order to ensure that stakeholders were engaged with the use of the PAM in practice, some sites have changed the types of patients who were the focus of the piloting work.

2.2.2 Designing and introducing new services or interventions

In most sites, the PAM is being used in services or interventions that were newly introduced in either the current (2015-16), or previous (2014-15) commissioning cycles. This meant that the services themselves, not simply the incorporation of the PAM within them, have often faced challenges about implementation and set-up, and have needed to establish their legitimacy and value within the NHS service offer (for both staff and patients).

In some cases, organisations have felt that it would be beneficial to integrate the PAM into a new service or model of care so that the service could be designed around the tool, to ensure that staff had adequate time and resources to implement it. However, in practice, this has not always been the case and some projects have found that completing the PAM has been more time-consuming than expected.

In other cases, the PAM has been integrated into established services, but integrating a new tool into an existing service has to be seen as adding value. This will be explored in more detail in the second case study below, examining the use of the PAM in diabetes reviews in primary care.

2.2.3 When to use the PAM, and for what purpose

There is still a lot of learning to be done about implementing and integrating the PAM into routine care. In particular, when to record a patient's activation score and what the objective of doing so should be, is still a major consideration for many projects. So, decisions about when to record a patient's activation score must be carefully considered. For example, is it 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?

There is also uncertainty around whether the PAM should be administered before referral into a service which might require the patient to be sufficiently activated to benefit from this referral. For example, health coaching or an education-based intervention. There are some concerns that patients with very low levels of activation may be referred to services with which they are unable, or unwilling, to engage effectively at that point. This has been frustrating for some service providers, especially if the PAM is intended as an outcome measure of the impact of their service.

Therefore, while there are perhaps legitimate concerns about the potential for a patient's activation score to become used as an eligibility criterion for any particular service, its use as part of a person-centred assessment about which services are most appropriate may be beneficial in some cases.

There were residual worries about the time taken to complete the PAM if it was being used as an outcome measure in a short-term intervention, and how this could affect the amount of time available to work with a patient. Often, the PAM was only one element of the paperwork associated with signing up to a new service, and it was not the only outcome measure being used. Both the time taken out of the intervention,

and the burden placed on the patient to complete paperwork, may affect engagement with a service.

2.2.4 Mediated completion

Concerns about language, literacy and comprehension have been an ongoing concern for many, if not all organisations. These issues can sometimes mean that mediated completion is necessary. We have seen organisations and the individuals working within them take different approaches to this.

Within the telephone health coaching service in West Sussex, for example, coaches are clear that they do not deviate from the precise wording of the questionnaire when completing the PAM with a patient newly enrolled into the service. In an effort to ensure the tool and the data collected retain their validity, if a patient does not understand a question, the coach repeats it but does not elaborate or attempt to explain it. In contrast, when observing mediated completion within the context of diabetes annual reviews in Sheffield, a significant amount of explanation and elaboration was often provided to help patients understand the questions.

Based on the relatively small amount of observational work completed to date, the latter approach appeared to result in a more thoughtful completion of the PAM by patients, and certainly resulted in more varied responses across the different questions (e.g. rather than simply opting for 'agree' in each case). Frontline staff engaged in mediated completion also talked of instances in which this could give them a helpful insight into the patient's level of engagement (or more typically disengagement) with the questionnaire, with patients saying things like 'just put what you think.'

Given this, taking a more flexible approach to using the PAM perhaps relates to the purpose for which it is being used. If use of the PAM is in part about tailoring interventions to patients' needs, then arguably the supplementary knowledge provided by a more flexible approach is a valuable and legitimate resource. Where the PAM is being used as a before-and-after outcome measure, then greater fidelity to the wording of the tool, as is advocated by its authors, may be more important.

2.2.5 How PAM might contribute to delivering person-centred care

It is typically the case that organisations see their projects as being integrated into a larger programme of work, and used to support delivery of what they hope will be a truly person-centred approach to care.

The PAM continues to be regarded as 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. The PAM is seen by many as a tool that measures a concept likely to be of use and significance to a diverse range of stakeholders.

As PAM-related projects have started to become embedded into routine care, we asked what role integrating patient activation was playing in supporting the desired shift towards person-centred care; using the PAM to measure activation was not always seen as an end in itself, but sometimes as a tool to help facilitate or cope with the pace and scale of change.

'The outcomes that matter to clinicians, the outcomes that matter to patients, the outcomes that matter to finance managers, you can tell a story that brings everybody together around the PAM.'

One challenge mentioned by several sites is that of consolidating the use of patient activation within the broader patient centred care agenda. If the PAM had been introduced before integrated commissioning or holistic care planning, or presented as distinct from it, then getting frontline staff to recognise that there may be a relationship between these pieces of work to improve care could be difficult. In short, being clear about where PAM fits in the 'bigger picture' may assist in its uptake.

2.2.6 Evidence, data collection and analysis

Here we outline some issues around evidence, data and analysis that have surfaced from the evaluation. Our intention is not to offer solutions to these issues, but rather to highlight them for future users of the PAM.

2.2.6.1 Evidence

As noted above, the evidence base for PAM is derived largely from work in the US, and the UK evidence base is, as yet, limited. Work is underway to remedy this. This is important because we know that having a sound evidence base can be crucial in convincing others first that a problem exists and second that the proposed solution is the best way of going about tackling this.⁹⁻¹¹

In the case of PAM implementation, those working in organisations talked about how having a more robust evidence base could have helped to legitimise the proposed changes in service delivery they were seeking to make. It was felt that such evidence might have been useful to more effectively secure buy-in at a senior level to support change, and to help convince frontline staff that the changes they were being asked to make would be of benefit to both them and their patients. For example, in some sites, the concept of patient activation was often seen as a 'soft' outcome, an improvement in which did not necessarily provide evidence that a patient's health, ability to self-manage more effectively, or pattern of healthcare utilisation had changed for the better.

However, others suggested that people might be using concerns about the evidence base as an excuse to avoid engaging with the proposed changes to services, either for ideological or practical reasons.

'I don't think it is necessarily a resistance to the tool itself, it is simply the practicalities of implementing it, and how we can make sure that people get capacity and time to do something else in that consultation that hasn't been there to date'.

2.2.6.2 Data collection

The most appropriate ways in which to collect PAM data has given the sites considerable pause for thought. Sample bias remains a worry in that, if administration of the PAM takes place outside of healthcare settings (e.g. was sent out by post), it is possible that only more activated people might complete it. The issue of sample bias has been little explored in UK settings and, although some US evidence suggests that this may not be a relevant concern, more understanding of this issue is needed.

Questions were raised about whether the data collected through the PAM could always be taken at face value. A common theme was whether patients had really understood the questions included in the tool and, therefore, whether they had selected the most appropriate answers.

As well as specific concerns about how accessible the PAM is to groups with English as a second language, the American English of the original PAM has also proved problematic. Work is ongoing to develop an Anglicised English version of the tool for use in the UK.

2.2.6.3 Analysis

At the time of writing, where the PAM is being used as an outcome measure, often a baseline measurement has been taken, but not yet any further follow-up. No site has yet started to analyse the PAM data produced through their projects to make commissioning decisions at a population level. NHS Islington is collecting data annually across a large patient population - it has collected baseline activation scores for around 9,000 patients and plans to repeat this data collection a year later to assess the impact of introducing care planning consultations. However, accessing this data for routine analysis initially presented some problems as computer systems were not optimised to extract it.

Where sites have begun to analyse data, this has been at the level of the individual, to look at changes for any particular patient over a typically fairly short period of time. For example, the tailored health coaching service in Horsham and Mid-Sussex CCG and the diabetes work in primary care in Sheffield (see case studies below). Other projects, such as the self-management pilots in Tower Hamlets and the Tier 3 Weight Management Service in Horsham and Mid-Sussex were expecting to report outcomes data in late 2015, but the numbers of patients completing the PAM in these cases are still quite low. This has affected its use as an outcome to measure the effectiveness of the service, as significant conclusions cannot be drawn from the small number completed. This is an issue for several of the projects within the PAM learning set because they involve relatively small-scale piloting of new approaches. It

was noted that any findings were, perhaps, unlikely on their own to be sufficiently statistically robust to legitimise further investment in the interventions.

2.2.7 Engaging stakeholders

Even when sites had conducted significant piloting and planning work, getting frontline staff to engage with new services, both working in new ways themselves or referring patients on to new services, has sometimes proven difficult. Some sites had foreseen these issues and had gone some way to mitigate them by providing a supportive structure combined with financial incentives.

Some sites felt that engaging senior clinical stakeholders had been a successful element of work to date. In particular, getting senior, commissioning, and managerial staff on board with the person-centred care agenda was seen as a positive development. This was seen as something that could support system change and would ensure that major cultural changes could be seriously considered.

‘...the most senior people in the CCG and the most senior people in the provider partnerships – like chief executive level, chief finance officers – understand the pivotal importance of activation, they understand it. So I think we’re in a good position from which to build.’

Most of the sites have recognised that having enthusiastic early adopters to champion the value of using the PAM was vital to their success. Frontline staff were especially seen as valuable champions in ‘selling’ any service, and helping to identify any issues to facilitate early trouble-shooting.

‘Finding local champions [is] a big thing..’

One reason that champions were so crucial was because they spread the load of trying to engage the wider clinical community. If GPs and other primary care professionals did not see the value in referring patients to new services, or working within new systems themselves, then patients might not be presented with opportunities and support to improve their self-management.

However, getting people on board was often not an easy process especially when trying to work across different organisations. Several sites found that, even when they had identified people eager to take on a championing and or coordinating role, it was not always possible to keep them involved as staff changes affected momentum. Some ongoing resistance to PAM was encountered. This often came from front-line clinicians who regarded themselves as experienced and believed that they already understood their patients’ ability to self-manage and so did not need to use a questionnaire in order to effectively tailor their approach. In this context, the PAM was not seen as something that could ‘add value’.

2.2.8 Engaging patients

The UK Renal Registry has used the co-production approach in their Valuing Individuals programme, engaging with patients right from the beginning of their decision making process. Their programmed board is co-chaired by a clinician and a patient, as are their three work-streams – measurement, intervention (guiding decisions about what interventions to put into different environments) and commissioning (what services get commissioned, what should be written into service specifications). All the three work-streams aim to have equal representation of clinicians and patients/lay people to enable patients to be engaged and their views considered throughout the planning and delivery of the programme.

2.2.9 Effective sharing of PAM data

In common with some of the issues related to sharing data for analytical purposes, the wish to share data with other professionals, services or providers was sometimes an issue – especially given the increasing focus on holistic, integrated care provision. Small, practical details such as the wording of a letter to patients needed to be thoroughly thought through so that patients were clearly informed about how their data would be collected, stored, and shared.

Sites found that if the terms and conditions of data collection were not clearly stated, then they were unable to share data with external stakeholders. Examples included sharing information with local authority or voluntary sector providers if the data was held on the patients' electronic medical record. One project was using a patient-held record (PKB - Patient Knows Best) to communicate across different service providers, which started to help overcome this challenge. Another had spent considerable time re-working the information it provided to patients at the time of PAM data collection in order to allow the type of data sharing it thought would be beneficial.

2.2.10 Challenges of using PAM data as an outcome measure

Where the PAM score is being used as an outcome measure to assess the impact of an intervention, teams have had 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. Therefore, some sites have felt that there is a lack of clarity about what 'success' looks like.

Further, patient-reported scores may not always be seen as accurate reflections of behaviour or expected improvements (for example, in the NHS Horsham and Mid Sussex CCG case study). There is also anecdotal evidence of this from other sites, in which before-and-after intervention activation scores have shown a decline rather than the expected improvement. There are, perhaps, two main possible explanations for this. First, the baseline PAM completion may not be an accurate reflection of the patient's activation, perhaps because they did not fully engage with the tool, did not understand the questions, or because they wished to portray themselves positively. Second, engagement with an intervention or service may mean that patients come to realise they do not in fact possess the amount of knowledge, skills and confidence in

managing their health they thought and so now understand that their previous PAM completion was over-optimistic.

2.2.11 Using PAM with other measures

When assessing the impact of any particular service, PAM data is not typically being used in isolation. In a complex clinical system, project teams often wish to use other sources of data to be able to understand the full picture. Data are being collected and analysed about the effectiveness and acceptability of services, and to assess individual patient outcomes.

To understand the effectiveness of services, cost and value for money are being considered. Data about patient-reported outcomes and patient-reported experience, alongside activation, form the core of one site's plans to evaluate the impact of introducing person-centred interventions into the care pathway. Patient and clinician satisfaction with services are measured using questionnaires and in some cases supported by qualitative work to try to understand how new services are being received. Sites were very clear that measuring activation did not replace these other sources of data.

Sites were also measuring service usage and clinical outcomes, to try to understand the impact on patients' health. Many sites who were testing or piloting interventions were measuring other related outcomes, including well-being, using other questionnaires to complement the PAM – such as the Warwick Edinburgh Mental Well-Being Scale (WEMWBS). One site had developed a method of formalising and recording clinical judgements used to tailor care to support their work.

In summary, for all the sites, the PAM was seen as one way of collecting data on one aspect of patient behaviour within a suite of measurement tools needed to really understand healthcare service delivery. How any apparent contradictions or tensions within and between these data will be handled remains to be seen.

3 Key points for consideration

Our evaluation of the feasibility of using of the Patient Activation Measure to date has raised several important areas of focus for those thinking about how to use the tool.

3.1.1 Clarity of purpose

There is a need for clarity and a full understanding of why the tool is being used and what function it is serving. This is critical because many of the decisions about how the PAM can best be integrated into services, completed by patients, and how resulting data be shared and used, come back to this key point. Clarity of purpose can also facilitate engagement, in particular by enabling staff to understand how it fits within the broader agenda of patient centred care.

3.1.2 Acknowledgment of uncertainties and possible limitations

We have identified some concerns about the appropriateness of using the PAM as an outcome measure, including those from frontline staff who query whether it always accurately reflects the behaviour of the patient. For patients with multiple co-morbidities, their answers might vary depending on which health condition they are most focused on.

PAM scores depend, at least in part, on patients' self-insight. There is a sense that it is common for patients with initially high PAM scores to report lower scores after they have engaged with services to support their self-management. With this insight, they are able to revisit their activation level. This leads to two immediate questions:

- How to best ensure that PAM scores are a sufficiently accurate representation of activation (e.g. through method of data collection, approach to mediated completion)?
- Can a service potentially deliver no immediately measurable change in PAM score yet still be effective? If so, to what extent can the PAM be positioned as the right way to measure service effectiveness or impact?

These questions come back to the point about what changes in score might reasonably be expected during or following any intervention and over what timescale. This is important if PAM scores are to be used to assess effectiveness.

3.1.3 Value in the PAM completion process

Scores aside, there is some evidence that sometimes the activity of completing the PAM itself is of value either as a conversation starter, or to focus the consultation more effectively on what matters to patients. Using the PAM does seem to help providers identify possible 'quick wins' and patient concerns that they can deal with more easily and which may not otherwise become apparent. However, this will only work well if the provider is:

- Committed to person-centred care
- Has sufficient time available
- Has wider supportive services and systems available

It is important to note that the PAM may function effectively as a process to support patient centeredness, without necessarily acting as a measure of it. It is possible the value may lie more in starting the conversation about person-centred care and exploring what changes to support may be offered.

3.1.4 Thinking about when best to use it

Our early frontline work seems to suggest that if used at the optimal point in the care pathway, the PAM may have an important role in helping staff to tailor care. However, identifying the most effective point is critical. If the PAM is used too late it might only identify that a person is not in a position to benefit from the intervention to which they have been referred.

3.1.5 Responsible usage

If the PAM is being used to help tailor care, there are important questions about how this can best be achieved. The PAM can be used to tailor care within a service, but it could also be used as the basis for decisions about which service(s) will be offered to patients. In the case of using it to decide which patients should receive what service, there have been concerns raised about whether this could result in patients not being able to access services from which they may potentially benefit, i.e. that it becomes used as a gate-keeping or eligibility tool. Nevertheless, some frontline staff have suggested it may be useful to use the PAM as part of the referral process to ensure that when patients are referred, they are sufficiently activated to benefit from it.

3.1.6 Fidelity versus validity

Differences in the degree of flexibility permitted in completing the PAM is a clear issue. Based on work so far, this issue might be characterised as one of fidelity versus validity.

From what we have seen so far, using the PAM in practice seems to work better when patient and provider develop a rapport. This seems to help patients answer the questions more insightfully (although we acknowledge we have not yet interviewed patients themselves).

Users of the PAM must weigh up this potential fidelity / validity trade-off. For example, if a provider offers additional explanations about what is meant by the statements within the tool, it is likely that the patient completing it will understand them better, but fidelity to the precise wording of the questionnaire will then be compromised. This suggests that using the PAM as a conversation starter, although potentially very valuable in individual cases, would not necessarily sit well with

careful fidelity to the questionnaire. However, there were some suggestions from our participants that fidelity did not necessarily equal validity. Some participants felt that when the PAM was used flexibly, e.g. when questions were explained and illustrative examples offered, some patient responses were more accurate or fitted better with their subjective perceptions.

3.1.7 Context

Our early frontline work suggests that the way patients engage with PAM, and the scores that are generated, may be influenced by whether the tool is used as part of an ongoing relationship between a patient and known health professional, or within a new service. Based on our work so far, it seems likely that developing and integrating new services, raising awareness of these within the local health economy, and getting them up and running effectively perhaps makes successful use of the PAM within them more challenging. Equally, though, if the PAM is to be effectively integrated into existing services, the value it adds must be clear and accepted by those being asked to use it.

4 Case studies: Using the PAM in practice

4.1 Case study 1: Using the PAM in telephone tailored health coaching

The Tailored Health Coaching service was jointly commissioned by NHS Horsham and Mid-Sussex CCG, NHS Crawley CCG and West Sussex County Council. Impact Initiatives, a local charity, are the provider of the service. Three health coaches and a team leader were appointed to launch the service in April 2015. Immediate line management is provided by a project manager from the CCG and an experienced health coach from Impact Initiatives. The health coaches have previously worked in diverse health-related areas.

Initial set-up of new services often encounters teething problems; for the Tailored Health Coaching service, these centred on initial access to space and resources, and delays in access to patient information although these have now been remedied. The service began working with patients at the end of May 2015, but delays to the start gave the health coaches more time for training and considerations about how the service could work.

As the project is a pilot looking at the effectiveness and cost-effectiveness of Tailored Health Coaching, a number of impact measures have been selected. Outcomes measured before and after patients engage with the service are:

- activation level, measured using the PAM
- risk stratification score, including predicted use of healthcare services and costs
- well-being, measured using the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)
- number of goals set and achieved

The CCG is also recording data on patient contact and throughput, including number of appointments with the health coach.

4.1.1 How is the PAM contributing in this context?

The health coaches felt that it was important to adapt their approach to delivering healthcare to one which was informed by the ethos of person-centred care. The health coaches were using the PAM to understand how patients felt about managing their own health. Focusing on the patients' priorities was considered to be key to ensuring that patients engaged with the service and benefitted from it.

4.1.2 How is the PAM used in practice?

The Tailored Health Coaching service is targeted at those with one or more long-term condition at medium risk (45–65 percent) of increased health service utilisation. GPs have been asked to review a list of eligible patients and filter out any for whom the service might not work (e.g. those not fluent in English or people with hearing difficulties who do not use the telephone).

The practices contact patients via an 'opt-out' letter advising them that they had been referred to the Tailored Health Coaching service and will be contacted by telephone after three weeks, unless they contact the practice to opt out. After three weeks, the health coaches make contact with the patients who have not opted out, explain the service offered in more detail and, if the patient is agreeable, administer the baseline PAM and WEMWBS. As well as an outcome measure, the PAM is also used by the health coaches to tailor their approach to working with patients.

In practice, the health coaches have a laminated paper copy of the PAM, which they can complete easily whilst talking with patients on the phone. This enables them to concentrate on the patient's answers, rather than focusing on capturing data on the computer. Afterwards the laminated copy can be scanned and used again. Overall scores and dates when the first, last and any 'middle' PAMs are completed, are recorded. The score for each question, overall score and activation level are recorded in a separate spreadsheet. The health coaches also use this to 'sense check' answers, e.g. Q10 and Q13 cover similar issues – has the patient answered consistently? A monthly summary is collated into a report, and shared with the project managers and CCG leads.

4.1.3 Using PAM as a tailoring tool

The PAM is a central element of working with patients, and is used by the coaches to identify areas of concern or focus for the patient. It also enables the health coaches to alter their approach depending on the patients' needs. However, for some patients, although they were interested in accessing the health coaching service, areas for improved self-management identified by the PAM did not always match areas of concern identified by the patient.

The health coaches were aware that some patients did not always understand the PAM or the concept of an activation score, particularly at the start of the process. The overarching aim to provide a tailored service enabled the coaches to adapt their approach to meet the patients' needs and not focus so explicitly on activation in such cases.

Within the tailoring process, the health coach does not routinely share the score with the patient, though if an area shows a particular improvement this might be shared with the patient to encourage them to reflect on their progress.

4.1.4 Using PAM as an outcome measure

As the service is tailored to patient needs, the frequency of completing the PAM varies. All patients conduct a baseline PAM on entry to the service and will complete the questions again at the end of their coaching. If the health coach feels it would be useful, the patient may be asked to complete the PAM questions part way through their coaching, to provide a 'middle' or 'progress' PAM score. The health coaches feel that this can be useful because often the answers given later on are regarded as more honest and as showing more insight than those given for the initial PAM score. One challenge, highlighted below, is whether patients do answer the questions accurately when surveyed.

The population surveyed using the PAM has so far been very varied, with patients covering all four levels at baseline. The health coaches, for the most part, have found the score generated by the measure at baseline tends to align with their own assessment of the patient, and that they could get a good feel for a patient's activation level from the initial conversation with the patient while introducing the service.

However, this alignment between PAM score and health coach assessment did not always happen. In some cases, talking with the patient has led the health coach to conclude that the patient's score at baseline (taken at the start of the first interaction between patient and coach) may not be an accurate representation of their circumstances. Therefore even though coaches broadly felt that the PAM scores for their patients 'felt right', they could also suggest instances where this was not the case (typically that scores were too positive rather than vice versa).

An added consideration is whether changes in the PAM score really represent changes in a person's outlook and behaviour, and can reliably be used as an outcome measure to ascertain the effectiveness of the health coaching. This may play out in several ways.

First, some patients have shown an increase in PAM score over time but the health coach involved does not believe that that improvement can really be attributed to the work s/he has done with that patient, i.e. that something else is responsible.

Second, it is sometimes the case that the coach believes a patient to be making excellent progress and achieving goals, but this has not translated into an improvement in PAM score.

Third, repeat administration of the PAM may show an improvement but a coach has concerns about the validity of this, based on their knowledge of the patient. As an example, a patient who had initially scored as a level 1 subsequently improved this to level 3, but the health coach did not believe they had made sufficient progress to have resulted in an improvement on this scale. While the patient had started to make small changes in their behaviour (e.g. contacting a specialist service), they did not seem to have changed their outlook on self-management significantly.

4.1.5 Successes in using the PAM

Initially, the health coaches were concerned that the PAM might not be the most appropriate tool to work with patients, and felt that introducing it to patients might be difficult. However, these fears were unfounded.

'I think when we were looking at it, before we actually went about talking to people, we were looking at the way the questions were worded, and we felt – like the first one, 'when all is said and done' – it seems like a bit wordy but then actually when we're doing it over the phone with people it's not so bad. I think having read it beforehand we were a bit dubious, but it seems to work better than we thought it would.

On the whole, staff reported that patients had few problems with the PAM, and that it was not off-putting. This was in part because patients did not appear to be curious about, or interested in, the PAM or what the resulting score meant.

Overall, staff have been positive about the way in which using the PAM has helped them to work with patients and encourage behaviour change. The PAM is credited with helping to open up a conversation about patient priorities, particularly for those with multiple long-term conditions.

4.1.6 Challenges in using the PAM

Working with a patient over time and building a stronger rapport could have an impact on the way that the patient answered the PAM questions at subsequent completions (i.e. after the baseline measure). One reason for this might be that patients struggle with the questionnaire in cases when they have complex health issues. Patients sometimes asked the health coaches why there were only four options, stating that they 'sometimes' could answer in the positive and sometimes in the negative. For patients with multiple co-morbidities, the answer might vary depending on which health condition they were considering. So patients with more than one condition might understand how to manage their medication for, for example, diabetes, but not for COPD.

The health coaches did identify a number of points at which patients struggled more with the PAM, namely related to the questions asked and the meaning of the statements. One coach commented that they felt the first question in particular was problematic, and patients often did not engage with it properly.

4.1.7 Challenges to the wider service

One of the biggest challenges was related to the wider context of the local health service. As patients were referred via primary care, GPs were gatekeepers to accessing the service. Keeping GPs' knowledge up-to-date about what services were available locally presented some challenges as other new initiatives to improve care were brought in simultaneously but with different patient groups and referral routes. This sometimes caused confusion for GPs.

Although a locally-commissioned service was put into place to ensure that GP practices received compensation for their time in identifying and referring patients, delays in referrals occurred. These were due to systematic problems encountered with payment mechanisms and it was felt that a key learning point was that potential system problems should ideally be identified and addressed before going live with a service.

Similarly, the service could not accept referrals from other services, including social services and public health, or from patients themselves. This meant that patients who wanted to access the service could not always do so, and that those who were referred to the service did not always want to access it. GPs were also responsible for making judgements about a patient's suitability for the service and it was not always clear why some patients were, or were not, referred. This was apparent by the variability of the number of patients being removed from the referral lists between practices.

The arrangements for referring into the service meant that coaches tended to feel they were 'cold calling' patients when referral lists came through from practices. While some patients contacted remembered receiving the GP referral letter and were waiting for the coach's call, many others did not and were unwilling to engage with the service.

Potentially, using the PAM before referral may have helped to identify those people who wanted to engage with the service, but would not necessarily have meant that all those who needed to improve their outcomes would be included.

4.2 Case study 2: Using the PAM in diabetes care

Since 2004, the National Institute for Health and Care Excellence (NICE) guidelines for managing diabetes in adults have mandated an annual review for all diabetic patients, both type 1 and type 2.^{15, 16} NICE recommend that this review should include personalised reviews of self-care and support needed by patients.¹⁵ These reviews are typically completed in primary care.

Although these health checks are a required part of diabetes care, a survey by Diabetes UK suggests that not all patients are receiving the recommended checks.¹⁷ In particular, patient feedback is particularly poor about the availability of individual care plans, with 61 percent of the 6,500 patients questioned stating that they had not discussed individual needs with a healthcare professional.¹⁷

As part of the commitment to ensuring these checks are offered to all patients, one GP practice in Sheffield has re-designed the systems offering these appointments, using the PAM as part of the diabetes review process. From a healthcare professional point of view, managing patient flow and ensuring that patients receive these checks and are able to access appropriate support is also a logistical challenge. The practice manager estimates that there are around 700 diabetic patients in the practice population requiring annual diabetic reviews.

4.2.1 How is the PAM contributing in this context?

The PAM has been integrated into the delivery of existing services, within a re-designed appointment system. Changes to the appointment system have meant that clinical time can be re-allocated to offer a longer appointment using the PAM to tailor discussion to the appropriate level of activation. The aim is to remove barriers to providing person-centred care, such as clinical availability/time, training, and delivering support relevant to the patients' needs.

The PAM is seen as an integral tool in ensuring that resources are allocated appropriately and patients receive care tailored to their needs. It is also being used as an outcome measure, to evaluate the effect of the changes made on patient engagement with the new approach to managing care. Clinicians and patients are also being asked for feedback on the new processes as part of this work. It is very much one tool in the toolbox which can be used to help to shape a wider culture change. A key aim is to work with people at a lower level of risk to try to ensure good self-management routines are embedded in care and future complications prevented; identifying the motivation level of a patient is seen as an important initial step in this process.

4.2.2 How is the PAM used in practice?

The re-designed appointment system has three main aims:

- To ensure efficient patient flow, with all diabetic patients receiving recommended checks

- To encourage patients to have a greater input into their care
- To use face-to-face time with clinical staff more effectively

To ensure that clinical time can be used appropriately, changes to the administrative 'behind the scenes' system have been introduced. An administrator now manages the diabetic review appointments, using recall alerts in the electronic patient record based on the patient's birthday month. She is responsible for communicating with the patient, requesting they make a 20 minute appointment with the healthcare assistant (HCA) who conducts the basic diabetic checks and the PAM. The administrator then books their main review appointment after their test results become available.

The PAM, which is completed on paper in the HCA appointment, is then returned to the administrator, who calculates the patient score and enters this information, along with test results, in the electronic patient record. The questionnaire is also scanned into the patient record, and further information about the mode of completion (e.g. if the questionnaire was completed in translation by a member of the patient's family) is recorded.

The PAM is used to tailor the type of subsequent review appointment offered to the patient. If the patient's diabetes is poorly controlled, and/or their activation level is low, they are offered a 30 minute appointment with the practice nurse who specialises in diabetes management. If the patient's blood glucose level is stable and/or their activation level is higher (level 3 or 4) then the patient may be offered a 20 minute appointment with the specialist practice nurse, or may be seen by another practice nurse, who has less experience in specialised diabetes management. Changing the timing of receipt of test results (which are sent to the patient before their review appointment) also aims to encourage better interaction between patient and clinician.

From an administrative point of view, the burden of conducting the PAM is seen as very small. However, local leads still had some concerns about adding to staff workloads but these were offset against the potential for longer term improvement in care.

The changes made as part of this new way of working are predominantly administrative, but both frontline and more senior staff were clear that taking time to make these systems robust was critical in both embedding the routine use of the PAM in practice and supporting a person-centred model of care.

4.2.3 Using PAM as a tailoring tool

For frontline staff, the primary use of the PAM was as a tailoring tool. It offered staff an opportunity to change their approach to working with patients based on their needs. It also enabled staff to better understand patients' behaviours in the context of their lives outside of the clinic, for example, gaining a better understanding of why somebody might be reluctant to go to a weight management programme. Frontline staff believed this could enable them to make interventions and referrals that were more aligned to the needs of individual patients. This led to staff feeling that patients had more to gain from their consultations.

Staff have been initially positive about the way in which it has helped them to work with patients and encourage behaviour change. In addition, using the PAM as a tailoring tool was received positively as a justification for taking a new approach to providing care.

However, because the system was so new, both staff and patients were still adapting to the changes made. For staff, this was reflected in knowing how to manage different patients. Where patients scored at the extremes (1 or 4), it was relatively easy to know how to change their approach to the consultation. But if patients scored in the middle levels of activation, it was harder to know what element of their approach needed to change. So, it was one thing to use the PAM to triage patients and determine how long consultations should be; it was another to use it to inform the content and style of the consultation itself.

4.2.4 Using PAM as an outcome measure

Like the health coaches in Horsham, frontline staff also reflected on whether the PAM provided an accurate picture of patients' knowledge, skills and confidence in managing their long-term condition.

Although the aim is to use the PAM to measure the impact of the new way of managing diabetes reviews and to ascertain if patients feel the consultations have been more person-centred, frontline staff did not discuss this in detail. The evaluation of this work has been led by a member of the public health team. As the patient's activation level will be measured annually and recorded in the electronic patient record, a request will be made by the local Commissioning Support Unit to extract this data, which will then be analysed to look for change. PAM scores have been consistently recorded in the electronic patient record since January 2015, and so this data extraction will not take place until patients have completed more than one PAM. A prospective cost-benefit analysis, conducted using the New Economy model designed in Manchester, will also contribute to producing some evidence to ascertain the impact of the new ways of working with the people with diabetes.

4.2.5 Successes in using the PAM

Frontline staff presented examples of how taking a patient-led approach to the consultation could lead to better clinical outcomes. Although focusing on the patients' priorities could take the consultation off on a tangent – for example, allowing patients to discuss chronic pain, social isolation or housing, in a diabetes review appointment – this allowed the healthcare professional to refer the patient to other services who could support them with these issues. Often, the resolution of these issues was seen as an important precursor for a patient to be able to begin dealing with their condition.

As noted above, this sometimes meant that the PAM was used flexibly, with professionals expanding on the questions included in the PAM to open up the conversation to patients' priorities and concerns. Taking a patient-led approach, then, did not seem entirely in line with perfect fidelity to the PAM tool. The PAM was seen

as a 'conversation starter' in two main ways. First, it helped to identify areas in which the patient might require additional information and support.

'I might pick out an answer from the PAM, especially the ones that they answer with regards to whether they understand about their medications. I find that one quite a helpful one to open that conversation.'

Second, particularly for patients with whom the healthcare professional had an established relationship, the PAM could be used to increase confidence in abilities to self-manage. One practice nurse spoke about patients whose level of activation was recorded as quite low, but that she knew had significant experience of self-management. For these patients, though their skills and knowledge were higher, their confidence was lower.

4.2.6 Challenges in using the PAM

One challenge in using the PAM in practice was the way that the patient's score was used to influence the type of review appointment offered (i.e. how long this was and who it was with). Questionnaire completion relied on patients' honesty and self-insight. Although patients were encouraged to answer honestly and told that there were no 'right or wrong' answers, some patients who appeared to be disengaged with the process or were possibly trying to present themselves in a positive light responded positively to all questions. There was also a sense from health professionals that some patients lacked insight into their own activation – in some cases patients responded positively to PAM questions, but in the opinion of health professionals these positive scores did not reflect the patient's current engagement or ability to self-manage.

As described above, when using PAM to tailor care, staff felt there were challenges associated with deciding what form that tailoring should take, especially with high scoring patients who might only require some fine-tuned changes to their care approach: the PAM score could give insight into the level of change needed, but not necessarily the nature of the change needed.

Other concerns from staff included ensuring that there was time to fully use the results of the PAM in the consultation with the patient. Even in longer consultations, time could still be pressured and some were concerned that this extra time was not being adequately funded.

Ensuring that all clinical staff were engaged with the process was also seen as a challenge. For person-centred care, one question revolved around whether this style of consultation was more appropriate for nursing staff than medical staff. Engaging all stakeholders with a new approach to care could present difficulties; in particular, some longer-serving, 'traditional' GPs were felt to be less receptive to change.

Concerns with the evidence base surrounding the service changes were raised. It was felt that it would be easier to gain endorsement for change if 'hard metrics' (e.g. improvements in blood pressure or weight loss) could be produced. Improvement to

well-being was characterised as a 'soft' metric, in the sense that it was hard to measure and difficult to equate to improved clinical outcomes.

4.2.7 Challenges to the wider service

Again, wider challenges to the implementation of these new ways of working were experienced by frontline staff. In this case, although the new model had been rolled out across the whole practice, it was championed by two members of staff in particular. When one left the practice, the system stalled as there was not the capacity for someone else to pick up the role of champion.

5 Appendix 1: Individual site plans, updated September 2015

5.1 NHS Horsham and Mid-Sussex and NHS Crawley CCGs

NHS Horsham and Mid-Sussex CCG comprises 23 GP practices and is responsible for the health and well-being of over 225,000 people.¹⁸ NHS Crawley CCG is made up of 13 GP practices and commissions healthcare services for more than 120,000 people.¹⁹ Both CCGs share a management team and the governing bodies of both CCGs share some members, demonstrating their integrated working relationship.

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

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

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

5.1.1 Project 1 – Tailored Health Coaching pilot

Tailored Health Coaching is a new pilot service, jointly commissioned with West Sussex County Council from a local charity, Impact Initiatives, which launched in April 2015. Health coaching is targeted at those 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 contacts the patient by telephone, explains the expected outcomes and, if the patient wishes to engage with the service, undertakes the PAM to ascertain the current level of activation. The PAM activation level is then used to tailor the service provided, identify goals as part of the 'Well-being Plan' formulated by the coach and the patient. Service delivery is holistic and includes all health and social care services, so patients may decide to access support outside

those provided by the CCG. If patients are at level 3 or 4 of activation, support mainly consists of signposting to services. If patients are at levels 1 or 2, more motivational interviewing and greater support are provided. Those delivering the intervention have been trained in motivational interviewing and other coaching techniques. 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:

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

As of September 2015, four health coaches have been recruited and trained to deliver the Tailored Health Coaching service. Engagement with GP practices, which refer patients to the Tailored Health Coaching Service, has been slower than initially expected, with the first patients accessing the service in late May 2015. To encourage engagement, a locally commissioned service (LCS) has been put in place to compensate GP practices for the time needed to identify patients. Five practices signed up prior to the LCS, with a further 10 interested in participating. Other referral methods, including self-referral and referral from other health and well-being partners including social services are also being considered, following the pilot.

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

5.1.2 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'.

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

5.1.3 Project 3 – Tier 3 Weight Management Service

The Tier 3 Weight Management Service has been commissioned from a not-for-profit organisation since April 2014. It caters for up to 400 patients per year. The service is designed to support patients with a Body Mass Index >40 (or >35 with co-morbidities) to manage their weight. It is provided by a multidisciplinary team including bariatric physicians, psychologists, dieticians and physical trainers, who use cognitive behavioural therapeutic approaches to motivate and support patients. The PAM is used as an outcome measure, initially delivered over the telephone prior to attendance at the clinic. Activation levels will be measured at initial referral to the service and then every six months. Other outcome measures – including weight loss, health-related quality of life, patient satisfaction and bariatric surgery referrals – are also being collected. The Tier 3 Weight Management Service has been using the PAM since March 2015 as an outcome measure. PAM scores will be collected as a measure pre and post a 12-week intensive programme and at three month follow up. Over 90 PAMs had been completed by October 2015, but no data analysis looking at outcomes had been conducted.

5.2 NHS Islington CCG

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.²⁰ It is one of NHS England's 14 pioneer sites,²¹ developing a more integrated approach to care within the borough.

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 percent 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 ways in which the PAM is being used:

- Alongside care and support planning consultations in general practice, with ~28,000 patients
- Embedding into contracts for self-management support commissioning

Two other pieces of work with the Clinician support for patient activation measure (CS-PAM) are also being scoped by the site: as a training tool to measure clinician support for patient 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.

5.2.1 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); and liver disease.

GPs were initially commissioned (February 2013 to November 2014) to offer enhanced collaborative Year of Care support plans only to people with diabetes, and this was implemented via a locally commissioned service (LCS). From December 2014, this LCS was merged into an LCS which 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

percent 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 support and 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. They will also be asking GPs to pull relevant information from this sample of patient records to retrospectively review what else occurred with those patients. 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.

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 believe 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: e.g. 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.

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

analysis of this data. Plans are being finalised for the next wave of data collection, which begins in October 2015. Following analysis of this data, a more complete picture of patient activation in Islington will inform knowledge about health states, possible patient requirements and could inform commissioning.

As NHS Islington CCG are primarily using the PAM as an outcome measure to assess the impact of a service on an annual basis, little has changed in their use or planning of work involving the PAM. There is some evidence that individual GPs are looking at the PAM scores and considering different ways of working with patients based on activation levels.

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

An independent evaluation of the Year of Care diabetes care planning work is also being conducted, to ascertain if there are links between diabetic patients with care plans and improved clinical outcomes. The evaluation also focuses on implementation of Year of Care diabetes care planning, to understand how engaged GP practices have been with this process.

5.2.2 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. Work using the PAM started later than originally planned, and so data is not yet available. Staffing changes also affected the bariatric service programme, meaning that early enthusiasm for using the PAM was not followed through into data collection.

5.3 NHS Sheffield CCG

NHS Sheffield CCG comprises 87 GP practices and has responsibility for commissioning services for approximately 580,000 people.²² It was initially using the PAM in three areas:

- 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
- As part of diabetes self-management annual reviews in primary care - based in one GP practice, around 300-400 patients will complete the PAM
- 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 has been 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 hope to gain evidence from the evaluation about the PAM's application to the UK health system. They want to know if it is valid and reliable in this context, and whether it can be used as an outcome measure. They are hoping for a true critical appraisal, in the context of determining which outcome measures are actually useful for commissioning. They have commissioned an internal team to evaluate the citywide care planning commissioned service and the diabetes self-management work.

5.3.1 Project 1: Mental health pilot

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

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

5.3.2 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 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 and 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) with a HCA prior to their annual review appointment. The PAM is completed at this pre-testing appointment, and patients receive their results, including the PAM, from the administrator both over the phone and via a letter prior to their review appointment. At their 20-to-30 minute review appointment with a practice nurse, 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 as part of an evaluation being undertaken by the city council.

The practice staff are very positive about this new way of working, including the PAM, which they say provides a more robust system for ensuring diabetes reviews are conducted. Getting this system right, including where and when the PAM was completed by the patient, was critical to ensuring its success, and now this has been optimised from a practice point of view, plans are to continue using it in its current form. Since the initial phase of work, one of the practice nurses who led the diabetes work has left to work at another practice. This has led to some small scale changes in how the appointments are organised, with a GP seeing the more complex/uncontrolled diabetes patients and another practice nurse seeing the patients who have more stable HbA1c levels.

5.3.3 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 has been used since April 2015 to help to deliver person-centred care planning. It is administered by practice staff (particularly healthcare assistants, administrative staff

and nurses), 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, North, West and Hallam and South Localities (HASL)). Training for person-centred care planning and using the PAM was delivered in a group setting by a mix of internal and external experts, and supported by online training resources available from Insignia. Each GP practice was required to send at least one clinician and manager to one of 11 repeated standard training afternoons. Follow-up support was then available via multidisciplinary locality support teams, 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.

Of the 87 practices, 80 have signed up to participate in the care planning work. Following feedback from the training sessions, the CCG allowed individual practices to make a case for using the care planning approach and the PAM with a different cohort of patients with long-term conditions, if they felt it would be more effective. Fourteen practices had taken this up for the purpose of the pilot work. The CCG started to receive completed PAM questionnaires in July 2015, at the end of the first quarter of the year's piloting implementation. By October 2015, there had been over 650 PAM questionnaires returned.

Recruitment to the locality teams supporting the implementation of person-centred care planning was initially slower than expected, but multi-disciplinary team support is now in place across the city. The CCG is also evaluating the pilot work, assessing the extent to which healthcare professionals' attitudes towards person-centred care have changed.

5.4 NHS Somerset CCG

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.²³ 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.²⁴

Building on this work, Somerset CCG is working with providers to develop a capitated budget, outcomes-based commissioning framework for all services for people living with long-term conditions in Somerset. 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. In July 2015, the CCG published a comprehensive document which outlined the way in which outcomes-based commissioning would be implemented going forward.²⁵

The strategic intention of the CCG at this stage, before the outcomes-based commissioning framework, becomes compulsory has been 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. Additionally, there are a number of smaller pilot projects, including:
 - West Somerset Living Better project for 100 people with long term conditions, particularly those who are lonely, isolated and do not have a good support network
 - Musgrove Park Hospital Patient Voices programme was a small project focussing on care planning for people with long term conditions being discharged from hospital
 - DESMOND diabetes management in the community, with 100 patients completing the PAM as an outcome measure
 - Mendip Health Connectors provides a peer support and social prescribing service to enable people living in Mendip to improve personal and community resilience. This may be on a one to one or group basis
 - MCBT (mindfulness-based cognitive behavioural therapy) group for long-term conditions, with 100 patients completing the PAM as an outcome measure

2. Symphony care hub, as part of long-term condition management in primary and secondary care with people with three or more long-term conditions.

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

5.4.1 Project 1: Outcomes based commissioning

As part of the SPQS, 56 GP practices agreed to focus on the needs of people with long-term conditions, building towards the new outcomes-based commissioning framework planned for 2017. As part of the personalised care planning work currently being conducted, 18 organisations are using and completing the PAM with patients. The initial focus was on GP practices that had been trained in the House of Care approach, but this was expanded to include other 'test and learn' sites in Somerset. It has been used as an outcome measure, administered before and after House of Care training for GP practices. It has also been used more broadly as an outcome measure looking at whether improving PAM score has an impact on avoiding hospital admissions. Around 9,000 copies of the PAM were sent out to use with these patient cohorts. By the end of August 2015, 18 organisations had returned 700 completed questionnaires.

The PAM was not being marketed locally as a separate initiative, but as integrated within the House of Care approach. The Local Medical Committee and CCG sent a letter out to GP practices asking them to get patients to fill in the PAM and this commenced in November/December 2014. This caused some problems in March 2015, when GP practices assumed that the work had been completed and they no longer needed to return the questionnaires. 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 selecting their cohort of patients to use the PAM, though it has been suggested that the House of Care might be useful to use with the top 2 percent 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 aim is to encourage local use and adaptation based on need, so its use will evolve as clinicians and programme managers decide where and when it should be used.

Included in the 18 organisations who have returned data are the West Somerset Living Better project, based on an approach established by Age UK, which uses a guided conversation between patients and healthcare staff to inform their personalised care and support plans which can then be shared among all practitioners (including social care) responsible for that patient's care. The aim of the project is to support people with long term conditions, particularly those who are lonely and isolated, to better self-manage and improve their quality of life through reconnection to their lives and the communities in which they live, thereby reducing their need for healthcare usage. The PAM is being used as one of the measures to monitor outcomes.

Similarly, the Musgrove Park Hospital Patient Voices project was a small-scale pilot delivered by the voluntary sector to provide personalised care planning and signposting to services at the point of hospital discharge, to ensure better liaison between primary and secondary care to create a supportive environment and reduce the likelihood of re-admission. The PAM was used as an outcome measure.

DESMOND, the diabetes self-management training programme, is delivered in groups based in the community. PAM has been used as an outcome measure with around 100 patients in the programme. 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 has been used with around 100 patients as an outcome measure. Again, those leading the programme were told to 'play with it' and use it as they 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.

The Mendip Health Connectors service was initially trialled in East Mendip. The service demonstrated it was possible to improve the ability of patients to self-manage. This is reiterated by similar national evidence. As a result the service has been developed and expanded to cover the whole of Mendip. The service is available to adults who would benefit from non-medical support with health and wellbeing issues. This can include, for example, learning techniques to better manage a long-term health condition, increasing social connectedness or changing health behaviours. Patients self-refer to the service or may receive a recommendation from any of the health professionals who are providing clinical support. The PAM is now being used as one of the outcome measures.

5.4.2 Project 2: Symphony

Within the federated GP practice model, the Symphony Care Hub maps onto the South Somerset federation area and provides additional services for patients with three or more long-term conditions. The aim is to provide integrated care for these patients, using what is known as the 'complex care' model. The complex care model involves working with the four percent of the population who have three or more co-morbidities (around 1,500 people) who account for around 50 percent of health and social care costs.

The Symphony Hub involves: Yeovil District Hospital Foundation Trust, Somerset Partnership Foundation Trust, Somerset County Council, Somerset Clinical Commissioning Group, and the South West Commissioning Support Unit.²² It is one of NHS England's 'vanguard sites' working to deliver an integrated primary and acute care system.

The model is a 'hub' system, with access to doctors, care coordinators and key workers with health and social care backgrounds and skills in health coaching and motivating people to self-manage. Questions from the CS-PAM were included in the recruitment process, so that those who were focused on self-management were selected for the roles. The 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.

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

The PAM is now integrated as a routine part of the baseline data collection when a patient accesses the service, and will also be collected at three, six and 12 months as an outcome. Symphony is currently working across health and social care, and in September 2015 around 73 patients had been enrolled in the hub's services.

5.5 NHS Tower Hamlets CCG

NHS Tower Hamlets CCG comprises 36 GP practices in eight commissioning networks and has responsibility for commissioning services for around 254,000 people.²³ It is one of NHS England's 14 pioneer sites, and one of its priorities is to develop a more integrated approach to care within the borough.

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 2015-16, this was initially put on hold and the PAM used in three pilot projects and to contribute to one commissioning initiative. All pilot projects were run with the Integrated Care team and delivered with the voluntary sector with a plan to deliver them between August 2014 and September 2015, to allow for evaluation before the next commissioning cycle. This has been extended to December 2015 to increase recruitment to the services. 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. The projects were:

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

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 were 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 supported. As the projects are diverse, both clinical and voluntary sector providers were involved in delivering the interventions and thus administering and interpreting the PAM. The majority of questionnaires were delivered face-to-face, using patient advocates to translate if needed, to access the questionnaire in community languages. Throughout the process, there have been concerns about the impact of this mediated completion on validity, which Tower Hamlets CCG is keen to resolve.

5.5.1 Project 1: Esteem self-management

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

- Harmony, 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 different 'cohorts' of potential service users, totalling 219 people, and plan to look holistically at their health and social care needs. The PAM has also been used to tailor interventions to the needs of the cohort, though as it is delivered to patients after referral, this has not always been achieved in practice. Services were provided by Community Options (lead), and referral services were Poplar and Limehouse Health Networks, Barts Health Diabetes Care Centre, Barts Health Adult Community Respiratory and Rehabilitation Service and East London NHS Foundation Trust.

5.5.2 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 were 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). The aim was for each group to have 25 participants, and 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), with referral services including East London NHS Foundation Trust, Poplar and Limehouse Health Network, Neighbours in Poplar and the SE Locality Integrated Care Team.

5.5.3 Project 3: Managing your health and well-being

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 (e.g. being overweight, having high blood pressure) and frequent use of services. The cohorts included people with long-term physical conditions, severe mental illness and learning disability. The PAM was used to help tailor support to patient need. Interventions included coaching and support interventions and group and one-to-one exercise programmes. Services were provided by Ability Bow (lead), with referral services including Primary Care network 8, Healthy Island Partnership, Community Options and Health Trainers.

5.5.4 Project 4: Diabetes education

Diabetes education and self-management programmes have historically been delivered by acute services and by two voluntary sector organisations. All contracts were due to end in April 2015, but were 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.

5.5.5 Further information

Using the PAM as an outcome measure in the self-management pilots (projects 1-3) encountered initial teething problems, but is considered to have proceeded relatively smoothly from the CCG perspective. Similarly, the diabetes structured education teams are also collecting PAM scores from patients as part of the on-going evaluation of service provision. Data collected as part of these evaluations, including the PAM scores, will be used to inform commissioning decisions.

NHS Tower Hamlets CCG, in collaboration with Barts Health NHS Trust, East London NHS Foundation Trust and London Borough of Tower Hamlets, has been awarded vanguard site status by NHS England, focused on providing integrated care. As part of this integrated care work, the CCG plan to deliver the PAM from October 2015 with around 1,000 patients.

As originally planned, the CCG are also using the PAM in general practice, as part of their person-centred care planning work. The aim is to tailor care and support based on PAM level. This work has been running since April 2015, but implementation of the PAM has been slow to start, with some concerns from GPs about capacity to complete the PAM coupled with a lack of awareness about the potential benefits of doing so. Decisions are still being made about using the Carer-PAM within the integrated care planning for patients with dementia, who make up a significant section of the cohort. Discussions about how to engage diverse populations, including those who don't speak English, patients with learning difficulties, patients with serious mental health problems and children, are also on-going.

5.6 The UK Renal Registry

The UK Renal Registry (UKRR) is part of the Renal Association, a not-for-profit organisation registered with the Charity Commission.²⁴ It collects, analyses and reports on data from 71 adult and 13 paediatric renal centres in the UK, as mandated by the NHS National Service Specification, and provides access to a clinical database that can be used in research. UKRR holds extensive data on renal patients: this is mainly clinical information but they are interested in extending this to include patient-reported outcomes. Within the renal community, there is growing interest in shared decision making and patient-reported outcomes.

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

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 and information on shared decision making along the pathway of care. An event was held with stakeholders across Europe to agree consensus on PROMs and PREMs to be collected for renal work. Initial considerations for the PROMs included the SF-12 (a 12-item health survey) and POS-S renal (a short measure combining the most common symptoms renal patients experience with concerns beyond symptoms, such as information needs, practical issues and family anxiety) to record symptom burden score.

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

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

- Can PAM data, along with other PROM and PREM data, be collected on a national basis – what is the feasibility, cost-effectiveness, and robustness of the data gathered?

- Are PAM levels associated with other patient-reported outcome measures (PROMs, PREMs, symptom burden)?
- Are PAM levels associated with clinical outcomes?

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

Because the focus of the programme is to test feasibility and consider sustainability in the longer term, questions about practicability are being prioritised going forward. This has led to extensive and detailed project planning, particularly considering the scale of the project. Initial plans outlined 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 percent for each participating unit. As UKRR has access to patient identifiable data, it will also be investigating what types of patient do or do not complete the PAM.

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

The UKRR have worked hard to optimise collection of the PAM and other measures to balance the need for high quality data with the potential burden of data collection on renal units. PAM and the selected PROMs will be measured quarterly. The PREM has yet to be finalised, but will be taken as a one-off measurement later in the programme.

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 quality improvement project, trialling interventions across different units and assessing improvement; they may be able to randomise units to interventions.

The 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 support for patient activation are also being considered.

Following the launch event in February 2015, the UKRR conducted a number of conference calls with renal units interested in participating in the programme, to ascertain engagement and start to think about how to tackle any potential challenges. As part of this work, they appointed a person-centred care facilitator (in June 2015), who will provide support to the individual renal units and CCGs participating, and provide a link to the central programme board. In August 2015, the preparatory work for the wide-scale roll-out of this programme was still being completed. All the renal units had received the CS-PAM electronically, to measure clinician support for patient activation, and preparations were being made to administer the PAM, PREM and PROM questionnaires for patients.

To manage capacity, renal units have been split into two cohorts, with 10 beginning to measure in December 2015 and the facilitator working with the remaining 13 in 2016, building on the learning gained in the first ten units. A launch event in November 2015, invited participating sites to share ideas, concerns and overcoming practicalities in delivering the programme.

6 References

1. Department of Health. (2015) NHS Five Year Forward View. Available at: <http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>. Accessed 20 May, 2015.
2. The Health Foundation. (2014) Helping measure person-centred care. Available at: <http://www.health.org.uk/publications/helping-measure-person-centred-care/>. Accessed 20 May, 2015.
3. The Health Foundation. (2014) Person-centred care made simple. Available at: www.health.org.uk/publications/person-centred-care-made-simple. Accessed 27 March, 2015.
4. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res* 2004; Aug;39(4 Pt 1):1005-26.
5. Hibbard JH, Greene J, Shi Y, Mittler J, Scanlon D. Taking the long view: how well do patient activation scores predict outcomes four years later?. *Med Care Res Rev* 2015; Jun;72(3):324-37.
6. Kinney RL, Lemon SC, Person SD, Pagoto SL, Saczynski JS. The association between patient activation and medication adherence, hospitalization, and emergency room utilization in patients with chronic illnesses: a systematic review. *Patient Educ Couns* 2015; May;98(5):545-52.
7. Hibbard JH, Gilbert H. (2014) Supporting people to manage their health: An introduction to patient activation. Available at: http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf. Accessed 20 May, 2015.
8. Coulter A, Ellins J. (2005) How engaged are people in their healthcare? Findings of a national telephone patient survey. Available at: <http://www.pickereurope.org/wp-content/uploads/2014/10/How-engaged-are-people-in-their-health-care-....pdf>. Accessed 20 October, 2015.
9. The Health Foundation. (2013) Closing the gap through clinical communities. Available at: <http://www.health.org.uk/areas-of-work/programmes/closing-the-gap-through-clinical-communities/>.
10. The Health Foundation. (2013) Using clinical communities to improve quality: ten lessons for getting the clinical community approach to work in practice. Learning report.
11. National Institute for Health and Care Excellence. (2015) Type 1 diabetes in adults: diagnosis and management (NICE guideline 17). Available at: <https://www.nice.org.uk/guidance/ng17>. Accessed 20 October, 2015.

12. National Institute for Health and Care Excellence. (2009) Type 2 diabetes: The management of type 2 diabetes (NICE Guideline 87). Available at: <https://www.nice.org.uk/guidance/cg87>. Accessed 20 October, 2015.
13. Diabetes UK. (2015) Care survey results 2014. Available at: <https://www.diabetes.org.uk/Guide-to-diabetes/Monitoring/15-healthcare-essentials/Care-survey-results-2014/>. Accessed 20 October, 2015.
14. NHS Horsham and Mid Sussex Clinical Commissioning Group. (2015) About us. Available at: <http://www.horshamandmidsussexccg.nhs.uk/about-us/>. Accessed 20 October, 2015.
15. NHS Crawley Clinical Commissioning Group. (2015) About us. Available at: <http://www.crawleyccg.nhs.uk/about-us/>. Accessed 20 October, 2015.
16. NHS Islington Clinical Commissioning Group. (2015) About us. Available at: <http://www.islingtonccg.nhs.uk/about-us/>. Accessed 20 October, 2015.
17. Department of Health. (2013) Integration pioneers leading the way for health and care reform. Available at: <https://www.gov.uk/government/news/integration-pioneers-leading-the-way-for-health-and-care-reform--2>. Accessed 20 October, 2015.
18. NHS Sheffield Clinical Commissioning Group. (2015) About us. Available at: <http://www.sheffieldccg.nhs.uk/about-us/>. Accessed 20 October, 2015.
19. NHS Somerset Clinical Commissioning Group. (2015) About us. Available at: <http://www.somersetccg.nhs.uk/about-us/>. Accessed 20 October, 2015.
20. Somerset Local Medical Committee. Somerset Practice Quality Scheme. Available at: <https://www.somersetlmc.co.uk/somersetpracticequalityscheme>. Accessed 27 May, 2015.
21. NHS Somerset Clinical Commissioning Group. (2015) Governing Body agenda and papers, 16 July 2015, Enc D - Outcomes Based Commissioning. Available at: <http://www.somersetccg.nhs.uk/about-us/governing-body/meetings-and-papers/governing-body-agenda-and-papers-16-july-2015/>. Accessed 22 October, 2015.
22. Calkin S. (2013) South Somerset Local Integration Plan. Available at: [www.york.ac.uk/media/che/documents/newsevents/South-Somerset-integration-plan%20\(1\).pdf](http://www.york.ac.uk/media/che/documents/newsevents/South-Somerset-integration-plan%20(1).pdf). Accessed 20 October, 2015.
23. NHS Tower Hamlets Clinical Commissioning Group. (2015) The Tower Hamlets Population. Available at: <http://www.towerhamletsccg.nhs.uk/about/The-Tower-Hamlets-Population.htm> . Accessed 20 October, 2015.
24. The UK Renal Registry. (2015) Welcome to the UK Renal Registry. Available at: <https://www.renalreg.org/>. Accessed 20 October, 2015.