

Patient Activation

At the heart of self-care support

**Frequently
asked
questions**



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Publications Gateway Reference: 04988

Document Purpose	Implementation Support
Document Name	Patient Activation - Frequently Asked Questions
Author	NHS England/Person-centred care team
Publication Date	25 April 2016
Target Audience	CCG Clinical Leaders, CCG Accountable Officers, CCGs, new care model vanguards, integrated personal commissioning sites, integrated pioneers, PAM learning set and the Health Foundation
Additional Circulation List	Care Trust CEs, Foundation Trust CEs , Medical Directors, Directors of PH, Local Authority CEs, Think tanks, academics, patients and public among others, NHS Trust CEs
Description	NHS England has agreed a five-year licence to use the Patient Activation Measure tool with up to 1.8 million people through key NHS change programmes, including the new care model vanguards and IPC demonstrator sites. In the first year, around 40 CCGs and other primary care organisations will be granted access to PAM licences subject to an application process. These FAQs will support interested sites with information about using the PAM tool in their local areas.
Cross Reference	Patient Activation narrative
Superseded Docs (if applicable)	N/A
Action Required	N/A
Timing / Deadlines (if applicable)	N/A
Contact Details for further information	<p>england.patientactivation@nhs.net Person centred care team Patient and Public Participation and Insight Nursing Directorate NHS England</p> <p>https://www.england.nhs.uk/ourwork/patients/patient-participation/self-care/patient-activation/</p>

Document Status

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Patient Activation: At the heart of self-care support

Frequently asked questions

Version number: 1

First published: 25 April 2016

Prepared by: Person-centred care team

Classification: OFFICIAL

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

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1 About patient activation

1.1 What is patient activation?

Patient activation describes the knowledge, skills and confidence a person has in managing their own health and care¹.

The concept of patient activation links to all the principles of person-centred care, and offers care that is suitably personalised and supports people to recognise and develop their own strengths and abilities. It is an asset-based approach that puts individuals in the driving seat by increasing their capability. It supports people by giving them information they can understand and act on, and provides them with support that is tailored to their needs.

It is closely linked to other concepts such as 'self-efficacy' and 'readiness to change', and is a broader and more general concept, reflecting attitudes and approaches to self-management and engagement with health and healthcare, rather than being tied to specific behaviours.

You can find out more about patient activation in The King's Fund '[Supporting people to manage their health](#)' report.

1.2 Why is patient activation important in the context of the NHS?

In England, more than 15 million people have a long-term condition (LTC). This group tend to be heavy users of the health service, accounting for at least 70 percent of all NHS spend but are likely to spend less than 1 percent of their time in contact with health professionals². The rest of the time is spent with their carers, their families or managing on their own as 'experts by experience'. People with long-term conditions manage their health on a daily basis, but may need additional help to develop their confidence in fulfilling their role as a self-manager.

A growing body of evidence emphasises the importance of effective self-management of long-term conditions. People who recognise that they have a key role in self-managing their condition (and have the skills and confidence to do so) experience better health outcomes.¹ Yet, the ability of people to successfully self-care and stay well at home can vary considerably from person to person. People with LTCs and their carers need to be better equipped to manage their own condition(s).

In recognition of this, 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

¹ The King's Fund (2014) [Supporting People to Manage their Health: An introduction to Patient Activation](#)

² The King's Fund (2013) [Delivering better services for people with long term conditions: Building the 'House of Care'](#)

avoiding complications'³. In addition, NHS England has a mandate commitment to ensure that people are empowered to shape and manage their own health and make meaningful choices about their care⁴. 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.

As the individual's ability to successfully self-manage their long-term condition and to stay well at home depends on their knowledge, skills and confidence, it is in the NHS interest to understand what this level is, also called their activation level. This can then be used to 'meet people where they are' to support them in ways appropriate to these individuals on their 'journey of activation'.

Evidence shows that as the level of activation is improved, people experience better health, have better outcomes, report better experience of care, engage in healthier behaviours, and have fewer episodes of emergency care that leads to lower costs for the NHS⁵. A study found that less activated patients had 8 percent higher costs in the base year and 21 percent higher costs in the following year than more activated patients.⁶ Evidence has also shown that when patients are fully informed about their options and outcomes, they choose fewer treatments, reducing the gap between what they want and what doctors think they want, decreasing the risks of silent misdiagnosis.⁷

All of this will help to reduce the pressure on NHS services, improve quality and ensure that resources are focussed on those patients with the most complex health needs.

1.3 Why are we using the term 'patient activation'?

People rightly reject being labelled as patients. The idea of activation can imply an underlying passivity. However, the concept of patient activation has gained credence among clinicians, academics and think-tanks⁵, so at this point in our journey, it is a useful phrase to use. But at NHS England, we recognise that the term may be problematic and not universally liked.

However, we would like to emphasise that this is about focusing on the knowledge, skills and confidence that individuals have to manage their health. We welcome alternative suggestions to the term 'patient activation'.

³ NHS England (2014) [NHS Five Year Forward View](#)

⁴ Department of Health (2016) [The Government's Mandate to NHS England for 2016/17](#)

⁵ The King's Fund (2014) [Supporting People to Manage their Health: An introduction to Patient Activation](#)

⁶ Hibbard J et al (2013) Patients with lower activation associated with higher costs; delivery systems should know their patients' 'scores', [Health Affairs \(Millwood\)](#);32(2):216-22

⁷ The King's Fund (2012) [Patients' preferences matter: Stop the silent misdiagnosis](#)

1.4 How can measuring patient activation benefit people?

Evidence shows that people at higher levels of activation tend to experience better health, have better health outcomes and fewer episodes of emergency care, and engage in healthier behaviours (such as those correlated to smoking and obesity). On the other hand, patients with lower activation have low confidence in their ability to have an impact on their health and often feel overwhelmed with the task of managing their health and wellbeing.

It is estimated that between 25 and 40 percent of the population have low levels of activation (levels 1 and 2)⁸. These people are unlikely to respond to opportunities to improve their health through self-management. They do not understand their role in care process and have limited problem solving skills. Often they have experienced failure in trying to manage and have consequently become passive with regard to their health and wellbeing. As a result, they engage less with preventative healthcare and are involved in more costly emergency care episodes.

Measuring patient activation can drive real improvements as:

- Understanding activation levels help patients and clinicians to determine the realistic “next steps” for individuals to take in term of self-management;
- It allows for training and education resources to be tailored to the levels of activation of different individuals within the population;
- Targeting and allocating resources more appropriately to provide more in-depth support to those who are less activated and confident about their ability to manage their own care.
- It can enable equality and health inequalities to be tackled more effectively by targeting interventions at disadvantaged groups to increase their health literacy and patient activation.

There is evidence to show that patient activation is changeable and effective interventions can help to increase people’s activation levels and their confidence in managing their health⁹. A number of programmes have demonstrated the ability to raise activation scores in people - these typically focus on the individuals gaining new skills, encouraging a sense of ownership of their health, changes in their social environment, health coaching and educational classes. All of these help to empower people to take greater control of their health, leading to better outcomes and improved experience of the health service.⁹

Evidence has also shown that when patients are fully informed about their options and outcomes, it reduces the gap between what they want and what doctors think they want, decreasing the risks of silent misdiagnosis.¹⁰

⁸ Hibbard JH, Cunningham PJ (2008) ‘How engaged are consumers in their health and health care, and why does it matter?’, [Health System Change Research Briefs](#), (8) 1–9

⁹ The King’s Fund (2014) [Supporting People to Manage their Health: An introduction to Patient Activation](#)

¹⁰ The King’s Fund (2012) [Patients’ preferences matter: Stop the silent misdiagnosis](#)

1.5 How can measuring patient activation help clinicians?

Measuring patient activation gives the healthcare professionals a starting point to meet the patients 'where they are', helping them to tailor their approaches to the individuals appropriately. Using a measure helps the professionals to assess the ability of the person to take on self-management tasks and generally respond to their health needs, rather than having to depend on guesswork. It shapes the agenda for the consultation, including exploring patient expectations and motivations and ways in which the patient's level of activation may be increased or maintained.

It helps the clinician to focus on the interventions which the patient is likely to both agree to and be able to engage successfully with. It can also help identify where a carer's help may be needed in, say, adherence to a medication regime. It can help clinicians to monitor progress, for example, where a care plan is being used. Measuring a patient's activation at different stages in the plan provides objective feedback to both clinician and patient on goals relating to self-management.¹¹

All of these support clinicians to develop a more person-centred approach in their interactions with patients.

1.6 How can measuring patient activation help commissioners?

Understanding people's activation levels can help commissioners to put interventions in place to meet their population's needs more appropriately, such as commissioning training and education resources tailored to the levels of activation of different individuals within the population. It can enable targeting and allocation of resources more appropriately to provide more in-depth support to those who are less activated and confident about their ability to manage their own care.

Measuring patient activation can help commissioners in measuring the effectiveness of services and in quality improvement through assessing whether an intervention, tailored to the person's level of activation, made a difference to their level of knowledge, skills and confidence. This can help to support commissioning activity to make any required changes to the types of services to ensure it meets the needs of their local population.

1.7 Can people be supported to increase their activation? If so, what are the types of interventions that can help to increase it?

Studies show that targeted interventions can increase an individual's activation score and their capacity to self-manage their condition more effectively. Less activated individuals need more in-depth one to one support as compared to the more activated individuals. When appropriately supported, evidence shows that the least activated patients make the most gains.¹²

¹¹ Rix A, Marrin K (2015) [Prudent health care and patient activation](#)

¹² The King's Fund (2014) [Supporting People to Manage their Health](#)

A range of interventions tailored to individuals' needs are required to support people to increase their knowledge, skills and confidence. You may already have some of these services/interventions, such as social prescribing, volunteer health roles and time banking in place in your local area.

NHS England's [Realising the Value programme](#) has also identified five evidence-based approaches that engage people in their own health and care¹³. The five areas of practice are self-management education; peer support; health coaching; group activities that promote health and well-being; and asset-based approaches in a health and well-being context.

The programme recognises that person-centred and community-based support needs to be both holistic and tailored around the individual, and there are connections between these approaches and other key enablers such as care and support planning and social prescribing. Interventions linked to these approaches can help to increase people's activation.

It is also important to note that efforts to improve patient activation will be more successful when supported by a whole system approach including training of clinicians in these new ways of working.

1.8 Can a person's activation level go up and down over time?

A person's level of activation is a dynamic concept, and not a label. The individual may have high levels of knowledge, skills and confidence, and so be highly activated. However, if they then get diagnosed with a new condition or have a new complication not experienced before, their level of knowledge, skills and confidence would be lower in response, until they have learned to manage it well. At that stage, their level of activation will rise again.

1.9 How can clinicians support patients to increase their activation more effectively?

Improved communication skills for clinicians and training in areas such as motivational interviewing and health coaching, can support them to address the individual needs of patients at different levels of activation more effectively.

Some of these were identified by clinicians in a [survey](#) done by NHS England in 2014-15.

¹³ 'At the heart of health: Realising the value of people and communities' report, Feb 2016. <http://www.nesta.org.uk/project/realising-value>

1.10 Can supporting people to increase their activation have an impact on reducing costs for the NHS?

Evidence shows that increasing people's activation can help with cost reductions as less activated patients engage less with preventative healthcare and are involved in more costly emergency care episodes. Studies show that targeted interventions can increase people's activation scores and their capacity to self-manage their condition more effectively; and when appropriately supported, the least activated patients make the most gains.¹⁴ Supporting these patients will help to improve their outcomes, their experience with the health service and also reduce their rates of hospitalisation and visits to accident and emergency departments. This will result in reducing the healthcare costs of these patients in the NHS. A study found that less activated patients had 8 percent higher costs in the base year and 21 percent higher costs in the following year than more activated patients.¹⁵

2 About the Patient Activation Measure (PAM)

2.1 What is the 'Patient Activation Measure' (PAM)?

Individuals have different knowledge, skills and confidence to assume responsibility for their own health and well-being. In order to tailor support according to their needs and to increase their capability to look after themselves more effectively, it is important to be able to measure a person's level of activation.

The Patient Activation Measure (PAM) is a validated, commercially licenced tool and has been extensively tested with reviewed findings from a large number of studies. It helps to measure the spectrum of skills, knowledge and confidence in patients and captures the extent to which people feel engaged and confident in taking care of their condition.¹⁴

Individuals are asked to complete a short survey and based on their responses, they receive a PAM score (between 0 and 100). The resulting score places the individual at one of four levels of activation, each of which reveals insight into a range of health-related characteristics, including behaviours and outcomes. The four levels of activation are:

- Level 1: Individuals tend to be passive and feel overwhelmed by managing their own health. They may not understand their role in the care process.
- Level 2: Individuals may lack the knowledge and confidence to manage their health.

¹⁴ The King's Fund (2014) [Supporting People to Manage their Health](#)

¹⁵ Hibbard, J et al, (2013) 'Patients with lower activation associated with higher costs; delivery systems should know their patients' scores', [Health Affairs \(Millwood\)](#),(2):216-22

- Level 3: Individuals appear to be taking action but may still lack the confidence and skill to support their behaviours.
- Level 4: Individuals have adopted many of the behaviours needed to support their health but may not be able to maintain them in the face of life stressors.¹⁶

The PAM tool is licensed by the US company, Insignia Health LLC.

2.2 Are there any existing programmes using PAM in the NHS?

PAM has been robustly tested in the USA and is used extensively there. It has also been used in different settings across a number of countries, including Denmark, Germany, Japan, Norway, Canada, the Netherlands and Australia. Results from the Picker Institute study indicated that the PAM is a valid and appropriate tool for use with a UK population as well.¹⁷

In England, we are currently testing the use of PAM in a learning set of 5 CCGs and the UK Renal Registry with about 100,000 patients with long term conditions from 2014-16. The programme, funded by NHS England, is looking at different ways to embed PAM in local commissioning and delivery systems. The learning set is helping with ongoing learning around:

- the feasibility of measuring PAM across the NHS;
- how activation can inform support for self-management;
- what support clinicians and commissioners need to use the measure effectively; and
- building the evidence that whether supporting activation can improve outcomes, reduce costs and reduce inequalities for patients in the NHS.

NHS England and the Health Foundation have commissioned the University of Leicester to conduct an independent evaluation of the PAM learning set and some of these findings are available [here](#).

2.3 How can PAM be used in practice?

The PAM can be used as:

a) A tailoring tool – Measuring patient activation gives the healthcare professionals a starting point to meet the people ‘where they are’, helping them to tailor their approaches to the individuals more appropriately to support them on their ‘journey of activation’. Using the PAM in this way as a tailoring tool encourages the provision of proactive system support for people with long-term conditions to develop the skills, knowledge and confidence to manage health and

¹⁶ The King’s Fund (2014) [Supporting People to Manage their Health](#)

¹⁷ Ellins J, Coulter A (2005). How engaged are people in their healthcare? Findings of a national telephone patient survey. [London: Picker Institute](#).

keep well at home. For example, one GP practice in Sheffield has redesigned their diabetes review process through offering longer appointments using the PAM to tailor discussion according to the individual's level of activation.

b) Tailoring tool and outcome measure - As a quantifiable measure, PAM can be used at scale and to assess whether the services/interventions are providing effective and tailored support to people's needs. Aggregate/cohort PAM scores can be used to evaluate commissioned programmes to understand if they increased people's activation, or if any changes are required to the types of services required in the local area according to people's needs. It can be used to compare outcomes from different programmes.

For example, NHS Horsham and Mid Sussex CCG and NHS Crawley CCG have commissioned a tailored health coaching service in their area where health coaches use the PAM to tailor their approach to working with patients. PAM is also being used here as an outcome measure as the patients complete a baseline PAM on entry to the service and complete it again at the end of their coaching.

You can use the PAM in one or more ways listed above as per your objectives. Case studies from the PAM learning set and the findings from the independent [evaluation](#) will also be useful in this context.

2.4 Is the PAM survey available in other languages?

Yes, it is available in other languages such as Urdu, Gujarati, Hindi, Bengali, Punjabi, Polish, Slovak, Somali, Czech and Romanian to meet the needs of your population at no extra cost. Please email: england.patientactivation@nhs.net if you need the survey in other languages.

2.5 Why is the NHS supporting the use of PAM above other measures?

To our knowledge, PAM is presently the only validated, evidence-based tailoring tool to support services in building individuals' skills, knowledge and confidence to manage their health and care. NHS England's Self-care programme is interested in measuring and responding to people's activation levels.

We are interested to learn about other tools that have been developed in this space and are being used locally. If you are aware of such tools, please email: england.patientactivation@nhs.net

3 About the application process for Patient Activation licences

3.1 Why are you inviting applications for Patient Activation licences?

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 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. 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.

More information about the application process is available on [our website](#).

3.2 Can we get PAM licences to use in our area?

In the first year (2016-17), around 40 CCGs and other primary care organisations, including New Care Model Vanguards and Integrated Personal Commissioning sites, will be granted access to PAM licences subject to an application process. If your bid is successful, you will receive PAM licences to use with your population. This will support your organisation to be ready to become a key partner in NHS England's Self-Care programme, which will begin to deliver further support later in the year.

More information about the application process is available on [our website](#).

3.3 Will we need to sign an agreement to use the PAM licences?

Yes, organisations will need to sign an Affiliate Agreement and a Memorandum of Understanding (MoU) with NHS England.

3.4 Is there a minimum or maximum number of licences that I can apply for?

We would encourage organisations to apply for a higher number of PAM licences as part of the application process.

Measuring patient activation is a core enabler for NHS England's 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. Small projects using only a few licences will not be able to demonstrate how their use of the measure will have the desired wider reach and impact across their local health system.

Evidence has shown that trialling the use of PAM with only a few licences does not meet intended outcomes as little progress is made to align the organisation and systems around the importance of activation, such as processes, staff and leadership. These smaller pilots do not create the programmes necessary to leverage the PAM to target resources and tailor support to people with LTCs. The small sample sizes also do not allow reliable conclusions to be drawn from a statistical perspective.

3.5 Will there be any support available if our bid is successful?

NHS England will provide some delivery support alongside PAM licences to the successful organisations/local health economies.

You will have the opportunity to attend regional/thematic learning sets. You will also benefit from the experiences of the current learning set, who have been using PAM over the last two years in their local areas.

However, you will need to plan and implement your interventions that tailor services to empower people to manage their own health. No direct programme or project financial support will be given to put these interventions in place.

For any queries, you can email england.patientactivation@nhs.net

3.6 Will successful organisations be given training to use PAM?

It is mandatory that successful applicants attend at least one Patient Activation training workshop, provided by NHS England in collaboration with Insignia Health. These will be full day sessions supporting sites to understand how patient activation can influence the way in which people are supported to manage their long-term conditions and will provide in-depth training on how to use the PAM tool.

The first of these workshops will be held on 14th June 2016 in London, and 16th June 2016 in Leeds. Further training days are scheduled in September 2016.

In addition to the training workshops, Insignia Health will lead a number of (free) webinars to support participants in using the PAM tool. It is expected that Patient Activation sites will contribute to the design of these webinars to ensure content is tailored to meet their needs. Webinar attendance by participants is encouraged, but not mandatory. These webinars have been scheduled for early August and early November.

3.7 How is the PAM questionnaire completed? How can we engage with patients to administer it?

Practical questions around the administration of PAM and using it effectively will be covered in good practice 'How to' guides that NHS England will publish shortly. These will capture the learning from the use of PAM by the learning set and other resources.

3.8 How long are the PAM licences valid?

The licences are valid up to April 2021 in the current agreement.

A PAM licence is constituted as 'used' only when it is completed with or by a patient for the first time. Upon the return of a completed questionnaire to the organisation coordinating the administration, the licence's expiry process will commence.

3.9 How many PAM licences do I need to assess the activation of the same person over several years?

You only need one PAM licence per person – it can be used any number of times with the same person up to the end of the licence agreement.

3.10 Are there other derivatives of PAM available for people with different needs?

Yes, PAM tools available to use as part of the licence agreement include the Parent/Carer PAM and validated language translations of PAM derivatives (as

required). Use of the PAM tool with a patient and their carer(s)/parents only counts as one licence.

Please email england.patientactivation@nhs.net if you need to access the measure in languages other than British English.

3.11 Is the Clinician Support for Patient Activation (CSPAM) tool available to use with clinicians as part of the licence agreement?

At the end of 2014, NHS England used a modified version of the CSPAM tool and surveyed over 1750 clinicians, including doctors, nurses and allied health professionals, to explore their attitudes and beliefs, their self-reported behaviours and practices to support people in taking a more active role in managing their health and care. The findings from the survey are available on our website [here](#) and it also provides an insight into clinicians' perceived barriers and their support needs.

The CSPAM tool is not part of this licence agreement. If you wish to use it as a reflective tool with your clinicians, you will need to contact [Insignia Health](#) directly.

3.12 Can we use the digital or online version of the PAM?

As part of NHS England's licence agreement with Insignia Health, we are providing organisations with access to paper-based version of the PAM at no cost. However, should you choose to utilise System PAM (the online Survey and Scoring System developed by Insignia Health), then you will be responsible for the costs incurred. The decision of whether or not to purchase and/or use System PAM is at your discretion and NHS England makes no recommendation and gives no advice in relation to the same.

We will be looking at options for embedding the PAM questionnaire, levels and scores within digital systems, drawing on the experiences of the current PAM Learning Set in this context. This may help you to develop your own methodology of recording them digitally within your local systems.

3.13 If a site uses System PAM, is there an issue with sending patient non-identifiable data to Insignia Health's server hosted in Dublin in terms of information governance? Who is responsible for any risk assessment/due diligence?

You will need to ensure that locally, you complete due diligence and local risk assessment to ensure you are compliant with arrangements to send patient non-identifiable, non-clinical data via the server in Dublin.

3.14 If a site wants to embed the PAM spreadsheet into its local IT system, can it be done? Who is responsible for complying with information governance?

Yes, you are compliant with the licence agreement if you want to embed the spreadsheet within your IT system. A site would need to follow the terms of the affiliate agreement, their usual IG protocol and complete due diligence to ensure this complies with local governance rules.

3.15 Is the Insignia Health tool 'Coaching for Activation' available for use as part of the NHS licence agreement?

No, it is not part of the licence agreement. If you wish to use it, you will need to contact [Insignia Health](#) directly.

3.16 Do we need to complete an Equality Impact Assessment (EIA) for using the PAM?

Equality Impact Assessments (EIAs) are no longer a statutory requirement in England. However, they continue to be used by public sector organisations as a way of demonstrating compliance with public service equality duty.

NHS England will not require an organisation using PAM to complete an EIA. It is the decision and individual responsibility of each organisation using the PAM to undertake an EIA in line with their local patient activation plans and broader context of how they will use PAM, which will be unique for each locality.

3.17 Will we need to do our own evaluations locally?

No, it will be done at a national level and you will need to engage with the evaluation process.

3.18 We are interested in using the local PAM CQUIN with our providers - can we do that?

Yes, you can, provided your vision for using PAM is aligned to our patient activation narrative and you are successful in securing the use of PAM licences as part of this process.