Module 1: PAM®

implementation - quick guide

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Document Status

Foreword

Patient Activation: at the heart of personalised care

How do health and care systems support people to develop the knowledge, skills and confidence to manage their health and wellbeing?

For nearly 70 years, the NHS has been there for us. It is a constant in our lives, from cradle to grave. But the NHS was never designed for the 21st century. It was never designed to provide ongoing support for people with long term conditions (LTCs). These people have conditions which can only partly be treated. So, when medicine can only do so much, what else can or should public services do to support people to live well despite their medical conditions?

We are now beginning to understand that the roots of health lie not in hospitals or GP surgeries, but in our people and communities. 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 and wellbeing. To meet this commitment, NHS England has been working to scale up support for people living with LTCs. Patient activation is a measure of a person's knowledge, skills and confidence to manage their own health and wellbeing, and is a core enabler for supporting self-management and personalising care.

When I first heard about the concept of patient activation, it was a 'light bulb' moment for me. It has since helped me to understand why some people find it difficult to engage with managing their long term conditions. I began to tailor what I was saying to individuals – it was not about telling people what to do, ticking boxes or delivering care; it was about helping them to develop the confidence and understanding to allow them to participate more fully in the management of their health and care. This helped to improve their health-related behaviours, and resulted in better outcomes, better experiences of care and fewer episodes of unplanned and emergency care, leading to financial benefits for the healthcare system.

If we don't address the levels of activation in people, there is sufficient evidence to tell us that they are unlikely to benefit from interventions we provide; they are unlikely to take the medications we prescribe, or even turn up for appointments.

We hope that this guide will help you to understand why it is important to focus on people having the knowledge, skills and confidence to manage their health and wellbeing, and how you can use the Patient Activation Measure® more effectively. It will help you to understand and respond appropriately to the levels of activation of people in your local area, and so help realise the national aspiration for personalised care in the NHS.

Professor Alf Collins
Clinical Advisor, Personalised Care Group, NHS England

Background to Personalised Care and Patient Activation

This quick guide is an introduction to the use of the Patient Activation Measure PAM® which should be used in the context of a fully integrated approach to personalised care as set out below.

The Next Steps on the Five Year Forward View has brought added impetus to the need to roll out personalised care across England, to realise the significant contribution this can make to meet the triple aim of improved health and wellbeing, better care and greater value for the public pound. Demographic and financial pressures, technological advances and changing attitudes require a transformation in the way we think about health and care. A more proactive, holistic and personalised approach, involving greater engagement with people and communities is now the only sustainable path.

Personalised care means people having choice and control over decisions that affect their own health and wellbeing within a system that harnesses the expertise, capacity and potential of people, families and communities in delivering better outcomes and reducing health inequalities. It has been defined by people who use health and care services as "I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me." Personalised care incorporates:

- A whole population approaches to supporting people of all ages, and their carers, to manage their physical and mental health and wellbeing and make informed choices and decisions when their health changes;

- A proactive and universal offer of support to people with long term physical and mental health conditions to build knowledge, skills and confidence through supported self-care and community-centred approaches; and

- Intensive approaches to empowering people with more complex needs to have greater choice and control over the care they receive.

The objective is that in future, people should expect the same focus on their independence, the same regard for their wishes and the same opportunities to make choices and take control, whether they have a long term physical or mental health condition, a complex need, or are deciding about particular care or treatment, such as maternity services or at the end of life.

The purpose of the Personalised Care Programme is to take the learning to date from Integrated Personal Commissioning and the Vanguards programme to scale up personalised care to:

- Improve people's health and wellbeing outcomes and experience of care, through involving them more fully in designing support around their individual needs and circumstances;

- Prevent crises in people's lives that lead to unplanned hospital and institutional care through supporting effective self-management;

- Deliver improved value for the health and care system through quality improvements, better integration of care and reductions in demand and cost.

Making personalised care an everyday reality for people requires the systematic implementation of a number of evidence-based interventions, involving changes to communities; front line practice; and to commissioning. As well as stronger partnerships and integration across health, social care and the voluntary, community and social-enterprise (VCSE) sector and co-production with people with lived experience. Whilst the ways and means will be diverse and locally distinct, a number of specific elements will need to be universally adopted to realise the full potential of personalised care:

- Enabling choice and embedding Shared Decision Making, so that people are informed and supported as equal partners in decisions about their care and treatment;

- Systematic referral to sources of non-clinical support through social prescribing and community connecting roles, aligned with wider approaches to community capacity building and stronger partnerships with the voluntary sector;

- Personalised care and support planning as a proactive process, bringing together people's physical, mental health and wellbeing needs into a single conversation focused on what is important to them and coordinating better access to personalised care and treatment, alongside psychosocial and community based support;

- Supported self-care tailored to people's level of knowledge, skills and confidence, including health coaching, self-management education and systematic access to peer support options; measured through tools such as the Patient Activation Measure (PAM®);

- Integrated personal commissioning, including personal health budgets and integrated personal budgets; enabling people who could benefit to take direct control of resources available for their health and care; providing an essential counterbalance to a 'one-size-fits-all' commissioning approach, with a greater choice of care and support options.
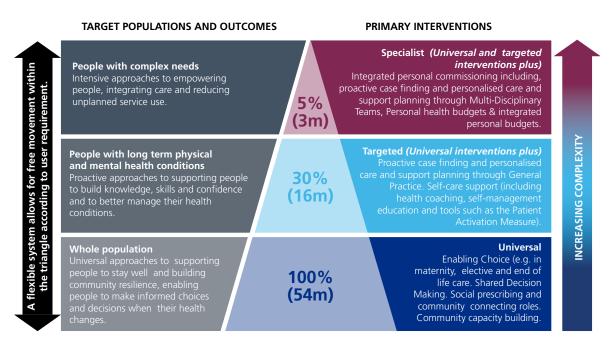
TARGET POPULATIONS AND OUTCOMES		PRIMARY INTERVENTIONS

People with complex needs
Intensive approaches to empowering people, integrating care and reducing unplanned service use.

5% (3m)

Specialist *(Universal and targeted interventions plus)*
Integrated personal commissioning including, proactive case finding and personalised care and support planning through Multi-Disciplinary Teams, Personal health budgets & integrated personal budgets.

People with long term physical and mental health conditions
Proactive approaches to supporting people to build knowledge, skills and confidence and to better manage their health conditions.

30% (16m)

Targeted *(Universal interventions plus)*
Proactive case finding and personalised care and support planning through General Practice. Self-care support (including health coaching, self-management education and tools such as the Patient Activation Measure).

Whole population
Universal approaches to supporting people to stay well and building community resilience, enabling people to make informed choices and decisions when their health changes.

100% (54m)

Universal
Enabling Choice (e.g. in maternity, elective and end of life care. Shared Decision Making. Social prescribing and community connecting roles. Community capacity building.

A flexible system allows for free movement within the triangle according to user requirement.

INCREASING COMPLEXITY

Figure 1: The Universal Personalised Care Model

The elements of the whole population approach are illustrated in figure 1.

What is Patient Activation?

It is now widely acknowledged that people who have the knowledge, confidence and skills to manage their own health tend to have better health outcomes than those who have a more passive approach. Patients with high levels of activation understand their role in the care process and feel capable of fulfilling that role. Individuals with long term conditions, who are more highly activated, are more likely to engage in positive health behaviours and to manage their health conditions more effectively. On the other hand, people who have low levels of activation are less likely to play an active role in staying healthy. They are less good at seeking help when they need it, at following advice given by healthcare professionals and at managing their health when they are no longer being treated. Their lack of confidence and their experience of failing to manage their health often means that they may prefer not to think about it.

There is also growing evidence that, while individuals may have an underlying level of ability and inclination to be active in managing their own health, patient activation can be increased by offering support and providing opportunities to develop both condition specific and general health knowledge and skills. The key to self care is a new relationship that puts the needs of the individual first.

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[1] Together, these underlying capacities and capabilities are referred to as 'patient activation'

[2] Hibbard, J. and Gilburt, H. (2014) Supporting people to manage their health: An introduction to patient activation. London: Kings Fund. Available at https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf

The Patient Activation Measure (PAM®)

The PAM® can make a valuable contribution to assessing a patient's ability to self care at any given time. This assessment helps support next steps on what would be needed to increase their levels of knowledge, skills and confidence in order to improve their health and wellbeing outcomes. It can be used to tailor interventions to individual needs, significantly increasing the likelihood that people will adopt behaviours that contribute to better health. It can also help commissioners to make available the kinds of interventions needed, especially for those with low levels of activation who have most to gain.

This guide aims to provide some practical and operational support to organisations looking to implement the PAM®. For organisations who are considering using the PAM®, it will help them to understand why focussing on patient activation is important and to think through things they need to consider before they start to implement it.

The content of this guide

This guide has been written based on the experience of a learning set on their use of PAM®, as part of a planned intervention to provide support to people. It draws on the learning from an independent evaluation of the PAM® learning set by the University of Leicester, which was jointly funded by NHS England and the Health Foundation to inform the wider implementation of the PAM®.

Furthermore it reflects experiences of other new users given access to PAM® licences which were provided as part of NHS England's work to support self care . In a short space of time, this learning informed NHS England's decision to make available a further 1.8 million licences for use by over 60 pioneering health organisations including integrated personal commissioning sites and new care model vanguards. Confidence that healthcare organisations can rise to the challenge of delivering people-centred care has been boosted by the success reported in the Realising the Value programme.

The quick guide covers preparatory work, how to ensure good quality data and how the PAM® can ensure that plans for services and support are tailored to an individual's needs.

The full version of this guide is available from the Patient Activation: Knowledge, Skills and Confidence collaboration platform[6].

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[3] https://www.england.nhs.uk/ourwork/patient-participation/self-care/patient-activation/pamlearning/

[4] https://www.england.nhs.uk/ourwork/patient-participation/self-care/patient-activation/licences/

[5] http://www.nesta.org.uk/publications/realising-value-ten-actions-put-people-and-communities-heart-health-and-care

[6] https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2Fpamn%2F

Next steps

Supporting people to have the knowledge, skills and confidence to manage their health and wellbeing should become the normal way of working across the NHS. NHS England is supporting the use of PAM® through:

- Provision of PAM® licences to key NHS change programmes and other organisations ;
- the establishment of local networks;
- the creation of communities of interest through the Future NHS Collaboration Platform where organisations can share resources and exchange ideas;
- maintaining a bank of exemplars and case studies;
- pooling knowledge from evaluations.

Additionally, a series of training webinars will be available to sites implementing the PAM® to address common challenges, and further individualised support is being provided. Further details of these webinars can be found on the Patient Activation Knowledge, Skills and Confidence collaboration platform.

To develop the learning around its implementation, NHS England invites organisations using the PAM® to share:

- any issues encountered and how these were solved;
- materials which have developed that may be useful to others;
- ideas of the types of support required from NHS England to ensure the correct support is provided to local areas to implement PAM® effectively;
- the successes from implementation and how these were celebrated;
- any suggestions for improvement, and whether or not these have been tried and tested.

More information about patient activation is available on the NHS England website and the Patient Activation team can be contacted at england.patientactivation@nhs.net.

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[7] https://www.england.nhs.uk/ourwork/patient-participation/self-care/patient-activation/licences
[8] https://future.nhs.uk/connect.ti/pamn/
[9] https://www.england.nhs.uk/ourwork/patient-participation/self-care/patient-activation/

What is the Patient Activation Measure (PAM®)?

The PAM® is a validated, licensed tool that measures people's knowledge, skills and confidence (referred to as 'patient activation') in managing their own wellbeing. It is expected that by understanding a patient's activation level, care can be planned appropriately with the individual, leading to improved wellbeing and fewer episodes of unplanned and emergency care.

The PAM® is a validated questionnaire comprising 13 questions and is licensed from Insignia Health LLC. The responses match the respondents to one of four levels of 'activation', each of which reveals insight into a range of health-related characteristics, including behaviours and outcomes.

The PAM® should be used in conjunction with care and support planning and a range of interventions to support self care.

Level 1	Level 2	Level 3	Level 4
Disengaged and overwhelmed	Becoming aware, but still struggling	Taking action	Maintaining behaviours and pushing further
Individuals are passive and lack confidence. Knowledge is low, goal-orientation is weak, and adherence is poor.	Individuals have some knowledge, but large gaps remain. They believe health is largely out of their control, but can set simple goals.	Individuals have the key facts and are building self-management skills. They strive for best practice behaviours, and are goal orientated.	Individuals have adopted new behaviours, but may struggle in times of stress or change. Maintaining a healthy lifestyle is a key focus.
Their perspective: "My doctor is in charge of my health".	Their perspective: "I could be doing more".	Their perspective: "I am part of my health care team".	Their perspective: "I am my own advocate".

Increasing level of activation →

Figure 2: PAM® activation characteristics by level

Source: Adapted from Insignia Health PAM® practice manual

Why is knowing the PAM® score useful?

- Services and support can be tailored to 'meet patients where they are'. The right intervention can help to increase their knowledge, skills and confidence and so, improve their ability to look after their wellbeing;

- Higher activation levels correlate to healthy behaviours, better health outcomes and experiences of care, and fewer episodes of unplanned and emergency care.

Where PAM® can support self care

Person-centred care is based around developing a patient-professional relationship that seeks to understand and value equally the perspectives of both parties. The process of changing the relationship begins with the initial conversations clinicians and others have with patients. The initial conversation includes a systematic exploration of the patient's readiness to begin to take charge of their health. This exploration paves the way for the joint creation of an individualised health plan, reflecting the patient's preferred outcomes and agreed timescales and measures. Some of these measures may be biometric indicators, for instance lowered blood pressure, while others reflect the patient's own goals and desired outcomes, for instance, effective use of public transport to maintain a social life for a patient no longer able to drive a car. Adding PAM® data introduces an evidence based and consistent measure to help further inform this process.

Evidence shows that around 25% of people have the highest level of activation (level 4). This indicates there is a lot of scope to improve levels of activation in a population, especially in the lowest levels (levels 1 and 2), where the greatest gains can be made . Services need to target resources at those most in need; at the same time providing more appropriate support to sustain those who are already actively managing their condition. During the evaluation of the learning set, staff commented that those with higher levels of activation can often benefit from lighter-touch care and that this would release time and resources for those at lower levels. However, there were some concerns that those at lower levels were also the hardest to reach, which meant that they were less likely to engage with the PAM®.

[10] http://www.yearofcare.co.uk/

[11] NHS England have produced resources and guidance for personalised care and support planning: https://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/ltc-care/; and https://www.england.nhs.uk/ourwork/patients/patient-participation/patient-centred/planning/

[12] Collins, A. (2014) Measuring what really matters: Towards a coherent measurement system to support person-centred care. London: Health Foundation. Available at http://www.health.org.uk/sites/health/files/MeasuringWhatReallyMatters.pdf

[13] Hibbard, J. and Gilburt, H. (2014) Supporting people to manage their health: An introduction to patient activation. London: Kings Fund. Available at https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf
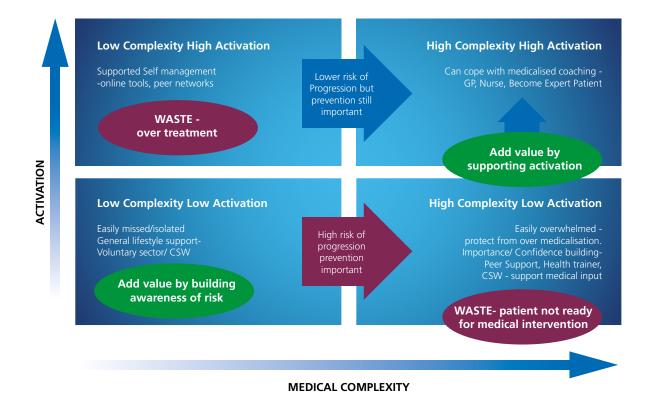
Figure 3: Dr Ollie Hart, NHS Sheffield CCG at The Kings Fund event, 27 April 2017

Ten steps towards implementing the PAM®

The PAM® is a validated, licensed tool that measures people's knowledge, skills and confidence (referred to as 'patient activation') in managing their own wellbeing. It is expected that by understanding a patient's activation level, care can be planned appropriately with the individual, leading to improved wellbeing and fewer episodes of unplanned and emergency care.

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The PAM® should be used in conjunction with care and support planning and a range of interventions to support self care.

1 **Identify need**

- Which patients are we targeting?

- What improvement in activation levels are we aiming for?

- What would be the impact if patients had higher levels of knowledge, skills and confidence?

- What can we put in place to influence patients' levels of activation?

2 **Involving people and co-production**

Workforce engagement	Patient engagement
Engage senior managers and ensure staff are kept informed and engaged. Aim to provide (as a minimum): • a briefing, and question and answer sessions for all the workforce using the PAM® • clarity on who is responsible for particular elements of PAM® implementation • lists of tasks, with 'how to' sheets for those who are responsible for particular actions.	People's understanding of why they are completing the PAM® influences how honestly they answer it. Services should provide an information sheet that covers: • what the PAM® is, what it does, and how its data will be used • who will be targeted and why • what the benefits are for patients and staff • how it can improve outcomes for patients.

3   Clarify the reason for its use

To help engage staff and patients, be clear early on about why you are collecting PAM® data, what it measures, and how it can help support patients. Developing a logic model through a workshop engaging stakeholders and patients may help with this. The process may also alert you to likely sources of support and resistance.

4   Develop options for supporting self care

Knowing a patient's PAM® score can help ensure that care and support planning is tailored to the individual. To tailor support, you will need a range of services suitable for people at different levels of activation.

5   Micro-planning

To understand what is required to administer the PAM® successfully, it is a good idea to map the processes involved, both from a patient and from the practitioner's perspective. It is useful to consider:

• At what point do we start tailoring for patient need?

• What options can we offer?

• How will we know that the chosen option is making a positive difference?

People with the lowest levels of activation are likely to benefit most from services tailored to their needs.

6 **Use the process map to identify resources needed**

Training	IT integration	Ongoing costs
• Proper staff training is essential. As a minimum, two people trained in administering the PAM® and with knowledge of the practice system are required. • Trained health coaches will be needed if the PAM® is being used as a tailoring tool.	• It will vary depending on the system – the essential requirement is for additional coding to allow entry of the PAM® scores into your IT system. • Answers to individual questions in the PAM®, as well as the overall level, form the basis of the tailoring conversation with the patient. • There should be some means of connecting PAM® scores to a patient's clinical condition(s), risk scores and a record of attendance at the planned intervention.	• Identify who will take overall ownership of PAM® as part of their job plan, even if the scale of implementation is small. • Staff training to administer PAM®, and retraining costs in the event of staff turnover. • Identify staff to input data (and assure quality); and to send correspondence to patients. • Costs of commissioning and implementing the intervention(s) but these can help to achieve financial and wider social benefits.

7 **Complete your implementation plan**

Use the information and insight gathered in the previous steps to produce a plan that is viable and supported by other people in your organisation. You can base your implementation plan on your proposal also, but it should contain:

• what using PAM® well looks like for individuals and staff;
• a timeline;
• resources;
• roles;
• activities/tasks assigned to specific staff members;
• monitoring and evaluation arrangements.

8 Provide ongoing support

To get the most out of using the PAM®, you will need a support mechanism that is both general and specific. There will be common needs, but individuals and teams may also experience issues that are unique to them. Practices tend to benefit greatly from sharing experiences and having the opportunity to explore options and share success. You can do this through the Patient Activation: Knowledge, Skills and Confidence collaboration platform.

9 Plan continuous monitoring and evaluation

Monitoring and evaluating the implementation is essential to understand:

• the delivery of the PAM® project (e.g. the efficiency of the delivery model; fidelity to original project plans);

• the outputs of the PAM® project (e.g. the number of licences, patients, practices, sessions delivered);

• the PAM®'s impact and outcomes (e.g. the effectiveness of the project in achieving desired outcomes).

10 Be prepared to support healthcare professionals in the implementation

Healthcare professionals and patients may need support with the implementation of the PAM®. Some concerns for healthcare professionals may be simply about change in general, but others could be specific to the PAM® itself such as a misunderstanding of the concept or its effectiveness.

Collecting PAM® data

Standardise administration

The way the PAM® is administered is known to affect the results and its subsequent usefulness. It is worth investing some time in getting this process right. It is important that the process is:

- Standardised;
- Routine;
- Timely;
- carried out by trained staff;

- recorded;
- part of a reliable service;
- unadulterated;
- quality controlled.

Different methods of administering the PAM®

There are many ways in which the PAM® can be administered but there are some strong indications on what to do and what not to do. A one-to-one mediated session provides the best chance for patients to fully understand the questions and produce the most consistent responses. This can be done face-to-face or on the telephone. It provides an opportunity:

- for the patient to clarify the PAM®'s purpose or the meaning of questions;
- for the administrator to provide useful feedback to the patient and to set expectations about future data collection.

Other methods may be in a group situation (e.g. group clinics) or through the post. Further detail is available in Module 3 "Collecting PAM® Data" in the full version of this guide.

Training staff

Whatever method is used to administer the PAM®, staff must be properly trained. Training should cover:

- Insignia online training (available at: http://training.insigniahealth.com/login.aspx);
- how the PAM® works and its purpose; the importance of keeping to its wording;
- how to introduce the PAM®;
- how to address language and literacy issues;
- how to respond to a patient's needs;
- all of the possible influences on patients completing the questionnaire and their impact;
- how staff can be supported to deliver the PAM® within routine workflows.

Timing and frequency of data collection

Insignia Health recommends that the PAM®:

- should be administered as early as possible in the coaching process; and repeated every six months. If there are frequent and/or intense patient interventions, possibly more frequently;

- should not be administered within two weeks of a new diagnosis or life event; or more than four times a year unless there are frequent and intensive interactions with the person.

Analysis

Converting responses into PAM® scores and the four levels of activation is controlled by Insignia and is part of the licence agreement with NHS England. The scores are recorded on an interactive spreadsheet provided by Insignia and the results are then entered onto the patient record. Keeping the original response sheet (or scanned version) is useful as individual answers may be used as prompts in coaching sessions.

Information governance

For any data collection exercise involving personal data to be lawful, you must establish a clear legal basis for its use and inform patients about its proposed use. Collecting data for one stated purpose and using it for another is unlawful and unethical. Your information governance lead can support you to manage these risks.

What to do with the PAM® results

The decision to share the PAM® score with patients routinely will depend on the context in which it is being used. Scores must always be shared with patients who wish to know their results as part of the ongoing conversation. The purpose of the measure is to help ensure that services and support is tailored to the individual's needs. Examples of how the PAM® score can help to tailor services and support include:

- patients with low activation could:
    - o be given longer appointment times and more frequent follow up appointments;
    - o receive self management education and access to wider support opportunities;
    - o be encouraged to make small behaviour changes to help build their confidence;
- patients with high activation could be given more choice around attending routine follow up appointments and make greater use of telephone consultations.

Using the PAM® in commissioning

Though the PAM® was not developed as a commissioning tool, it can play a role in assessing and developing services through encouraging the provision of personalised care. It can positively influence the design or choice of interventions that meet the needs of individuals and/or populations that are most at risk or who might benefit the most. Changes in activation scores/levels can help demonstrate timely evidence of the effectiveness of the commissioned intervention(s). The PAM® can also be used across health and social care, providing a useful measure to promote integration of services.

See Module 5 in the full version of the guide for further information on using the PAM® in commissioning.

Get in touch

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