

The NHS logo, consisting of the letters 'NHS' in white on a blue rectangular background.

Wessex
Clinical Networks

The Patient Activation Measure

A photograph of a healthcare professional and a patient in a clinical setting, overlaid with a semi-transparent circular graphic. The healthcare professional is on the left, wearing a light blue shirt, and the patient is on the right, wearing a purple top. They are both smiling and looking at each other. The background shows a window and some office equipment.

A tool for facilitating supported
self-management in long term conditions

Guidance and lessons
learnt from across Wessex



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How many times have you attended meetings looking to redesign patient pathways to meet the challenges posed by an aging population with increasing frailty? And how often have you heard reference to implementing self-management, patient centred care, expert patient programmes, patient empowerment...? Yet has your individual patient contact or commissioned service fundamentally changed to incorporate these ideals?

If, like me, your answer to this is 'no' or 'only partially', then maybe the Patient Activation Measure (or similar tools) can offer you something. Whilst 13 simple questions cannot cure all of the challenges faced by people with long term conditions, they can help guide and reframe the nature of our conversations as commissioners, clinicians, managers and patients within the NHS. Taking the time to understand how capable and ready people are to manage their complex health needs on a societal level, can help ensure our limited resources are commissioned in the most effective manner. It can also enable individual clinicians to offer treatments which are most appropriate and personal for each person.

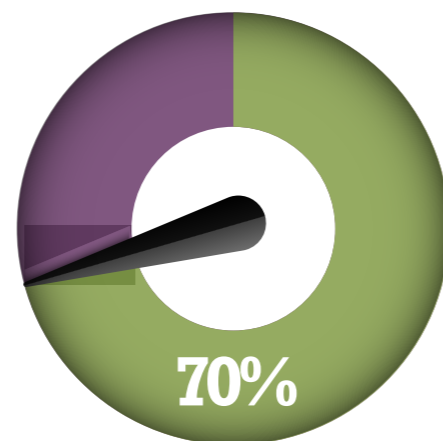
Following the progress of the pioneering teams in this project has re-enforced the reality that behavioural change must first start with me as a clinician if I am to help the people I see in clinic to effectively self-manage their complex needs. So I hope that if like me, you aspire to improve your practice, management or commissioning of services you will find the information and lessons learnt within this booklet a useful stepping stone to delivering more meaningful, individualised and effective care.

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Supported Self-Management

The NHS spends 70% of its budget supporting people living with long term conditions (LTCs) – a staggering statistic – and yet many people don't feel that they have the knowledge, skills and confidence to manage their own health and wellbeing successfully.

Supporting people to take an active role in managing their health is a core part of current health agendas. But how do we really know if people are engaged with understanding and managing their health? And how can we best support the 1.5 million people with LTCs to live more independently?



What is Patient Activation and why is it important?

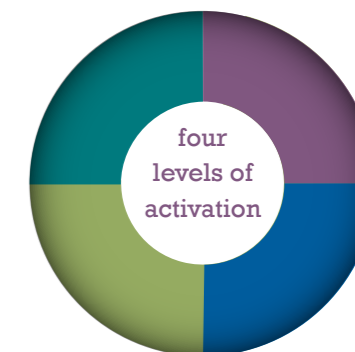
Patient activation describes the knowledge, skills and confidence a person has in managing their own health and healthcare. It is a good predictor of health outcomes, and can be raised through targeted interventions.

The concept of patient activation is linked to the principle of person-centred care. It enables the delivery of personalised care that supports people to recognise and develop their own strengths and abilities. Supporting people to develop capability to manage their own health and care by giving them information they can understand and act on, and providing them with support that is tailored to their needs, underpins the concept of patient activation¹.

What is the Patient Activation Measure (PAM)?

The PAM provides a simple, evidence-based mechanism for establishing the capacity of individuals to manage their health – and then using that information to optimise the delivery of care².

It is a validated, 13 point questionnaire with multiple choice answers. It measures how activated an individual is. This enables generation of an activation level for that individual, at that point in time. 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 knowledge and confidence in managing their health.

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.

Adapted from Hibbard and Gilbert (2014) Supporting people to manage their health. An introduction to patient activation. The Kings Fund.

Knowing someone's activation level provides an insight that can help **health and social care professionals** to:

- identify interventions and options that are appropriate and realistic for each individual (tailoring)
- measure the impact of these interventions over time (outcome measurement)

Mapping activation levels across populations can help **commissioners and service providers** to:

- specifically put services in place that meet their population needs – targeting and allocating resources that are proportional and most effectively facilitate self-care for each patient group.

Why use the PAM?

- It is a quick (3-5 minutes) and easy to use evidence based intervention. Changes in levels of patient activation are positively correlated to health behaviours, clinical outcomes, patient experience and reduced health care costs²

¹ NHS England <https://www.england.nhs.uk/ourwork/patient-participation/self-care/patient-activation/pa-faqs/> Accessed March 2017

² Hibbard and Gilbert (2014) Supporting people to manage their health. An introduction to patient activation. The Kings Fund.

A Practical Guide to using the PAM...

Due to licencing restrictions, we cannot reprint the PAM within this document. However, you can find copies of the PAM in the Kings Fund document – Supporting People to Manage their Health [details can be found at the end of this guide].

Based on the experiences of the pilot teams in Wessex, we recommend....

Step 1: Prepare!

- The PAM is about more than filling in a form and generating a score. A number is just a number without the intelligent thought and interpretation that goes with it! But, used well, it is a potential enabler to better conversations, different ways of thinking, and more individualised support for people with LTCs.
You need to get your team on board. Learn about patient activation to create a shared understanding, and reflect with your team. Four key questions to think about:
 - What do you [the team] understand by the term supported self-management?
 - What do you [the service] already do to support self-management with your service users?
 - How do you [clinicians] know if this is effective?
 - Could the PAM be used within your service, and how will you know if it has been worthwhile?
- **The PAM is a commercially licensed tool** – contact Insignia Health for further details - www.insigniahealth.com/products/product-licensing. You will need access to PAM licences before proceeding.
- PAM scores are generated through a Microsoft Excel document which requires internet access – check with your IT department to ensure access will be possible (firewalls may need removing).
- As part of the licensing agreement, services using the PAM are expected to contribute to a national database. Information submitted to this database is not identifiable; however, you should ensure that this conforms to your organisation's Information Governance requirements.
- **Plan and agree how you will use the PAM** – who, how, when?

Step 2: Delivery

- The PAM can be delivered in different ways – local services have tried administering via email, over the telephone, as a paper survey completed independently by the patient, or as part of a face to face conversation with a healthcare professional.
 - We have found the PAM to be most useful when used as part of a **face to face discussion**. This enables the PAM to shape a conversation between the patient and healthcare professional, giving richer insights and allowing potential actions to naturally develop.
 - **Before using the PAM, you should inform the person that:**
 - There are no right or wrong answers
 - The PAM will help you (the clinician) to personalise the support you offer that person
 - It will take just **3-5 minutes** to complete
 - Responses will be held in confidence
 - Scores from PAM will contribute to a national database, but this remains entirely unidentifiable.
 - Use the PAM calculator to generate a PAM score and level. Remember, this is a score for that individual, at that point in time.
 - Document the score in your clinical records.
- More detailed information about PAM administration can be found in the PAM Practice Manual, which is supplied as part of the licence agreement (Insignia Health, 2016)

Stage 3: Action

- Self-management interventions can be **tailored**, based on an individual's PAM level.
- Use the score, level, and the individual answers to talk to the person about their priorities. Support should then be offered in a way that is appropriate to that person's current level of activation.

Tailoring for Patient Activation Level

Level 1: Foundation

Support the person to:

- Develop basic knowledge, self-awareness and confidence
- Self-monitor their current behaviour and how this makes them feel
- Jointly agree small, short term (for today) action steps
- Understand their role in their own health – building understanding that their role is vital; it is not the responsibility of others.
- Think about the here and now – how does what you do today make you feel today?

Level 2: Developmental

Support the person to:

- Increase knowledge and skills
- Start making small but meaningful changes – one step at a time
- Ensure the person has all of the tools necessary to achieve this change
- Connect their health and choices to immediate problems, not long term goals.
- Start to identify any causes of stress, and build problem solving skills for managing stress and condition symptoms.

Level 3: Affective

Support the person to:

- Initiate new behaviours
- Increase their knowledge and skills in relation to their condition(s)
- Set bigger, medium term goals
- Connect choices to long-term outcomes – understanding that positive changes have long term benefits
- Problem solve – when a new goal hasn't been achieved, reflect on this together
- Start to establish routines for key behaviours.

Level 4: Optimal

Support the person to:

- Maintain behaviours and techniques
- Not only to set goals and actions, but to identify potential barriers (and how to overcome them).
- Develop problem solving skills – what to do in certain circumstances.
- Sustain healthy behaviours in times of stress or challenge.

Adapted from Hibbard and Gilbert (2014) Supporting people to manage their health. An introduction to Patient Activation. The Kings Fund.



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SELF-MANAGEMENT
 could you be doing it better?

Examples of the PAM being used in Wessex

PAM has been used by 5 very different teams across Wessex

Specialist Community Diabetes Team, West Hampshire:

This service offers specialist support for people living with diabetes throughout the pathway of care, whenever they need it. The PAM was trialed with patients with Type 1 diabetes, on the telephone, in the nurse lead clinic, and before the education sessions.

What they have found:

- The tool was difficult to use as part of a telephone consultation
- The tool was easy to use face to face; receptionists gave out the questionnaire in the waiting room, and clinicians were able to follow up in clinic.
- The PAM seemed to be a good reflection of where patients felt they were in their own self management

iCOPD, Southampton:

This service offers an integrated approach to supporting people with COPD in community settings, as well as the acute hospital. The team is multi-professional.

The PAM was used in two clinics at Bitterne Health Centre and Royal South Hants Hospital.

What they have found:

- The PAM may be helpful in determining which self management tools are useful at any particular time.
- The PAM was completed with ease by patients while waiting to go into each clinic. It prompted some specific conversations around health management during the clinic.
- evidence to ascertain the correct level to target self - management interventions and to assess the interventions we already have in place.

Sexual Health Services, Wessex:

This is a specialist team, commissioned by NHS England to support people living with HIV across the whole of Hampshire. The PAM was introduced as part of a CQUIN in June 2016. The team underwent NHS England training with Insignia. Over 300 licenses have been used to date.

What they have found:

- The tool was straightforward to use.
- The team plan to review what good interventions look like for each activation level in their 3 locality areas.
- They have plans to audit the PAM score against behaviour of those clients to triangulate the activation levels.

Community Occupational Therapy Housing & Adaptation Service, Isle of Wight:

This service enables people to maintain, improve, or restore their occupational performance. This is achieved by supporting people to improve their own health and wellbeing by assessment of need, and possible use of interventions such as design and construction methods, assistive technology and activity modifications. The service also provides advice, guidance and signposting to people who are experiencing difficulties with activity participation.

The Service piloted the PAM in their new screening clinics. What they have found:

- The Clinician Supported - PAM (CS-PAM) demonstrated the varied beliefs and attitudes of the clinical team toward patient activation. This led to some reflection regarding the team's confidence, attitude and skill, with regard to supporting people to take an active role in their health. The CS-PAM is a useful tool, which can help clinicians to consider their role in patient activation.
- A local written information and consent form given with the PAM, provided the patient further information and met local information governance needs.

Parkinson's Disease Nurse Service, South East Hampshire:

This is a community based service which provides specialist assessment, support and monitoring to people with Parkinson's Disease and their families. The service delivers nurse-led clinics, supports Consultant-led clinics, and provides home based intervention. People with Parkinson's Disease are reviewed at regular intervals, but can also request a review at any point.

The Parkinson's Nurse Service piloted the PAM in one of their weekly clinics, and during home visits. What they have found:

- One-size doesn't fit all - it was not a useful tool for people at the more advanced disease stage.
- The PAM is potentially most useful if used right at the beginning, when patients are newly diagnosed; ensuring that interactions, information and interventions are tailored right from the start.
- Administrating the PAM face-to-face provided a useful structure for discussing self-management challenges and approaches.

Dorchester

Bournemouth

Ringwood

Lymington

Southampton

Newport

Basingstoke

Farnham

Petersfield

How might Patient Activation influence my practise, as a clinician?

Patient Activation focuses on giving patients the skills, knowledge and confidence to be active in their own health care. Clinicians must work in partnership with patients to support and develop this active role. If patients are to have ownership and a sense of control over their health, then clinicians must take a more long-term, individual approach, which helps patients to gain this ownership. This may represent a significant shift in the perceived role of many clinicians³

How can I understand my own beliefs around Patient Activation?

The Clinician Support for Patient Activation Measure (CS-PAM) is a tool which assesses how the clinician views the patients' role in the care process³ – it assesses how 'ready' clinicians are to support Patient Activation.

How ready were the Wessex clinicians in supporting Patient Activation?

Across Wessex, the clinicians we surveyed were evenly spread along a spectrum from low to high, in the views they expressed around the patient's role in care. In other words, whilst many clinicians were supportive of people taking an active role in their own health and care, an equal number were less so. Whilst this is just a snapshot from Wessex, the findings are not dissimilar from a large national survey using the CS-PAM⁴

As clinicians, what are our next steps towards patient led care, self-management and Patient Activation?

If we are to truly shift towards a more patient led approach, promoting and supporting individuals to have control of their health, then we must first start with understanding, and if necessary changing, the mind-set and attitude of clinicians. We encourage you to reflect with your colleagues – what are your attitudes and practices toward supporting people to take a more active role in their health; and do you have the confidence and skills to do this effectively? The CS-PAM is a useful tool to support this reflective process. Can you be an inspiring facilitator of supported self-management?



SCOT Analysis

You can use this table to think about how you currently support people to be more independent in managing their health.

Strengths	Challenges
Opportunities	Threats

³ Hibbard, Collins, Mahoney, Baker (2010) The development and testing of a measure assessing clinician beliefs about patient self-management. Health Expectations, 13,65-72

⁴ NHS England (2015) How much do clinicians support patient activation? Person Centred Care Team, NHS-E, London.

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