The Strategy Unit.

Person-Centred Intelligence (PCI)

Perspectives on patient activation and Patient Activation Measure (PAM) – including case examples





About this guide

- This guide forms part of the Strategy Unit and Ipsos MORI's series about person-centred intelligence.
- This guide presents perspectives and case studies from a range of stakeholders on 'patient activation' focussing more specifically on the implementation of Patient Activation Measure (PAM) as a high profile measure of patient activation.
- It supports a further guide, which explores the concept of 'patient activation' in particular findings from published literature.
- Nine interviews were conducted with a range of stakeholders working in/with the NHS (full list in appendix A) implementing measures of patient activation.
- The aim of the interviews was to explore real-life use of PAM to inform practical guidance (<u>interview topic guide can be found in appendix B</u>).



What is patient activation?

What is the Patient Activation Measure (PAM)?

Why use PAM as a measure of Patient activation?

Implementation factors

Evaluating PAM & case studies

'Patient Activation' is described as...

"... about somebody's **knowledge, skills and confidence to selfmanage** health and wellbeing. It's about having the knowledge, so they are confident enough to have that behavioural change. It's not static"

"... a concept in health which enables people to become more in **control of their health**. Proxy measure for self-management of health. It's activating people (in their health), enabling them to make better health choices"

"... how activated and motivated a person is. It goes back to the ability **to put** skills into practice that they have learnt"

What is the Patient Activation Measure (PAM)?

PAM is a tool used to measure Patient Activation, focussing on; **knowledge, skills and confidence.** Interviewees categorised uses of PAM into the following 3 categorises: .

Tailoring tool	Used to tailor the conversation between clinicians and patient to delve into "what matters to the patient and assessing how they can potentially manage their health and wellbeing in a different way" by knowing how to "position the conversations." "If used in it that way, it is a powerful tool to have the right conversations with the right patients at the right time, to help them make a difference."
Outcome measure	Measures outcomes following a programme / intervention to assess its impact and how 'activated' a patient is. This is useful from a healthcare and commissioning point of view, for functions such as; "service evaluations to show the value / impact of interventions and to use to support an evidence base on whether something is worth investing in."
Segmenting tool	"It can be used to work out those who require the most support vs those who are already activated and might not need as much support, knowing this helps decide what intervention to use and for who ."

Why use PAM as a measure of patient activation?

Interviewees considered PAM a good measure of patient activation as it:

- Focusses on measuring the key elements of patient activation; "knowledge, skills and confidence."
- Is a validated tool which seems "robust and well designed."
- Aids **clinical decisions making** in patient activation interventions; *"it helps us see where they are and ensure any intervention we introduce is pitched at the right level."*
- Forms part of patient activation interventions; "it's a conversation starter."
- Different agencies use their own measures "so PAM can be a shared language."
- Supports **strategic and commissioning decision making** "by stratifying the population to find out how activation levels help deploy resources."
- Goes wider than a traditional medical model, fitting in well with a move towards **social prescribing**, **personalised care**, **person-centred care and health literacy**.

However ... Interviewees also stated...

- Users should consider "its **not the only way** and needs to be done properly".
- Users should understand "it is not an intervention, it **needs to work with the intervention** to inform change in the system."
- It should not be imposed but **used only in appropriate circumstances.** There are many specialities that have condition-specific measures that already incorporate patient activation outcomes. E.g. there are many holistic measures used in mental health and similarly the British Rheumatological Society already addresses similar elements in patient questionnaires.



Implementation factors



Implementation factors

There are several key factors that need to be considered when implementing PAM.



As well as enabling successful implementation, these factors also present challenges – these are discussed in the following slides.

Several stakeholders felt implementing patient activation successfully requires a **change of culture** "You won't see immediate change. It's a behavioural concept. It's not going to happen tomorrow." "It's a cultural thing. Its about asking what matters to you? Rather than what's the matter?" "In order for PAM to work there is a mindset shift that is needed."

Patient Engagement

Key considerations for patient engagement were cited, including:



Staff engagement

Key considerations for staff engagement were cited, including:

Training	 Training on use of the tool is a start but not sufficient. Training should articulate the purpose of measuring and include practical administration. Delivery of training is best <i>"done by health care professionals who staff can relate to and share experiences with"</i>. Peer support can also support implementation. Training should be holistic in addressing how information can be used <i>"for personalised conversations and finding out what matters to patients"</i>.
Leadership / Management buy-in	 Leadership and management should clearly communicate the value of addressing patient activation and how measures will be used. Staff should be empowered to utilise the findings and develop "agency to make changes." Management should facilitate implementation through resource allocation and the necessary processes being put into place.
Ownership	 Staff should be supported to build professional capabilities, to know how to action findings of measures and patient activation interventions. Examples of impact of measures should be shared so people understand the importance. Implementation of PAM might mean changing existing professional practices, which some may find threatening to their personal and professional identity. Involve those carrying out the intervention to improve patient activation, through co-design and co-production - as they are best placed to inform delivery.
Inclusivity of all staff groups	 All staff groups should be made aware of PAM and its purpose, so they can support successful implementation. Training should be available across the board – so everyone has a good understanding of the purpose and can support the implementation in their individual functions.

Information governance and I.T systems

Key considerations for IG and IT were cited, including:

Alignment with existing systems • Electronic PAM data collection can be facilitated using proprietary tools, however these do not *"interface with (all) GP systems*." and thus scores can not be recorded on all patient records in an automated way.

Integrating systems

- Not everyone is able to access current web-based systems and PAM scores are **not linked across organisations** and thus there are challenges in sharing and potential for duplication.
- PAM scores are **not routinely shared across organisations/agencies** who may use different measures, however PAM has the potential of being a *shared language*.

Resourcing

There were two main considerations of resources discussed;

• Licenses are **commercial** and thus financial implications need to be taken into account.

Licenses

- Access to licenses can be a barrier. In some cases it has been challenging to get a suitable number of licenses for their population.
- There are instances where licenses have been made accessible as "*part of an agreement* using it for CQUIN".

Incentives

- The use of PAM can be determined by commissioning or CQUIN requirements
- Financially incentivising the delivery of PAM runs the **risk of shifting focus** from *"encouraging patient activation to delivering a quantity of measures to bring in finance".*

Administering PAM

"Data collection is difficult, it's challenging, it's really challenging. And the administration of the tool needs to be really, really thought through in enormous detail."

Key considerations for administration of PAM were cited, including:









Evaluating PAM

It was evident that it is not easy to distinguish effectiveness of PAM from the effectiveness of a patient activation intervention. *"No formal evaluation has been done on the use of PAM"* and there were several reasons cited for this:

- PAM was often **used as a conversation starter**, which meant the tool itself became a patient activating intervention.
- PAM use was not previously widespread and thus a "true matched-cohort study is not possible in most cases".
- An evaluation of PAM would concentrate on the qualitative elements, such as staff and patient experience, as a change in the PAM score would be a reflection of the effectiveness of the intervention for activating patients, and not the effectiveness of the tool.
- As "PAM doesn't have any therapeutic bearing on anything" evaluation of it has not been routinely carried out.

For these reasons, the most that can be assumed regarding PAM is that, it **indirectly contributes to the outcomes observed for an intervention**, by being an enabler of the intervention.



Case studies

Examples of the use of PAM



Case studies

The following slides present examples of the implementation of PAM. They discuss the practicalities and effectiveness of the implementation, as well as describing lessons learnt during the process.

Intervention / Programme	System	Description	
<u>Self management –</u> <u>Education</u>	Penny Brohn UK	PAM was used to measure activation of patients who attended a 'Living Well with the Impact of Cancer' (LWC) course.	
<u>Diabetes self</u> <u>management</u>	The Slough Medical Centre, Sheffield CCG	The practice was incentivised through QOF mechanism to carry out care plans and administer PAM as part of a type 2 diabetes self management project.	
<u>Self-management -</u> Live Well Wakefield	South West Yorkshire Partnership NHSFT	As part of a self-management course delivered by the Trust, the 'Live well' team provided support to help patients manage their long term health conditions and PAM was used in the evaluation of the course.	
Personalised care planning for COPD patients	Solent NHS Trust, Southampton	The Trust used PAM as part of a CQUIN from the CCG for person- centred care planning.	
<u>Community</u> <u>Pharmacy Future</u>	West Yorkshire	A community pharmacy service that focussed on agreement of goals between the pharmacist and patient during multiple consultations over 12 months used PAM in its evaluation of the service.	
Enhanced Primary Care and Complex Care Hub	Symphony project, South Somerset Vanguard	The vanguard used PAM to measure the impact of two new models of care: <i>Complex Care Team and the Enhanced Primary care</i> .	

The challenge

Penny Brohn UK (PBUK), an integrative cancer support charity, developed the 'Living Well with the Impact of Cancer' (LWC) course using a **"whole person approach" to help support people suffering with cancer.** PAM was perceived as a useful measure, as it was related to activating people and self-management, which aligned well with the 'living well' courses delivered at PBUK.

The approach

- The LWC is a motivational 15-hour group intervention, which aims to promote long-term health and well-being and facilitate self-management of health for adults living with any type of cancer and their supporters. It involves a combination of physical, psychological, emotional and spiritual support using information, lifestyle advice, education, group support, activities, and self-help techniques. It was designed by a team of health care professionals to run alongside conventional treatment, at any stage of the cancer continuum.
- **PAM was used as proxy measure** (pre- and post-intervention) to find out whether people attending the course were enabled to live better and self-manage their health and whether the education provided had been delivered effectively.
- The average activation level for those coming to Penny Brohn UK is Level 3. PAM was administered face-to-face by course facilitators and via post or completed online by service users. A team of volunteers input data into a spreadsheet.

The impact

• In the evaluation, PAM data showed that people had a **significant shift in their "activation" scores** six weeks after the course. This indicated that people are potentially more able to self-manage their health after the course. 86% of people reported they were more able to self-manage their condition. People reported that self-management incoroporated key themes of diet, exercise and stress-management techniques.

- **System incompatibility** was an issue, as using the US version of PAM led to increased security requirements and the lock down of data. Additionally the spreadsheet used did not recognise missing data which impacted on the overall PAM score.
- It was felt that **PAM should be integrated into interventions** that will have a demonstrable impact and are relevant.
- The questionnaire was felt to be quite wordy for patients who questioned the purpose, as they felt it did not have a bearing on care. It was suggested that PAM was not person-centred, because some of the questions were not relevant to some people and failed to be individually tailored to the person answering.

Diabetes self management (The Slough Medical Centre, Sheffield CCG)

The challenge

A five year person-centred programme was commissioned in Sheffield, where **45 GP practices were incentivised through the QOF** mechanism to **carry out care plans and administer PAM** with a predeclared proportion of the population. This approach was then made more flexible, leaving it to practices to decide their target population, what would be the most useful and have the most impact in their system. The Slough Medical Centre Practice used PAM as part of a type 2 diabetes self-management project.

The approach

- The practice **used PAM to segment medically complex diabetic patients** into four quadrants (<u>see next slide</u>). It was used as decision making tool to tailor health coaching for patients with diabetes to build their self-management capabilities. Depending on where they sat on the quadrant, appropriate wider support was provided and targets for that person's diabetic care were produced.
- Healthcare professionals were provided with training and support via virtual support team on; motivational interviewing and how to administer the PAM effectively.

The impact

- **PAM was felt to be a lever for patient activation**, however there were some patients who did not engage with it. The results from the pilot showed that 8% of people refused/ did not respond to three invitations for an annual review.
- The **feedback from patients was positive** and they felt this was an appropriate and acceptable model to pursue. Some people highlighted the value of an appointment to help 'maintain their motivation'. However, they acknowledged that this could be seen as a lower priority in a system under strain.



MEDICAL COMPLEXITY

- **1.** Low medical complexity, high PAM scores: Treated with a light touch often via a letter from the practice encouraging them to carry on doing what have been doing.
- **2. High medical complexity, high PAM scores:** invited into the practice for a review with a doctor or a nurse the high PAM scores suggest they will respond to a more medicalised approach.
- **3.** *High complexity, low activation:* Low activation suggests people might be overwhelmed with other life issues. It is assumed that they are more likely to benefit from non-medical support, with the option to see a nurse or doctor later if they choose.
- 4. Low complexity, low activation: Focus on prevention and health literacy.

- Accessing licenses and registration was an onerous task and should be planned well in advance.
- The PAM online survey has no interface and linkages with GP systems – so results could not be easily accessed and shared.
- Some healthcare professionals perceived PAM as an additional task and found it timeconsuming. A shift in mindset is needed towards one where patients are involved in decisions around healthcare.
- Flexibility of use was crucial to providers engaging with PAM – though allowing them to identify the cohort to use it with led to small numbers.
- **Delivery of training** needs to be by someone that providers can relate to, preferably by a clinician with experience of using it.

Self-management (Live Well Wakefield, SW Yorkshire Partnership NHSFT)

The challenge

In 2017 Wakefield CCG commissioned a **self-management course** at SW Yorkshire Partnership. The 'Live well' team at the Trust provided support to help patients manage long-term health conditions. PAM licenses were purchased for **programme evaluation**.

The approach

- The self-management programme is a 6 week course for people over 18 with long term conditions (physical or mental). The course
 is delivered in various community venues and referrals are taken from wider range of public sectors, including NHS healthcare
 professionals, job centre, or self referrals. The course is structured and developed by a multidisciplinary team and the content is
 evaluated, reviewed and quality assured every 5 years.
- PAM is **administered with patients before and after they attend the course**, for evaluation purposes. The PAM data is then sent to Public Health England for analysis, who provide information on the effects of the programme on Patient Activation levels.
- PAM is administered by the self-management team (including a nurse, support worker and a group of trained volunteers who are
 also experiencing a long term condition). No medical advisc is given whilst administering the PAM.

The impact

- 62% of people had improved their PAM score, 16% maintained their score, and 22% reduced their score within 6 weeks.
- The continuation of the programme depended on **patient feedback**, thus it allowed patients to feel they were contributing and helping with sustaining the programme. Patients were able to contribute to the evaluation process and improvement of the service via PAM.
- It was found that having people with a long term condition deliver the programme put patients at ease.

- The **questions were not always clear** for patients and sometimes required further explanation, support and time to complete. Initially there was debate around the best time to administer the PAM. The team found it made little difference.
- Steps must be taken to ensure that it is used as **more than an evaluation metric**, it was important that patients and healthcare professionals understood its intent and purpose.
- The **personalised approach** adopted made it feel aligned with the person-centred agenda, as the PAM consisted of statements as opposed to questions. Patients responded well and felt their views were considered.
- Additional administrative support was required to input data; those most familiar with the measurement were best placed to do this task.

The challenge

Solent NHS Trust were offered a **CQUIN for person centred care planning** from their CCG. The Trust thought of various ways of making person-centred care planning measurable, achievable and effective. They bought licenses for PAM, as it was viewed as a validated objective test that could score patient activation effectively. The language of the questionnaire and the length of the questionnaire was also viewed as viable for a clinical consultation.

The approach

- **Patients at PAM level 1** with COPD and multi morbidities were targeted, as these patients typically felt overwhelmed and lacked the skills, knowledge and confidence to self-manage.
- PAM was **used as an outcome measure,** initially to identify baseline activation levels. These scores were used to review and refine personalised care planning and to tailor discussions and personalise the provision of support. It was also used to assess improvements in activation levels.
- The PAM tool was **embedded into clinical assessment processes**, where staff were provided with education and training on how to use it.
- The intervention was defined as personal care planning (PCP) which was structured into a series of six consultations. Patients were seen by the specialist nurse, who had extensive COPD knowledge and trained in motivational interviewing. The team developed an interactive approach to PCP, using constructs such as: "What matters to you?" The care plans were based on small goals, set by the patients themselves, including what they would like to change in their lives. For patients with low PAM scores, the tailored nurse-led intervention was either at home or in a clinical setting, on a one-to-one basis.

Personalised care planning for COPD patients (Solent NHS Trust, Southampton) -continued

The impact

- The personalised approach based on PAM saw a **change in thinking and practice** within the service including; improved conversations, shared goal setting and supporting patients to understand the different components of their complex conditions.
- There was a **noticeable improvement in PAM scores**; with an average improvement of 10 points in a patient's activation level. Some patients have been able to achieve their predefined goals. It was felt that patients responded very well, with specific outcomes and experienced improvements associated with individual goals. *E.g. A 73-year-old gentleman with severe COPD, atrial fibrillation, hypertension, stroke and heart attack, accessed the self-care programme. He was a smoker with a 72 pack per year history and had 2 exacerbations in the previous 12 months. His aim was to reduce smoking by the next consultant appointment. He achieved his goal by reducing smoking to 10 a day for 2 weeks. His PAM levels increased from 36.8 to 65.5 (level 1 to 3).*
- The team reported **feeling equipped to provide the right care, at the right time**. Staff and patients welcomed the new approach to care and assessment.
- **Staff feedback** included: "The PCP PAM approach has significantly changed the way I approach a patient consultation. Active listening...and developing a true patient-led way of working is difficult, as you want to always suggest options. But it does yield excellent patient experience and long-term health changes, because the patients really want to make that change for themselves."

- The CQUIN **allowed a dedicated person to work on the project**, push it forward and develop it. It also allowed administration support including a HCA who was able to upload scores and embed them within patient notes.
- Patients had trouble understanding the questions and sometimes required an explanation from the healthcare professional.
- Healthcare professionals felt that **clinical risks could be highlighted through administering PAM**. Therefore, it was recommended that PAM is administered by an experienced healthcare professional.
- It was felt that healthcare professionals should prioritise the goals and needs of patients to achieve outcome that are important to them, rather than what healthcare professionals view as important.

The challenge

A new **community pharmacy service** in West Yorkshire incorporated the **PAM measure into its evaluation**. It focussed on the agreement of goals between the pharmacist and patient during multiple consultations over 12 months. The aim was to determine the change in patient activation in patients participating in the service.

The approach

- The community pharmacy care plan was implemented across different pharmacies, organisations and involved a steering group that
 oversaw the project. It was also linked to general practice and was positioned alongside the support given in GP practices. It
 supported patients with a pharmacy care plan who were attending community pharmacies to help them manage their long-term
 conditions.
- **PAM was used to tailor a conversation** with patients and investigate levels of activation. It was also used to find out what was important to patients, help them through their health journey, manage medicines and reach goals they defined themselves.
- **PAM was used alongside other measures** including EuroQol EQ-5D-5L, Morisky MMAS-8. It was administered before and after the intervention. It was designed to be of minimal length in order to maximise patient engagement in the service.

The impact

- In total, 710 patients registered for the service in 42 pharmacies. Of these 378 (53.2%) had complete data from the questionnaire at baseline and follow-up.
- The mean (SD) baseline PAM score was 60.5 (14.3) compared to 65.9 (15.5) at follow-up; a significant difference (P < 0.001)
- Patients with the highest activation score (level 4) increased from 57 (15.4%) at baseline to 100 (27.0%) at follow-up.
- In terms of goals, 683 (96.2%) of patients set goals during the service, frequently setting more than one goal.

- **Training was required** to support pharmacists, staff and healthcare professionals to avoid seeing it as a tick box exercise and develop skills on how to tailor the conversation in a timely way.
- It was felt that it **takes time for people to have good quality conversations and to embed** that conversation into practice. This can be challenging given time constraints.
- There is a **danger that PAM can be used purely as a metric tool in itself**, rather than supporting conversations with patients and contributing to the personalised care agenda.

Enhanced Primary Care and Complex Care Hub (Symphony project, South Somerset Vanguard)

The challenge

As part of the South Somerset Vanguard, **two new models of care were developed; the** *Complex Care Team and the Enhanced Primary care.* A stakeholder consultation was carried out on person centred care – which suggested a need to better support people with one or more long term conditions. Interventions to tackle this included a health coaching approach to build knowledge, skills and confidence and so PAM was chosen as a **way of measuring impact**.

The approach

• The CCG set a **CQUIN of using PAM for a proportion of people with long-term conditions**. It was decided this worked better in Primary care, where person-centred approaches could be delivered effectively.

The impact

- The evaluation team attempted a matched cohort study, but PAM was not part of routine practice.
- **People using PAM found it helpful** but within primary care the health coaches work slightly differently depending on their population; e.g. in a rural area with more elderly population more time was spent doing carer PAM and probably at a stage where health behaviour change was less likely as it was more about structural change and coordinating appointments and giving information so PAM was less appropriate. In other areas where such as in diabetes, obesity and drug and alcohol services PAM was done with a focus on influencing behaviour change.
- Generally **PAM supported a positive shift in ethos** to enable a suite of person-centred approaches to patient activation.

- South Somerset had a legacy of health coaches, complex care teams and huddles that enabled greater collaboration between practices before the advent of PCNs, which supported the implementation of PAM.
- Logistical barriers were experienced in rural areas, where paper-based PAM had to be used, as electronic versions in a person's home would be unreliable. This in turn led to challenges in sharing files, making them less accessible.
- Access to PAM was dictated by funding being available for licenses and training.
- Less experienced clinicians may find PAM a more helpful guide then those who are more experienced.
- There was a perception that where PAM was easily accessible with **training** support there was greater buy-in and that where it was imposed by a CQUIN or assessment it did not work as effectively.
- Staff need to understand how **personalisation**, the long term plan, health coaching and the need for measures like PAM all fit together, in order for frontline staff to be able to navigate systems and tools.







Appendix A: Interview participants

	Role	Organisation
Ollie Hart	GP Partner at Sloan Medical Practice Founder member of the NHS England PAM Royal College GP National lead for Activation	Sloan Medical Practice Royal College GP
Tim Williams	Director	Peak Health Coaching
Ursula Clarke	Senior Programme Manager	Kent Surrey Sussex Academic Health Science Network
Helen Seers	Research and Evaluation Lead	Penny Brohn UK
Eileen Hall	Locality Support Team Coordinator/Commissioning Manager	NHS Sheffield Clinical Commissioning Group
Tracey Thornley	Senior Manager Contract Framework and Outcomes	Boots UK
Janet Watson	Live Well Wakefield self-help advisor	South West Yorkshire Partnership (NHS) Foundation Trust
Lindsay Welch	Long Term Conditions Lead Nurse and Project support officer	Solent NHS Trust
Debbie Neal	Consultant physiotherapist & Clinical Lead Therapies	

Appendix B: Topic guide

The purpose of the semi-structured interviews was to identify examples of where PAM has been implemented and to discuss the practicalities and effectiveness of the implementation and lessons learnt.

The questions addressed included:

- 1. What do you understand by 'patient activation'?
- 2. What is the value of measuring patient activation?
- 3. What is the patient activation measure and how is it used in practice?
- 4. Describe how PAM has been used in a project/pilot, in your experience?
- 5. What were the facilitators and barriers to implementation?
- 6. What unintended consequences came from implementing PAM?
- 7. How has the use of PAM been evaluated?
- 8. What lesson can be learnt / shared from the example we've discussed?
- 9. How useful do you feel PAM was as a tool for measuring Patient Activation / Person-centre care?
- 10. How do patients and healthcare professionals engage with the implementation of PAM?
- 11. What (if any) other experiences of PAM can you share that may help inform this guide?