The Strategy Unit.

Patient-centred intelligence: A guide to patient activation

The Strategy Unit and Ipsos MORI

Ipsos MORI

About this guide

- This guide forms part of the Strategy Unit and Ipsos MORI's series about person-centred intelligence.
- This guide focuses specifically on the concept of 'patient activation' – in particular our findings within the published literature. The topic has been chosen given its recent prominence within national policy.
- It is supported by a further guide, which draws together perceptions from a broad range of stakeholders who have implemented measures of patient activation.

Contents

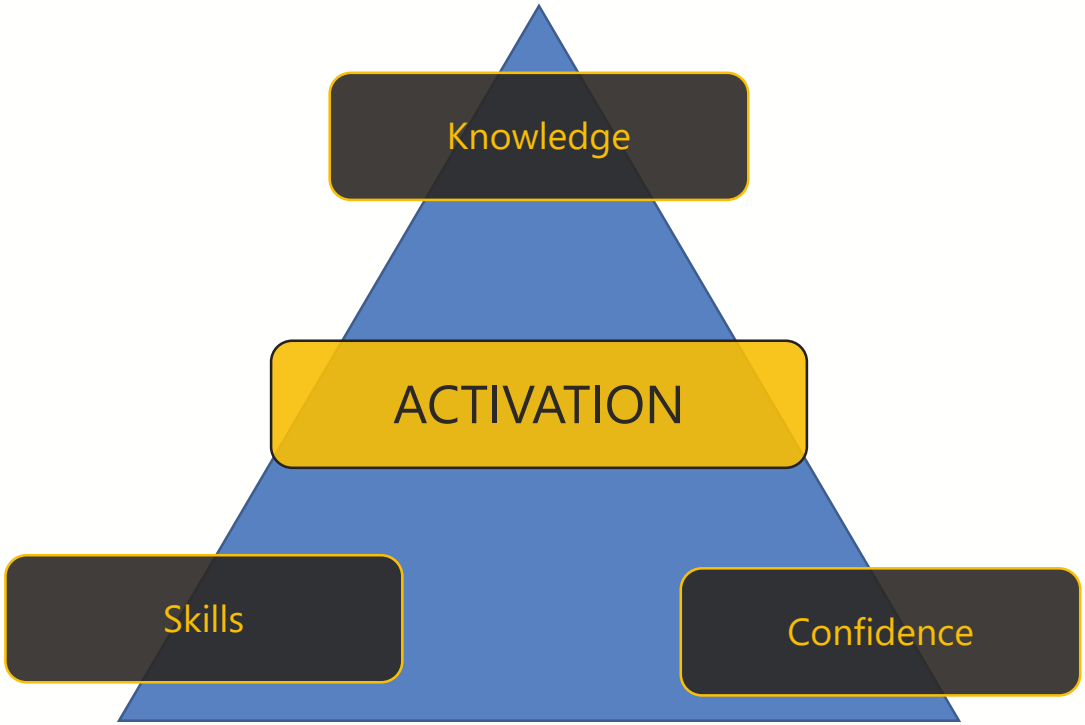
Why should we focus on patient activation?

What is patient activation?

Patient activation is *'understanding one's role in the care process and having the **knowledge, skill, and confidence** to manage one's health and health care'*. (Hibbard et al., 2004).

- Patient activation emphasizes patients' **willingness** and **ability** to take independent actions to manage their health and care.
- **Activation differs from compliance**, in which the emphasis is on getting patients to follow medical advice.
- **Activation is different to patient engagement**, however they are often used interchangeably. Patient engagement is a broader concept that includes activation.

(Hibbard and Greene, 2013)



Why is patient activation important?

Improved patient activation has been found to be associated with *better health outcomes, better care experiences and reduced use of healthcare resources* (Hibbard and Greene, 2013)

High activation

Characteristics:

- ✓ Plays an active role in staying well
- ✓ Self-manages condition when not being treated
- ✓ Confident in managing own health
- ✓ Seeks help when needs it
- ✓ Actively considers health and make more informed choices

Outcomes:

- Have higher quality of life
- More satisfied with care they receive
- Use less healthcare resources

Low Activation

Characteristics:

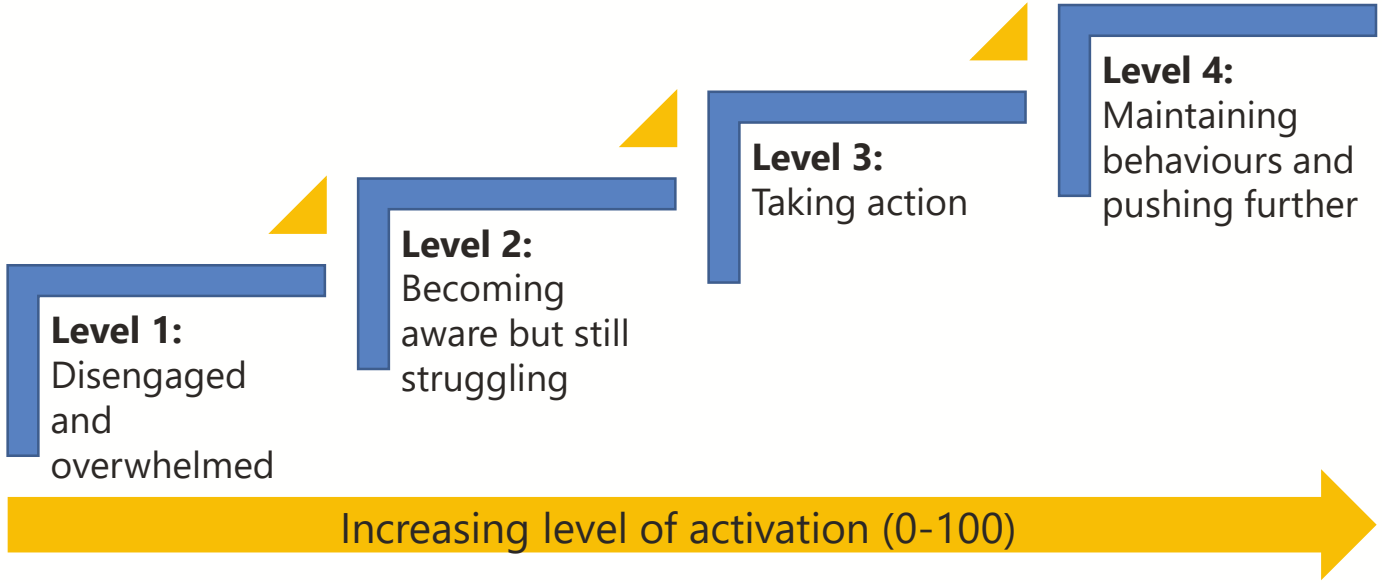
- × Plays a less active role in staying healthy
- × Less likely to self-manage when not being treated
- × Lacks confidence in managing own health
- × Less good at seeking help when they need it
- × Experience of failure to manage health means they are less likely to think about it

Outcomes:

- Have lower quality of life
- Less satisfied with the care they receive
- Use more healthcare resources

How do you measure patient activation?

- The **Patient Activation Measure (PAM)** is the most commonly used measure of activation.
- PAM is a validated questionnaire designed to measure the knowledge, skills and confidence that a person has to manage their own wellbeing (patient activation).
- PAM captures the patients beliefs about their ability to self-manage, as well as the likelihood that they will act on these beliefs.
- There are two versions available - long (22 items) and short (13 items).
- The PAM provides an individual 'activation' score on a 0-100 point scale. Higher scores indicate greater activation. Scores are categorised into four levels of activation.



Who is the target audience of PAM?

PAM measures the ability of people to self manage and is therefore particularly relevant for those living with **long term conditions**.

Almost a quarter of adults with long-term conditions report the lowest level of PAM, and may feel overwhelmed by their conditions (Deeny et al., 2018).

Patient activation is endorsed in NHS policy e.g. the universal personalised care programme and person-centred CQUIN (Commissioning for Quality and Innovation) payment scheme.

Universal Personalised Care programme

The Universal Personalised Care programme sets out how a comprehensive model of personalised care will be put into practice. Supported self-management and patient activation is one of six key components of the model (NHS England, 2019). This component aims to increase the knowledge, skills and confidence (patient activation) a person has in managing their own health and care, through systematically putting in place interventions such as health coaching, self-management education and peer support.

Person-centred CQUIN

In 2016, a person-centred care CQUIN was introduced (NHS England, 2016). This also incentivised introducing an activation system for patients with long term conditions (LTCs). The intentions were development of a system to measure skills, knowledge and confidence needed to self-manage long term conditions, to support adherence to medication and treatment and to improve patient outcomes and experience.

Uses of PAM

How can PAM be used?

- There are two main uses of PAM: as a **tailoring tool**, and for **measuring outcomes**.
- Uses of PAM are sometimes combined, so that it can be used as **both** an outcome measure and tailoring tool.
- PAM can be applied at three levels: individual, service or population level.

	Use as a tailoring tool	Use for measuring outcomes
Individual e.g. a patient or service user	• Tailoring within interventions, so that patients receive the most appropriate type of support for their level of activation.	• Evaluation (of individual improvement)
Service e.g. a health coach intervention	• Targeting specific groups - offering patients services and interventions appropriate for their PAM level. • Informing referral criteria	• Evaluation (of a service/ intervention)
Population e.g. patients with long term conditions	• Making commissioning decisions	• Evaluation (of a programme) • Analysis of a population • Informing contracts e.g. as part of outcomes-based commissioning

Current uses:
Tailoring tool
PAM is currently commonly used as a tailoring tool at the individual level and is starting to be used at the service level.

Using PAM as a tailoring tool at the population level currently remains aspirational.

Measuring outcomes
PAM is used to measure outcomes across these three levels.

Examples of using PAM as a tailoring tool

Individual level

New Care Model: Sunderland All Together Better (2017)

Guidance for staff suggests tailoring support based on PAM level:

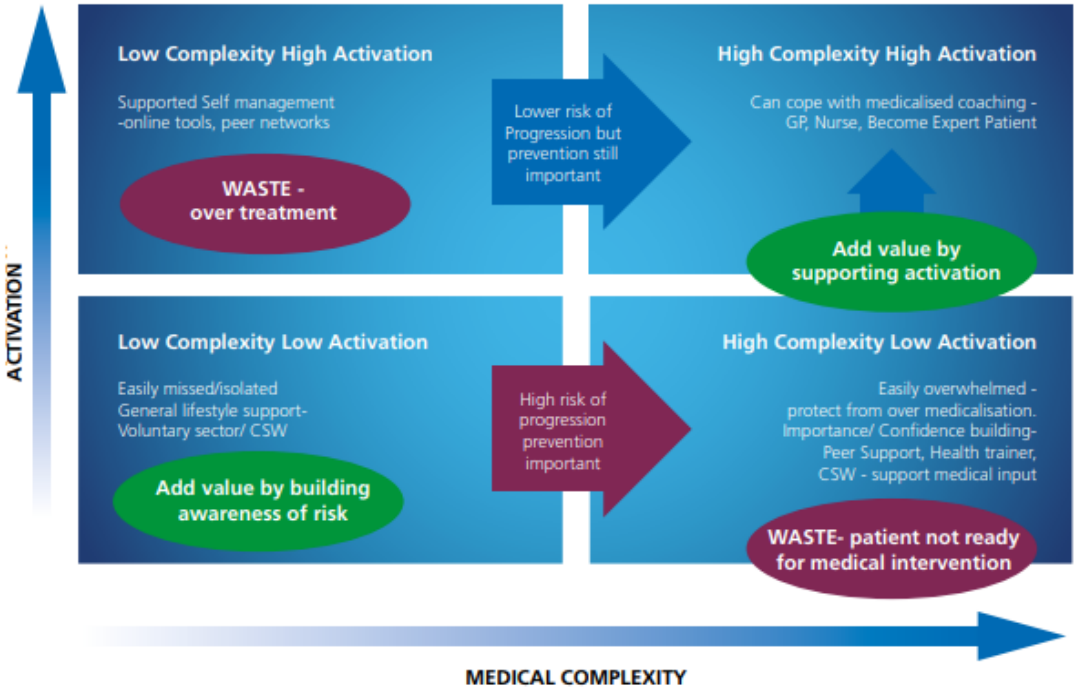
Level 1	• Meet regularly – weekly • One to one coaching • Small steps to build confidence • Focus coaching/intervention on the relationship between symptoms and behaviours, building self-confidence and awareness
Level 2	• Contact regularly – weekly/bi-weekly • Small steps - acknowledge success • Coaching/intervention should focus on helping them learn to monitor symptoms, behaviours and adverse triggers – adjusting accordingly
Level 3	• Monthly contact • Help them adopt new behaviours, like try to get 30 mins exercise 3 x a week • Help to develop condition-specific knowledge • Signpost to self-care resources
Level 4	• Bi-monthly or quarterly interactions • Signpost to self-care resources • Focus on sticking to good behaviours • Help trouble-shoot or pre-empt issues before they happen

Examples of using PAM as a tailoring tool

Individual level plus

Sheffield GP LTC service (PCC, 2018; NHS England, 2018)

At their annual review people with diabetes are assessed by a nurse for traditional markers of disease control. The nurse also uses a PAM to assess self-management skills, knowledge and confidence. Based on PAM and medical complexity patients are placed into one of four groups.



1. **Low medical complexity, high activation:** 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 activation:** 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.

Examples of using PAM as a tailoring tool

Service level

Psycho-social interventions to improve self-management of long-term conditions (Health Foundation, 2018)

Patients enter this project as part of their long-term condition review or following a new diagnosis in primary care. The intervention is based on their PAM score. Patients are offered stepped care approaches to psycho-social interventions, ensuring those with the lowest PAM scores are offered the most intensive intervention.

Level 1	Patient offered a programme of 5-6 face to face sessions with a Trainee Health Psychologist
Level 2	Patient has sessions supported by a Self-Care Practitioner
Level 3	Patient is provided with information from a Social Prescribing Navigator
Level 4	Patient has access to a mutual aid group.

Population level

Somerset CCG (Armstrong et al., 2017)

Somerset CCG have framed the use of PAM as a tailoring tool as one of their long–term aspirations.

Examples of using PAM to measure outcomes

Individual level

Horsham & Mid-Sussex and Crawley CCGs (Armstrong et al., 2017)

The PAM was used to help coaches tailor their approach to patients and as an outcome measure to assess the impact of coaching on patients. If the patient wished to engage with the service, the coach administered the PAM over the phone. PAM is repeated at the end of the intervention. For some patients, the PAM is administered during the intervention to assess progress.

Service Level

NHS Ayrshire and Aran Co-Creating Health initiative (Health Foundation, 2013)

PAM was used to evaluate the Moving on Together (MoT) Patient Programme. PAM was administered pre and post-programme and then at 3, 6 and 12 months post programme. The MoT programmes was found to have a positive effect on patients, as measured by the PAM and activation levels. Although results show that the effect declined slightly after the end of the programme, at 3 months patients still showed higher PAM scores and activation levels than at baseline. PAM questionnaires were issued at 6 and 12 months following the end of the MoT, but due to the timescale of the evaluation, they were unable to be included.

Using PAM to measure outcomes

Population Level

Islington CCG – Long-term conditions (Barker et al., 2018)

Islington Clinical Commissioning Group conducted a population-wide study which aimed to survey self-management capability from all patients with long-term conditions. A response rate of 17.2% and 15.4% was achieved in the 2 years that the PAM questionnaire was sent out. The 12,270 patient activation scores (from 9,348 patients) collected have been linked to longitudinal data on the utilisation of primary and secondary care. Self-management capability was shown to be associated with lower healthcare utilisation and less wasteful use across primary and secondary care.

Somerset CCG (Armstrong et al., 2017)

Somerset CCG is working with providers to develop a capitated budget, outcomes-based commissioning framework for all services for people living with long-term conditions in Somerset. In July 2015 the CCG published a comprehensive document which outlined the way in which outcomes-based commissioning would be implemented. The 'pay for performance' criteria to be used are currently under negotiation, but patient activation will be a core outcome measure.

PAM uses - considerations

There are a range of considerations to be taken into account when using the PAM for different purposes or at different levels – summarised below and explored in more detail in the following slides.

1. Use as a tailoring tool

- ❑ What groups are appropriate to use the PAM on?
- ❑ Little evidence exists on how to tailor effectively.

2. Use for measuring outcomes

- ❑ What is a significant change?
- ❑ How do you account for changes in medical condition?
- ❑ Is PAM an intervention and does this compromise its use as a measure?

3. Multiple uses

- ❑ Fidelity for data validity vs. flexibility for pragmatic use
- ❑ PAM score vs. PAM level

4. Use at service level

- ❑ Concerns that PAM will be used to support a gatekeeping function, rather than for tailoring.

5. Use at population level

- ❑ Issues with some groups completing the PAM prevent use at this level.

PAM uses – considerations: 1. Using PAM as a tailoring tool

What groups are appropriate to use the PAM on?

- ❑ There is little understanding of whether the PAM is more applicable to certain long-term conditions than others (Kidd et al., 2015)
- ❑ Stroke nurses using PAM to tailor a self-management support intervention for stroke survivors described that some found it challenging to complete and those delivering the intervention reported that it did not enable tailoring of appropriate care and support. (Roberts et al., 2016)

Little evidence exists on how to tailor effectively

- ❑ There remains little understanding of the meaningfulness of the 'scores' in relation to actual self-management behaviour and action, and little guidance for health professionals on how to use such 'scores' to tailor the delivery of self-management support. (Kidd et al., 2015)
- ❑ Stroke nurses using PAM to tailor a self-management support intervention for stroke survivors found that the specific needs of stroke survivors, and indeed subsequent information needed by stroke nurses to inform the delivery of their self-management support, may not be captured and addressed by the current version of the measure. (Kidd et al., 2015)

PAM uses – considerations: 2. Using PAM for measuring outcomes

What is a significant change?

- The PAM was not initially designed to be used as a performance measure and interpreting PAM scores in this context is not straightforward (Brewster et al., 2015).
- Increases in PAM scores may not necessarily be the best indicator of an effective, and more importantly, person centred service or intervention. Maintaining PAM score, rather than increasing it, may be a positive outcome (Roberts et al., 2016; Brewster et al., 2015).
- Increases in activation are likely to be greater and easier to achieve for patients who are starting from a low score (Brewster et al., 2015).
- The question regarding how PAM scores are to be used to assess effectiveness remains largely unresolved e.g. what changes in score might reasonably be expected during or following any intervention and over what timescale.
- Although sites have conducted their own evaluations for the purpose of demonstrating the effectiveness of what they have done and have cited increases in PAM scores as evidence, it is still not known how stable PAM scores are or what a significant change looks like or means. Many professionals have reflected that clarity around score stability and what represents a significant change would be welcomed. (Armstrong et al., 2017).

PAM uses – considerations: 2. Using PAM for measuring outcomes

How to you account for changes in medical condition?

- ❑ Patients may shift between PAM levels as their condition changes (e.g. moving from a higher to a lower level of activation as their condition worsens or their treatment changes) (Brewster et al., 2015).
- ❑ Increases in activation are likely to be greater and easier to achieve for patients who are starting from a low score (Brewster et al., 2015).

Is PAM an intervention and does this compromise its use as a measure?

- ❑ Completing the PAM may itself act as an intervention, particularly if it is completed as part of a consultation or referred to by health professionals as part of routine care to support self-management.
- ❑ PAM may therefore be considered a process to support person-centredness, and not necessarily as a measure of it (Armstrong et al., 2017; Brewster et al., 2015).

PAM uses – considerations: 3. Using PAM for multiple purposes

Fidelity for data validity (measurement) vs. flexibility for pragmatic use (tailoring tool)

- Using PAM as both a tailoring tool and for measuring outcomes can be challenging and create tensions. Outcomes data that can be aggregated and used for commissioning purposes must be based on robust comparative outcome data (measurement). PAM can also be used more flexibly as a means to provide more immediate benefit to individual patients (tailoring). (Armstrong et al., 2017)

PAM score v PAM level

- The use of either PAM score or level, and when each might be more or less appropriate, is another consideration.
- Generally when tailoring the type of service provided or the approach taken in a consultation, PAM level works well.
- As an indicator of initial activation to form the basis of efforts to improve activation or as a outcome measure individual PAM score is likely to be required. (Armstrong et al., 2017).

PAM uses – considerations: 4. Service Level

Concerns that PAM will be used as gatekeeping function, rather than for tailoring purposes

- There are some reservations about using PAM as the basis of decisions about which service(s) will be offered to patients. There is a fear that PAM could become used as a gatekeeping or eligibility criterion, meaning patients are not being able to access services from which they may potentially benefit (Armstrong et al., 2017).
- If PAM is about person-centredness, then it has to be accompanied by approaches that emphasise shared-decision making and patient choice. However, some frontline staff have suggested it may be useful to use the PAM as part of the referral process into services, to ensure that any patient being referred is sufficiently activated to be able to benefit from such services (Armstrong et al., 2017).

PAM uses – considerations: 5. Population Level

Issues with some groups completing PAM prevent use at this level

- Using PAM as a population-level measure may not be feasible in the short term, as problems with translation, and the difficulties of including those who cannot complete it unaided, need to be remedied (Armstrong et al., 2017).
- If using PAM at a population level, a way to administer it in an unmediated way to a broad range of the population needs to be found. There is also a need for a clear understanding of what a significant change in score might be. Until then, the greatest current value in using the PAM may lie at the individual or service level (Armstrong et al., 2017).

Improving patient activation

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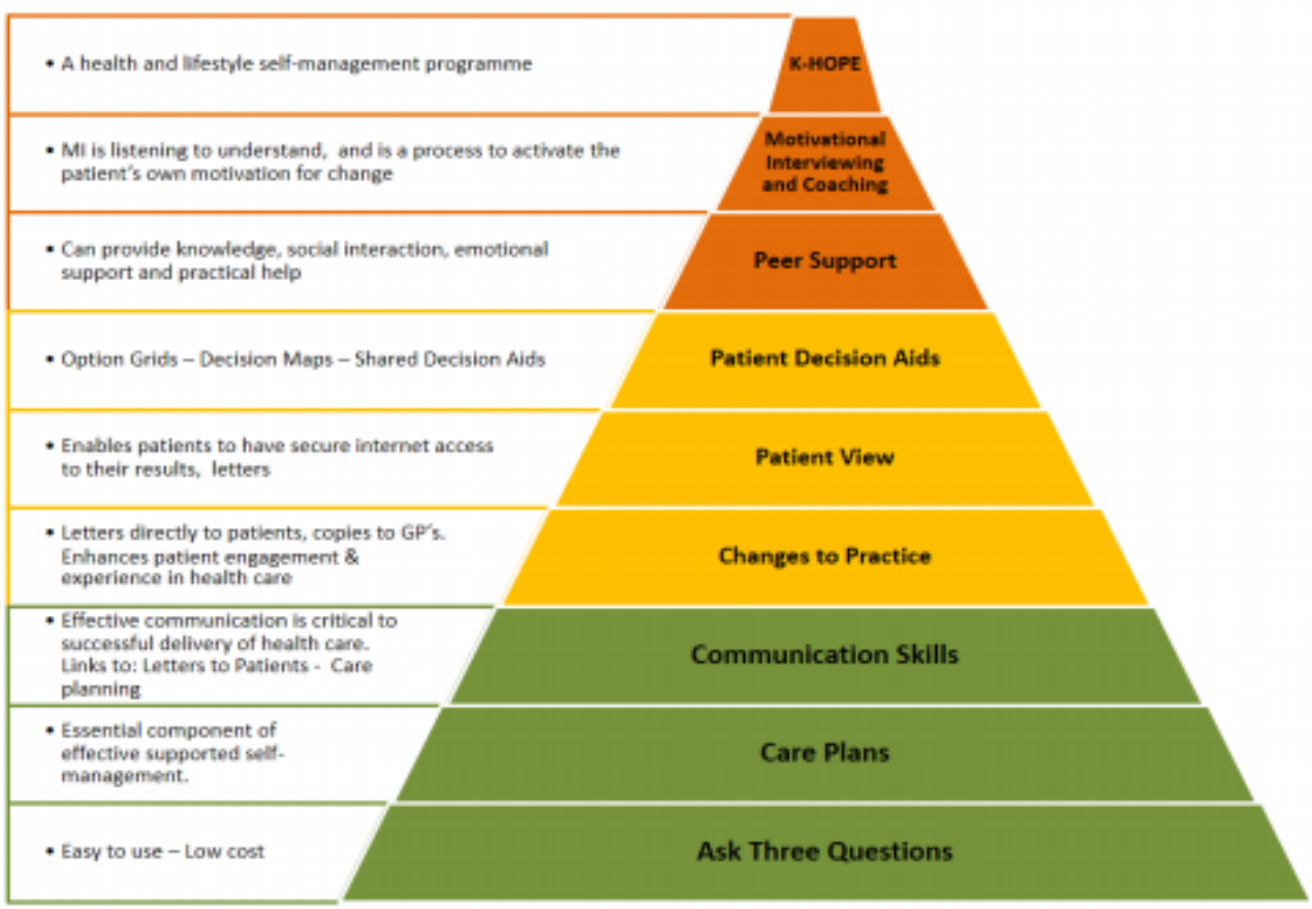
Patient Activation interventions – ease of implementation

The Transforming Participation in Chronic Kidney Disease (CKD) programme has devised a list of interventions to improve patient activation (Think Kidneys, 2016). The list is structured as a pyramid categorising interventions reflecting how easy they are to implement, with examples:

Top of the pyramid
These are less easily implemented, not universally available and may involve organisational change and cost. They are suitable for a specific cohort of patients or staff who will benefit from them.

Centre of the pyramid
These might be offered to all patients although not all will wish to participate. In order to implement these interventions, some organisational change may be required.

Base of the pyramid
These are easy to implement, applicable to all and requiring little resource. They are recommended to all.



Examples of patient-focused intervention activities

Quality Improvement Goal	Intervention	K	S	C
Improving health literacy	• Written health information	✓		
	• Alternative format resources (e.g. internet)	✓		
	• Targeted low literacy initiatives	✓		
	• Targeted mass media campaigns	✓		
Improving clinical decision making	• Communication skills training for clinicians		✓	
	• Coaching and question prompts for patients		✓	✓
	• Patient decision aids	✓	✓	✓
Improving self-care	• Self-management education	✓	✓	✓
	• Self-monitoring and treatment		✓	✓
	• Self-help groups and peer support			✓
	• Patient access to personal medical information	✓		✓
	• Patient-centred telecare	✓	✓	
Improving patient safety	• Infection control		✓	
	• Adherence to treatment regimes	✓	✓	✓
	• Patient reporting of adverse drug events			✓
	• Equipping patients for safer healthcare	✓	✓	✓
	• Preventing wrong site surgery	✓		
Improving access	• New modes of communication	✓		
	• Remote teleconsultation	✓		
	• Walk-in centres	✓		
	• Outreach clinics	✓		
Improving the care experience	• Patient surveys			✓
	• Provider choice			✓
	• Support for advocacy and complaints			✓
Improving service development	• Patient participation groups and forums			✓
	• Consultation and deliberative methods			✓
	• Lay representation			✓

K = Knowledge S= Skills C= Confidence

Taken from Prudent healthcare and patient activation, 2015

Implementation lessons

Common implementation challenges

A flexible and responsive approach is needed when designing and implementing PAM projects (Armstrong et al., 2017). Challenges are often experienced meaning an iterative approach to implementation is often required. Common challenges can be grouped into three main categories:

1.Engagement of healthcare professionals

2. Information Governance and IT systems

3. Administering PAM

1. Engagement of healthcare professionals

- Time spent early on scoping the project context and assessing system readiness for managing data and social readiness for engagement, is likely to be crucial (Armstrong et al., 2017).
- Promotion before a project is useful. As projects become live, additional time ensuring that stakeholders understand the context and rationale for using the PAM may also be beneficial (Armstrong et al., 2017).
- Common challenges are illustrated below and explored on the following slides:

1. Engagement of healthcare professionals

Missing the bigger picture

- The 'bigger picture' is understood by many at the strategic level, however the rationale behind using the PAM and how it fits in with a broader shift towards person-centred care may be unclear to many frontline staff and stakeholders. It cannot be assumed that the range of possibilities the PAM offers will be obvious to frontline users
- Initial discussions with frontline staff about using the PAM may be unsuccessful if it is felt that the promotion of the tool centres on a particular logic of use, such as high-level outcomes-based commissioning, rather than explicitly promoting the ways clinicians can use the tool to tailor the care they deliver.
- Consistent and clear messages about the 'bigger picture' are required when engaging with practices, and messages need to be tailored to how well staff understand the broader context of the PAM within person-centred care (Armstrong et al., 2017).

Gatekeepers

- Certain individuals may act as 'gatekeepers' and prevent engagement; gatekeepers are usually individuals who are in positions of power and who resist engaging or limit the engagement of others for a range of reasons (Armstrong et al., 2017).

1. Engagement of healthcare professionals

Professional boundaries

- Sometimes, resistance to engagement reflects deeper issues associated with professional boundaries. Often, self-management is not perceived as something especially 'medical' and is therefore not something that GPs feel is part of their remit

Overload (context)

- Ongoing pressures on time and resources in primary care can mean that it is often difficult to engage general practices around initiatives like the PAM. This is not because they are inherently change averse, but because they operate in a climate of increasing, and sometimes contradictory, demands from both patients and policy makers. Practices need clarity about how participating in the projects will directly benefit their patients as they may have little capacity to take on anything new.
- Generally, frontline professionals may be unclear about who was offering what and, if two interventions appear to offer equivalent patient benefit, then financial considerations may take precedence.

Evidence and engagement

- Getting information about projects to the frontline was generally challenging and sites had to be proactive about publicising their projects. Many sites found that they had to bolster their approaches to communication by investing more time and identifying which approaches would be best suited to reaching their target audience (Armstrong et al., 2017).

1. Engagement of healthcare professionals

Potential solutions to challenges with stakeholder engagement are shown below. These are explored in the following slides.

1. Engagement of healthcare professionals

Incentives

- Incentivising practices to participate in PAM-related work was treated with caution by some, as it was felt that paying for compliance could be unhelpful and encourage a 'box-ticking' approach. Incentivisation paired with support was believed to be more effective.

Mobilising stakeholders e.g. Early engagement with strategic-level stakeholders

- Many strategic level staff commented on the importance of identifying stakeholders early on, and getting information out to the broadest possible range of these. It was noted that the process of communication also acted as a means by which people could be educated about, and recruited to, the broader ethos of person-centred care

Champions

- Many spoke of the value of individuals who could act as champions. Any stakeholder could be a champion. Champions in the projects included nurses, healthcare assistants and patients, and often, they took on the role spontaneously.

Patient involvement

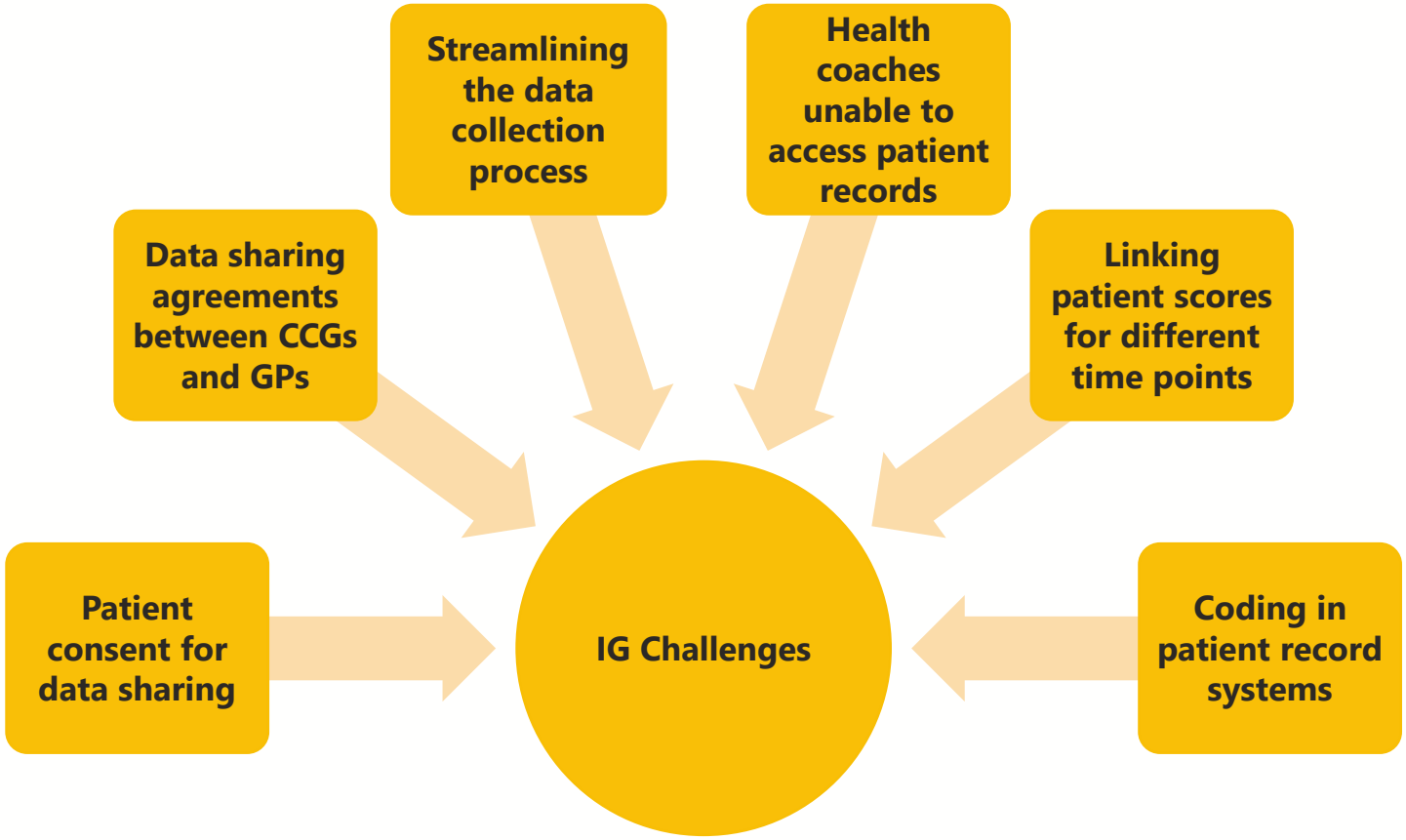
- One of the most powerful drivers for engagement was the clear alignment between what service users wanted and what the PAM could deliver. Many reported that emphatic messages about wanting to take control were coming from patients and that they used those to make a case for their work (Armstrong et al., 2017).

2. Information Governance and IT systems

- The time and effort needed to negotiate the complexity of IG requirements should not be underestimated
- IG arrangements take time to resolve, particularly if data is to be shared with third parties for analysis or part of the intervention. Concerns about confidentiality and data protection limit what can be done with which data and by whom.
- Ordinarily, a CCG can get permission from GPs to commission analysis of patients' electronic health records to guide commissioning and care. However, permission does not automatically apply to other data collected from surveys (such as the PAM).
- Patient-held records may offer a solution to governance issues, as the patient could manage their own information sharing settings. However, this solution is only practical at scale and with significant investment (Armstrong et al., 2017).

2. Information Governance and IT systems

Common IG/IT challenges are shown below. These are explored in more detail on the following slides.



2. Information Governance and IT systems

Patient consent for sharing data

Patients need to be informed about how their data will be used and with whom it will be shared. Solutions that have been tried include:

Solutions	Results
Designing a patient letter that is sufficiently informative, yet not off-putting for patients.	Designing a patient letter regarding data sharing is demanding and time-consuming. In one project, considerable time was taken trying to word the letter so that it could be understood by a broad range of people, and the letter went through a number of iterations. The time was considered well spent, as the site was pleased with the response rate it received (25% overall, although this varied by practice) and believed that this was, in part, due to the letter. Amongst other things, it made it clear that the PAM came from GPs, which gave it legitimacy amongst patients.

Data sharing agreement between CCG and GPs

Data sharing agreements and decision processes need to be in place between CCG and each GP practice. Solutions that have been tried include:

Solutions	Results
Arranging a meeting for each practice to sign off on the analysis.	Getting such processes in place is time consuming and may significantly delay any project.

2. Information Governance and IT systems

Streamlining data collection process

Delays can be experienced between administering the PAM and getting a patient's score. Workaround solutions to enable PAM to be completed 'live' and an immediate result obtained that have been tried include (Armstrong et al., 2017):

Solutions	Results
Using the PAM 'app'	As the server used by Insignia (the company which licences the PAM) was not in the EU, using the app would be in breach of the Data Protection Act which requires identifiable UK data to be stored within the European Economic Area. One site developed a system whereby identifiers were removed and replaced with anonymised codes before completed PAMs were sent in batches for analysis. This process meant that considerable time elapsed between taking the PAM and getting the score.
Low-tech paper-based solutions	This was found to be time consuming and vulnerable to error.
Insignia interactive spreadsheet or 'paper-based PAM'.	Using this approach, the patient completes the PAM on paper and then the scores are entered into an Excel spreadsheet, which has the PAM scoring formula embedded into it, thereby enabling the immediate generation of PAM scores. This improvement allows scores to be generated quickly at the point of administration, albeit in a slightly 'clunky' way. There remain issues about how and where PAM questionnaires and scores can best be stored to enable all healthcare professionals to have access to them, so they can become a routine part of practice. At the time of writing, the spreadsheet information does not automatically link with, and populate, patient records.

2. Information Governance and IT systems

Health coaches unable to access patient records

Health coaches are unable to access patient records – while they can use anonymised risk scores to identify that a general practice has a number of patients that might benefit from the health coaching service, they cannot link that data to a specific patient and contact them directly. Workaround solutions that have been tried include (Armstrong et al., 2017):

Solutions	Results
Coaches presented practices with a list of the patient codes, from which the practice generated a contact list.	This meant an additional burden in terms of practice time, even though practices were paid to do this. Some practices would allow the coaches to contact the patients themselves; other practices chose to make contact with the patients and compiled the list of patients who had agreed to participate for the coaches. In cases where coaches contacted patients directly, they had some concerns that it could be perceived 'cold calling' and that patients were sometimes unsure who the coaches were and whether their offer was part of a legitimate service.

2. Information Governance and IT systems

Linking patient scores for different time points

Early data collection methods could not link scores for different time points. This is needed when assessing change over time. Workaround solutions that have been tried include:

Solutions	Results
Interactive spreadsheet developed by Insignia can link scores for different time points.	The data collection process was perceived as 'clunky'. Using this approach, the patient completes the PAM on paper and then the scores are entered into an Excel spreadsheet.

Coding in patient record systems

Patient record system such as EMIS did not have Read Codes for the PAM**.** Workaround solutions that have been tried include (Armstrong et al., 2017):

Solutions	Results
In Sheffield, a new online care planning template has been developed which enables the PAM to be stored within it; a Read Code on notes shows that a patient has a care plan.	The process for managing the data and entering it into the patient record was quite laborious. The PAM information has to be actively searched for within the care plan.

3. Administering PAM

Several issues can be encountered when administering the PAM. Common challenges included:

Mediated completion	**Language, literacy & comprehension**	**Time to complete the PAM**
Patient acceptability	**Staff acceptability**	**Suitable staff to administer PAM**
Maintaining rapport	**Upskilling staff**	**Embedding PAM into clinical IT systems**

3. Administering PAM

Mediated completion

- It is recommended that PAM is administered in a standardised way. But PAM is not always straightforward to administer and therefore mediated completion might occur (i.e. completion with input or assistance from others, or where those inputting data completed PAMs make judgements about which answers to record).
- Mediated completion has implications when using data for population analysis, as high quality data is needed for aggregation e.g. so that significant changes in activation can be detected. Mediated completion may be less of a problem when data is used at the individual level.
- Mediated completion may be the only way some people can complete the PAM, and therefore disallowing this may exclude those who cannot complete the survey without help.

Language, literacy and comprehension

- The PAM has been translated into a range of languages, however it is not clear that this always worked well. Mediation can still be required for some where the PAM had been translated.
- Some languages such as Sylheti and Somali are less commonly written than spoken, so audio versions of the PAM might assist when using PAM with populations where this is the case.
- Using translation services may not be straightforward. They are often costly and when using informal translators, errors may go undetected (Armstrong et al., 2017).

3. Administering PAM

Time to complete the PAM

- It was not always obvious who will need help completing PAM and how long it will take. Some groups are likely to need more help than others e.g. when completion is mediated, people with translation needs.
- PAM guidance suggests PAM can take less than five minutes to complete – there is a suggestion that many in the general population might need more than five minutes to complete the survey. Consideration should be given for allowing extra time for completion of the survey.

Patient acceptability

- Patient acceptability varies widely. Some patients are highly engaged and have become advocates for the person-centred care, and encourage the routine use of PAM in consultations.
- Some patients did not understand the concept of activation. Some patients have little recollection of filling out the PAM, suggesting it did not stand out from other patient questionnaires.
- The completion of PAM can sometimes be problematic for patients e.g. inappropriate questions for them or confusion over which condition to consider when patients have multi-morbidity (Armstrong et al., 2017).

3. Administering PAM

Staff acceptability

- Staff acceptability ranges from highly negative to highly positive, with levels of enthusiasm and engagement also highly variable. Concerns include (Armstrong et al., 2017):
  - PAM is felt by some to be unnecessarily complex and contain lengthy statements that offers little benefit – as patients find it difficult to understand;
  - Feeling that PAM will not be well received by patients;
  - Recovering from interactional difficulties, where the PAM has not been found to be acceptable to patients;
  - The PAM score being used is isolation, rather than part of a broader conversational process e.g. focusing on a score rather than the delivery of holistic care;
  - Incentives to collect the PAM distracting from the true therapeutic or management value of the PAM process;
  - Concerns regarding the stability of PAM scores e.g. the affect of life changes and / or mental health issues on scores;
  - Lack of clarity on whether scores should be fed back to patients – some feel it is unethical not to, however others feels patients with low scores might feel stigmatised or dispirited.
- The Clinician Support for Patient Activation Measure (CSPAM) can be used to assess how far clinicians value people's role in the care process (NHS England, 2015).

3. Administering PAM

Suitable staff to administer PAM

- Health coaches may be more suitable to administer the PAM than a GP, as they are more likely to have time to provide personalised attention. This is important, because people may need support to respond to questions honestly. Rapport building during longer appointments is considered integral to encouraging accurate responses.
- Recruitment of staff should focus on key interaction skills, such as ability to put people at ease. This helps effective use of the PAM, where it is used to make a difference to patients' lives (Greenstock and Ahmad, 2018).

Maintaining rapport

- It can be difficult to maintain rapport with patients when completing the questionnaire electronically, as it involves frequently turning away from the patient to enter the answers. Completing via a paper copy, then writing this up post-appointment, enables maintenance of eye contact and focus (Greenstock and Ahmad, 2018).

Upskilling staff

- Up-skilling of the clinical workforce is required to support ongoing collection of these measures and the use of them as a clinical tool within practice (Gair RM et al., 2019).

3. Administering PAM

Embedding PAM into clinical IT systems

- Patient reported measures need to be embedded into clinical IT systems to regularise and sustain their use. This makes them easier to access and use in consultation. Having fit for purpose IT systems is also important for recording service use – providing data for monitoring, evaluation and commissioning purposes (Gair RM et al., 2019).
- Frontline staff are more likely to use PAM data within consultations if it is readily available in the electronic patient record. Some Read Codes have been put in place, but until this issue is thoroughly resolved, the PAM score is unlikely to become a routine part of primary care work (Armstrong et al., 2017).

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