

# Supporting people to manage their health

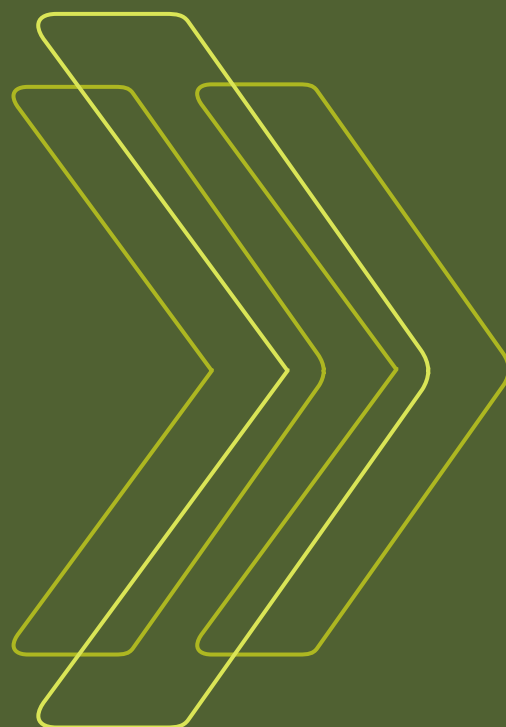
## An introduction to patient activation

Authors

**Judith Hibbard**

**Helen Gilbert**

May 2014





## Contents

<b>1</b>	<b>Key messages</b>	<b>3</b>
<b>2</b>	<b>Introduction</b>	<b>5</b>
<b>3</b>	<b>An overview of patient activation</b>	<b>7</b>
	What is patient activation?	7
	Measuring patient activation	8
	The relationship between patient activation and outcomes	11
	Can patient activation be increased?	15
	Summary	18
<b>4</b>	<b>How the measurement of patient activation is used</b>	<b>19</b>
	Intervening to improve patient engagement and outcomes	19
	Using patient activation in population segmentation and risk stratification to target interventions	27
	Measuring the performance of health care systems and evaluating the effectiveness of interventions to involve patients	29
	Summary	31



<b>5</b>	<b>Implementation of the patient activation measure</b>	<b>32</b>
	Using the PAM to reduce health inequalities	32
	Using the PAM to support self-management	32
	Using the PAM to deliver outcomes-based care	33
	Considerations for implementing the PAM in clinical care	34
	Considerations for implementation in risk stratification	36
	Support for implementation	38
	Summary	38
<b>6</b>	<b>Conclusions and key recommendations</b>	<b>39</b>
	Key recommendations	40
	References	42
	About the authors	51
	Acknowledgements	51



# 1 Key messages

- ‘Patient activation’ is a widely recognised concept. It describes the knowledge, skills and confidence a person has in managing their own health and health care.
- 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 a doctor’s advice 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 prefer not to think about it.
- The Patient Activation Measure (PAM) is a patient-reported measure that has been validated in the United Kingdom. It is a powerful and reliable measure of patient activation.
- Patient activation scores have been robustly demonstrated to predict a number of health behaviours. They are closely linked to clinical outcomes, the costs of health care and patients’ ratings of their experience. Highly activated patients are more likely to adopt healthy behaviour, to have better clinical outcomes and lower rates of hospitalisation, and to report higher levels of satisfaction with services.
- Patients with low activation levels are more likely to attend accident and emergency departments, to be hospitalised or to be re-admitted to hospital after being discharged. This is likely to lead to higher health care costs.
- The relationship between patient activation and health outcomes has been demonstrated across a range of different populations and health conditions.
- Intervening to increase activation can improve a patient’s engagement and health outcomes and is an important factor in helping patients to manage their health. Improvements in patient activation scores have been seen for up to 18 months following intervention.



- Tailoring service delivery according to patient activation levels can maximise productivity and efficiency by ensuring that the level of support provided is appropriate to the needs of the individual.
- Patient activation is a powerful mechanism for tackling health inequalities. Used in population segmentation and risk stratification, it provides new insights into risk that go beyond those obtained using traditional socio-demographic factors.
- Patient activation provides a unique measure of engagement and empowerment that can be used to evaluate the effectiveness of interventions and to measure the performance of health care organisations in involving patients in their own care.



## 2 Introduction

The UK health care system is arguably facing some of the greatest challenges in its history. Population growth, breakthroughs in the treatment and management of health conditions and changes to levels of patient need have led to a system that is increasingly under pressure and financially unsustainable. In considering how best to develop an effective system that delivers quality care and value for money – and one that is able to meet future demand – the role that patients play has become ever more important.

What people do in their everyday lives – what they eat, how much they exercise and how far they follow medical advice – largely determines their health and their need for health care ([World Health Organization 2005](#)). The influence of patient behaviour on health outcomes can be seen in everything from preventing illness in the first place through to the management of long-term health conditions. As 60 to 70 per cent of premature deaths are caused by behaviours that could be changed ([Schroeder 2007](#)), it is essential that patients and the general public become more engaged with adopting positive health behaviours.

A number of mechanisms to help individuals take a greater interest in their own health have been developed. These include public health initiatives aimed at changing behaviour and interventions such as shared decision-making and co-production to increase the number of health care decisions made jointly by patients and professionals. However, progress has been slow. A key consideration is how far people are able to participate in their own health care. While some individuals are very proactive about their health, many are quite passive. Until we can understand what it means to be an empowered patient and, crucially, how health services can help people become more empowered, it is likely that a substantial proportion of the population will fail to take a more active role.

This paper introduces a way of conceptualising and measuring engagement that is known as ‘patient activation’. Patient activation provides a better understanding of why some patients engage fully with their health and others do not. More importantly, the study of patient activation has led to the design of many effective



interventions, which in turn have led to greater patient participation and engagement in health care. Drawing on evidence from the United States and the United Kingdom, the paper demonstrates how using patient activation to intervene in the delivery of health and health care can reduce health inequalities, deliver improved outcomes, better quality care and lower costs.



# 3 An overview of patient activation

## What is patient activation?

Patient activation is a behavioural concept. It captures a number of core components of patient involvement, each of which is important for active engagement and participation. It is defined as ‘an individual’s knowledge, skill, and confidence for managing their health and health care’ (Hibbard *et al* 2005).

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.

Between 25 and 40 per cent of the population have low levels of activation (Hibbard and Cunningham 2008). Individuals with low levels of activation are more likely to:

- feel overwhelmed with the task of managing their health
- have little confidence in their ability to have a positive impact on their health
- misunderstand their role in the care process
- have limited problem-solving skills
- have had substantial experience of failing to manage their health, and have become passive in managing their health
- say that they would rather not think about their health.

Of course, these are all major barriers to an individual’s ability to manage their own health. If a patient feels overwhelmed, has little confidence and has experience of





failing to manage their health, imagine how they will respond when a doctor tells them that, because of a new diagnosis, they need to make multiple changes to their lifestyle – changing their diet, increasing their physical activity and managing new medications. They may try to make these changes, but when they cannot make all of them, they will most likely make none. By not understanding that a patient like this has limited self-management skills, their doctor has set them up for failure.

### Measuring patient activation

In health care, it is commonly understood that measurement is a necessary first step in effectively improving care. The Patient Activation Measure (PAM) is the most commonly used measure of activation. Like patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs), the PAM is a measure that patients complete themselves, although they can be supported in this process. The PAM contains a series of 13 statements designed to assess the extent of a patient's activation. These statements are about beliefs, confidence in the management of health-related tasks and self-assessed knowledge. Patients are asked to rate the degree to which they agree or disagree with each statement. These answers are combined to provide a single score of between 0 and 100, which represents the person's concept of themselves as an active manager of their health and health care.

Although patient activation scores lie between 0 and 100, for the purpose of intervention they are often subdivided into four groups, known as 'levels of activation'. These range from low activation to high activation. They are based on experience and observation; provide a means of understanding the patient's capabilities, beliefs and likely behaviours at different points along the scale; and are used to support patients more appropriately. However, the 0–100 score is the most useful for determining patient progress or assessing the impact of interventions. Table 1 provides an illustration of how patients at each level of activation differ.



**Table 1** The four levels of patient activation

<b>Level 1</b>	Individuals tend to be passive and feel overwhelmed by managing their own health. They may not understand their role in the care process.
<b>Level 2</b>	Individuals may lack the knowledge and confidence to manage their health.
<b>Level 3</b>	Individuals appear to be taking action but may still lack the confidence and skill to support their behaviours.
<b>Level 4</b>	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.

The PAM has been tested extensively across a number of different languages, cultures and demographic groups, and among people with different health conditions (Brenk-Franz *et al* 2013; Rademakers *et al* 2012; Fujita *et al* 2010; Maindal *et al* 2009; Steinsbekk 2008; Ellins and Coulter 2005; Hibbard *et al* 2005; Hibbard *et al* 2004). It has been found to be a scientifically valid and reliable tool, providing a consistent and accurate way of measuring changes in activation over time. In each group the measure has demonstrated that there is a full range of people – from those who score high on the measure to those who score very low. Even among those who are burdened by multiple conditions the full range of individuals from highly activated to less activated has been observed.

This is important because it suggests we should not assume that everyone in a particular demographic group is the same when it comes to engaging with health information, participating in health-promoting behaviours, following hospital discharge instructions, or even asking questions during a meeting with a health professional. To assume that all patients will respond to these situations in the same way is counterproductive. It also highlights the importance of measuring activation to understand these differences.

Socio-economic status is often considered to be an important factor in understanding the engagement of particular groups with their health care. In practice, however, patient activation scores are only moderately correlated with socio-economic status. Studies show that age, education, income and gender account for only 5 to 6 per cent of the variation in patient activation (Greene *et al* 2005). This demonstrates that



patient activation is not just a reflection of a person's income, culture or age – we cannot assume that, just because someone has a higher socio-economic status, they are also more activated and more likely to engage with their own health. Similarly, just because a patient comes from a lower socio-economic background, we cannot assume that they are less activated. Perhaps most importantly, patient activation is a much better predictor of health outcomes than known socio-demographic factors such as ethnicity and age ([Smith et al 2013](#)).

Patient activation is related to, but different from, a number of other concepts. It is broader in context to earlier constructs such as self-efficacy and readiness to change. These are by definition linked to a specific designated behaviour (such as smoking or healthy diet), whereas patient activation is a more generalised concept. These earlier concepts also rely on less robust measurements, which make it more difficult to look at changes in scores. However, patient activation has drawn on both self-efficacy and readiness to change, and the measure captures elements of each. It incorporates several self-efficacy items, as well as being founded on a developmental model where the individual moves through stages or phases as they become more effective self-managers.

Patient activation is different from health literacy, too. Although the two concepts are moderately correlated, health literacy is predominantly a skills-based construct that does not include motivational elements. Using health literacy alone to determine the needs of an individual, and simplifying instructions to that individual as a result, may miss opportunities to activate the person. As such, the person may gain the requisite skill set but not the mindset to take action ([Smith et al 2013](#)). However, the most important point is that, in comparison with each of these concepts, patient activation is the best predictor of healthy behaviour over a wider range of outcomes ([Nijman et al 2014](#); [Rademakers et al 2014](#); [Serper et al 2013](#); [Greene et al 2005](#)).

One demonstration of the PAM in practice was a survey conducted by the Picker Institute in the United Kingdom to explore levels of patient engagement in the UK population as a mediator for capacity to self-manage successfully ([Ellins and Coulter 2005](#)). The Institute conducted a telephone survey using the PAM with a population of 3,000 people, two-thirds of whom had chronic conditions. This study used the same questionnaire and PAM scale as the first PAM study in the United States, and the findings were very similar to findings reported there. The results indicated that the PAM was a valid and appropriate tool for use with a UK population.



Although the PAM was developed in the United States, it has been applied in different settings across a number of different countries, including Denmark, Germany, Japan, Norway, Canada, the Netherlands, Australia and the United Kingdom ([Brenk-Franz et al 2013](#); [Rademakers et al 2012](#); [Begum et al 2011](#); [Fujita et al 2010](#); [Maindal et al 2009](#); [Ellins and Coulter 2005](#)).

The PAM is licensed by the US company Insignia Health LLC. The company does charge a fee for licensing the PAM, but the price is intentionally low to encourage adoption.

### The relationship between patient activation and outcomes

One of the most important attributes of the PAM, which sets it apart from other measures of engagement, is its established relationship to patient outcomes. This is because, unlike measures of perceived support and health literacy, patient activation captures not only the patient's beliefs about their ability to self-manage but also the likelihood that they will put these beliefs into action. It has been robustly demonstrated that levels of patient activation are related to most health behaviours, many clinical outcomes, health care costs and patient experiences.

### The relationship to health behaviours and clinical outcomes

Patient activation is related to engagement in preventive behaviours, treatment and healthy behaviours. Empirical studies indicate that people who are more activated are significantly more likely to attend screenings, regular check-ups and immunisations, and significantly more likely to engage in healthy behaviours like eating a healthy diet ([Greene and Hibbard 2012](#); [Hibbard et al 2005](#); [Hibbard et al 2004](#)) or taking regular exercise ([Tabrizi et al 2010](#); [Fowles et al 2009](#); [Salyers et al 2009](#); [Becker and Roblin 2008](#); [Hibbard et al 2008](#); [Hibbard and Tusler 2007](#); [Hibbard et al 2007](#); [Mosen et al 2007](#)) compared with people who score lower on the activation scale. Conversely, less activated patients are significantly less likely to have prepared questions for a visit to the doctor, to know about treatment guidelines for their condition or to be persistent in asking if they don't understand what their doctor has told them ([Rogvi et al 2012](#); [Fowles et al 2009](#)). They are also two to three times more likely to have unmet medical needs and to delay medical care compared with more highly activated patients, even after controlling for income, education and access to care ([Hibbard and Cunningham 2008](#)).



In the management of long-term conditions, higher activation scores are positively correlated with adherence to treatment and condition monitoring, as well as obtaining regular care associated with the condition (Greene and Hibbard 2012; Rogvi *et al* 2012; Schiøtz *et al* 2012; Druss *et al* 2010; Lorig *et al* 2010; Rask *et al* 2009; Remmers *et al* 2009; Becker and Roblin 2008; Hibbard and Tusler 2007; Mosen *et al* 2007; Ellins and Coulter 2005; Hibbard *et al* 2005; Hibbard *et al* 2004). While most studies control for severity of illness and socio-demographic factors, these findings appear to be true for patients with a range of different conditions and economic backgrounds, including disadvantaged and ethnically diverse groups and those who have less access to care (Ryvicker *et al* 2012; Gerber *et al* 2011; Kansagara *et al* 2011; Lubetkin *et al* 2010; Alegría *et al* 2009; Rask *et al* 2009; Hibbard *et al* 2008). One study following disadvantaged diabetes patients over a six-month period found that more-activated patients were more likely to perform foot checks, obtain eye examinations and exercise regularly than less-activated patients (Rask *et al* 2009). Another study of patients' adherence to physical therapy regimens after spine surgery found that more highly activated patients were more adherent to and engaged in their physical therapy than less-activated patients (Skolasky *et al* 2008).

The relationship between activation and clinical outcomes has also been examined. More highly activated patients are more likely to have clinical indicators in the normal range, including body mass index (BMI), blood sugar levels (A1c), blood pressure and cholesterol (Greene and Hibbard 2012; Rogvi *et al* 2012; Terry *et al* 2011; Remmers *et al* 2009; Saft *et al* 2008; Skolasky *et al* 2008). A study of HIV patients found that every five-point increase in PAM scores was associated with a significant improvement in CD4 counts, adherence to drug regimens and viral suppression (Marshall *et al* 2013).

Patient activation has been linked with health outcomes among healthy patients, as well as outcomes among patients who have many different types of physical health conditions. These include diabetes, asthma, multiple sclerosis, chronic obstructive pulmonary disease (COPD), congestive heart failure, HIV, hypertension, arthritis, cardiovascular disease, osteoporosis, chronic pain, Parkinson's disease, cancer and multiple long-term conditions (Marshall *et al* 2013; Rogvi *et al* 2012; Stepleman *et al* 2010; Remmers *et al* 2009; Saft *et al* 2008; Mosen *et al* 2007). Furthermore, patient activation has been found to be highly relevant to the outcomes of people with mental health disorders, including depression, post-traumatic stress disorder, bipolar disorder, anxiety and schizophrenia (Cabassa *et al* 2013; Kukla *et al* 2013;



Druss *et al* 2010; Green *et al* 2010; Salyers *et al* 2009). In this group, higher activation scores are significantly associated with positive attitudes towards recovery, higher levels of hope, reduced mental health symptoms, positive self-management of illness, healthier coping strategies and more consistent adherence to medication regimens. Studies also show that higher activation is linked with lower levels of substance abuse (Kukla *et al* 2013; Green *et al* 2010; Salyers *et al* 2009).

These findings have been replicated in a number of different countries and settings (Brenk-Franz *et al* 2013; Rademakers *et al* 2012; Begum *et al* 2011; Fujita *et al* 2010; Maindal *et al* 2009; Ellins and Coulter 2005). Most studies have focused on health care settings, including primary care services, community services and acute inpatient services, but many outcomes are relevant to the broader remit of public health. Studies in the workplace highlight a relationship between patient activation, job satisfaction and absenteeism (Fowles *et al* 2009). As such, patient activation may be tapping into a concept that goes beyond health.

### The relationship to health care use and costs

Several studies have demonstrated a significant link between patient activation scores and health care costs, with more-activated patients having lower rates of hospitalisation and fewer visits to accident and emergency (A&E) departments, even after controlling for disease severity and demographics (Shively *et al* 2013; Greene and Hibbard 2012; Begum *et al* 2011; Remmers *et al* 2009). Furthermore, patients who are less activated are significantly more likely to be re-admitted to hospital within 30 days of discharge (Mitchell *et al* 2014; Kirby 2012; Begum *et al* 2011; AARP 2009), adding to the costs of care. The relationship between patient activation scores and cost has been observed over time. PAM scores have been shown to predict a patient's billed care costs for both the current year and the subsequent year, with less-activated patients having costs approximately 8 per cent higher than more-activated patients in the baseline year, and 21 per cent higher in the subsequent year (Hibbard *et al* 2013).

There appear to be no differences by activation scores in the use of primary care services. The cost differences between less-activated and more-activated patients appear to be largely due to differences in hospitalisations and the use of A&E departments (Hibbard *et al* 2013; Greene and Hibbard 2012). These cost differences remain statistically significant even after controlling for differences in demographics and disease severity.



Practical examples of the impact of this relationship include a study of patients with diabetes over a two-year period which found that those with higher activation scores at baseline were significantly less likely to be hospitalised than those who were less activated (Remmers *et al* 2009). A large population study of more than 25,000 patients in a single health care delivery system demonstrated that, for every 10 additional points of a PAM score, the predicted probability of making a visit to A&E was one percentage point lower (Greene and Hibbard 2012).

The relationship between patient activation and cost is meaningful for health care organisations struggling to find a way to improve outcomes with fewer resources. The fact that health systems can actually support and foster greater activation in patients (discussed in a later section) means that patients can be viewed as an asset or a resource for organisations to invest in.

### The relationship to patient experience

Importantly, patient activation is not only linked to clinical and economic outcomes, but also to the patient's experiences, with more highly activated patients having significantly more positive experiences of care (Greene *et al* 2013; Alexander *et al* 2012; Maeng *et al* 2012; AARP 2009; Mosen *et al* 2007; Glasgow *et al* 2005; Hibbard *et al* 2004). More-activated patients with chronic diseases report higher-quality interpersonal exchanges with doctors, greater fairness and more out-of-office contact with doctors than less-activated patients (Alexander *et al* 2012). They also report fewer care co-ordination problems (Maeng *et al* 2012; AARP 2009). It is thought that these more-positive care experiences may be a result of a transaction that is shaped by both the doctor and the patient. More highly activated patients report better care experiences than do less-activated patients when seeing the same doctor (Greene *et al* 2013). This may demonstrate that highly activated patients have the skills and confidence to shape more productive interactions with their clinicians, and are more adept at getting their health care providers to be responsive to their needs.





**Table 2 Evidence summary – the relationship between greater patient activation and behaviours, health care utilisation and clinical outcomes**

Disease-specific self-management	Use of health care services	Preventive behaviours	Healthy behaviours	Clinical outcomes
Adherence to medications*	Higher adherence to post-surgical physical therapy	Cancer screenings	Not smoking	Lower A1c
Monitoring biometrics	Fewer hospitalisations	Immunisations	Healthy diet	Lower blood pressure
Regular chronic care monitoring (eg, eye and foot exams, blood pressure checks)	Fewer re-admissions	Regular check-ups	Regular exercise	Lower cholesterol
Mental illness self-management and healthy coping	Fewer A&E visits			CD4 and viral suppression in HIV
	More positive care experiences			BMI in normal range
	Asking questions during a visit to the doctor			
	Having a regular source of care			
	Total cost of care			

\* Medications for HIV, diabetes, chronic heart failure, asthma, COPD, multiple sclerosis, schizophrenia, cancer, cardiovascular disease.

### Can patient activation be increased?

On its own, patient activation as measured by the PAM provides a useful and robust assessment of a patient's ability to engage with their health care, which in turn can be a reliable indicator of a number of health outcomes. More importantly, patient activation is changeable, and targeted interventions have been shown to increase it.





A number of programmes have demonstrated the ability to raise activation scores in patients. These typically focus on the patient gaining new skills or mastery and encouraging a sense of ownership of their health, often using peer support, changes in the patient's social environment, health coaching and educational classes.

One example is a programme aimed at increasing the activation of patients attending a clinic for people on a low income in the United States. The programme focused on teaching patients how to draw up and prioritise questions regarding their health care concerns and treatments before their meetings with health care professionals. The programme was evaluated as part of a randomised controlled trial, and found that the patients who were placed in the intervention group had significantly increased patient activation scores. In addition, they asked more questions during their meetings with doctors and were more likely to use decision aids (specially designed information resources) than those who did not receive the intervention (Deen *et al* 2011).

Programmes that are effective at raising levels of patient activation have a number of factors in common. The majority focus on the development of skills and on building confidence. Many patients do not see a role for themselves in managing their health, or are ineffective at doing so because they lack the necessary skills or confidence. As patients' activation levels increase, they gain a greater sense of control over their health and feel empowered to take action. Another important factor in raising levels of activation is the use of strategies that stimulate autonomous motivation. These programmes assume the individual's perspective and encourage the individual to make choices and to self-initiate behaviours. In doing so they help individuals to gain mastery, confidence and problem-solving skills (Ryan and Deci 2000).

One important thing to note, however, is that not all interventions to engage patients are effective for everyone. Less-activated patients are less interested in their health and more passive about health issues, meaning that they are unlikely to take advantage of any programmes on offer. For example, when patients in a large health care system were offered online access to their medical records, it was only the most highly activated patients who took advantage of this (Hibbard and Greene 2011).

Effective interventions are often those that are tailored to an individual's level of activation. For instance, tailored coaching attempts to meet patients where they are and tailor support to their PAM level. The theory is that if individuals



who are less activated have had a great deal of experience of failure to self-manage, they should be encouraged to take small steps where they are likely to experience success. Experiencing success can be highly motivating, just as failure can be demotivating. The tailored coaching approach is designed to build skills, motivation and confidence. Studies show that when coaching is tailored to the patient's level of activation, outcomes improve to a significantly greater degree than when patients are coached in the usual way (Lawson *et al* 2013; Shively *et al* 2013; Hibbard *et al* 2009). As such, an important element of determining the effectiveness of interventions has been assessing both their overall impact and who they have helped, whatever their level of activation.

Intervention programmes have been implemented in a wide range of settings, including the workplace (Terry *et al* 2011), the community (Lorig and Alvarez 2011; Druss *et al* 2010; Frosch *et al* 2010; Lorig *et al* 2010; **Qualis Health 2009**), hospital and primary care settings (Deen *et al* 2011; Parchman *et al* 2010) and via the internet (Solomon *et al* 2012). Although activation is an underlying concept of human behaviour and is not disease-specific, intervention programmes have been developed for people with a specific health condition, as well as for those with a number of different health conditions. Successful programmes range from those that can be delivered in a single session to some lasting 12 months, and many are supported by robust evaluations.

An important finding from the studies of these interventions is that patients who start with the lowest activation scores tend to increase their scores the most. This may partly be due to a 'ceiling effect' where no further improvements can be made by patients with high PAM levels. However, it also demonstrates that effective interventions can help those who are very disengaged to become engaged (Deen *et al* 2011; Frosch *et al* 2010; Hibbard *et al* 2009).

In aiming to increase overall patient activation, many programmes have also delivered improved health behaviours and clinical outcomes. These often relate to the focus of the programme, but can have a wider impact. Some of the outcomes demonstrated as a result of interventions include improved quality of life; improvements in clinical indicators (eg, in cholesterol levels and blood pressure); better adherence to treatment; improved lifestyle; reduced symptoms; asking more questions during meetings with health professionals; reduced re-admissions to hospital; fewer visits to A&E; and fewer nights spent in hospital (Deen *et al* 2011; Lorig and Alvarez



2011; Terry *et al* 2011; Druss *et al* 2010; Frosch *et al* 2010; Lorig *et al* 2010; **Richmond *et al* 2010**; **Hibbard *et al* 2009**; Lorig *et al* 2009; **Qualis Health 2009**). Studies have demonstrated that participants were able to maintain increased activation levels for up to 18 months following interventions (Lorig *et al* 2010).

## Summary

Patient activation is a unique concept that captures a patient's knowledge, skills and confidence in managing their health and health care and the likelihood that they will put these into action. It is separate from concepts such as health literacy or stages of change, and does not view socio-demographic factors as key to engagement. Furthermore, in capturing an underlying element of human behaviour, it is relevant to a broad spectrum of people, with or without different underlying health problems. Importantly, patient activation is supported by the PAM, a robust measure that has been validated in a range of populations. Patient activation scores can be linked to health behaviours, clinical outcomes and the cost of delivering care. Furthermore, appropriately designed interventions can increase patients' levels of activation, often bringing about associated improvements in health. The following section explores how this is being achieved in practice.



## 4 How the measurement of patient activation is used

The concept of patient activation offers a unique opportunity to inform our understanding of individual patients' ability to engage with health and decision-making. This has led to the PAM, a robust mechanism to measure patient activation, being applied in a variety of health care settings in the United States. It is also being used more frequently in England. The three main areas in which PAM is being applied are:

- intervening to improve patient engagement and outcomes
- population segmentation and risk stratification to target interventions
- measuring the performance of health care systems and evaluating the effectiveness of interventions to involve patients.

The following sections will provide a brief overview of each of these areas and some practical examples.

### Intervening to improve patient engagement and outcomes

Using patient activation as a means of improving outcomes is a prominent area of focus and development. In England, there has been a move from measuring success by the number of people who receive treatment to measuring success by the number of people whose health improves. This means that it is increasingly important to demonstrate the effectiveness of care and to intervene in order to maximise health outcomes. The work in this area has followed two particular pathways.

The first pathway has been to develop interventions that aim primarily at increasing patient activation. As patient activation is closely related to health outcomes,



raising levels of activation is a means of supporting both specific and broader improvements in health and health care engagement. This is important because investment benefits both the patient and the wider health and social care system. These programmes include a range of supportive interventions to increase patients' knowledge, skills and confidence in managing their health conditions.

**Table 3 Studies of interventions to increase patient activation**

Type of intervention	Increased activation?	Improved self-management measures	Improved clinical outcomes	Reduced use of health care services
<b>Tailored coaching</b>				
Randomised	Yes	Adherence		Hospitalisation
Quasi-experimental	Yes	Adherence	LDL, systolic blood pressure	A&E and hospital visits
<b>Stanford CDSMP</b>				
Randomised	Yes	Adherence, physical activity, lifestyle changes	A1c, LDL, BMI	Hospitalisation
<b>Workplace health programme</b>				
Randomised	Yes	Lifestyle, health information-seeking		
<b>Daycare centre for older people</b>				
Randomised	Yes	Lifestyle, smoking, exercise, diet		
<b>Participatory decision-making</b>				
Quasi-experimental	Yes	Adherence	A1c, LDL	
<b>Training in asking questions (low socio-economic status)</b>				
Randomised	Yes	Use of decision aids		

\* These are only a sample of intervention studies that have sought to increase activation, not a full list.



The Stanford Chronic Disease Self-Management Program is a well-documented example of an intervention to improve patient activation. The programme comprises two-and-a-half-hour weekly workshops delivered over a six-week period in a community setting or online. The workshops are facilitated by two trained leaders, one or both of whom are non-health professionals with chronic diseases. The workshops are open to people with different chronic health conditions, who attend together. They aim to help people handle their problems more effectively, engage in appropriate exercise and communicate with their families and health providers. Although the classes are taught, they aim to be highly participative, with mutual support and success building participants' confidence in their ability to manage their health and maintain active and fulfilling lives. Participants in the online programme have demonstrated increases in activation that have been sustained for up to 18 months (Lorig *et al* 2010).

The Co-creating Health improvement programme led by the Health Foundation is a similar project being undertaken across eight sites in the United Kingdom. Each site focuses on one of four clinical areas: long-term pain management, depression, diabetes or COPD. The Health Foundation has implemented a patient education programme, a skills training programme for clinicians and a service improvement programme. Together these seek to provide patients and clinicians with the knowledge, skills and confidence to support self-management and the infrastructure to enable this (Wallace *et al* 2012). As with the Stanford Chronic Disease Self-Management Program, the PAM is a core element of the evaluation of this programme, measuring the capabilities of patients entering the programme and any improvements they make.

In the delivery of programmes like these, peer support and changing beliefs about a patient's role have often featured as successful elements. A peer support and self-management skills development programme for older adults in a community day centre is an example of this. The programme used peers to improve monitoring and increase levels of physical activity among participants. The intervention was successful at increasing patient activation, physical activity, quality of life and health status over a six-month period (Frosch *et al* 2010). A key message in the programme was the importance of individuals taking an active role in managing their conditions, and providing them with specific strategies for doing so. Peers may prove particularly effective at conveying and validating these messages.



These programmes have focused predominantly on people with long-term health conditions, aiming to bring about improved levels of self-management. In practice they have run alongside standard treatment and care pathways. However, a second development pathway has sought to use patient engagement not just in conjunction with existing care, but to enhance or even to define that care. Here the level of patient activation is not the outcome in itself, but a tool to improve overall health outcomes.

This approach has arisen from the recognition that the outcomes of health interventions are often dependent on the baseline level of patient activation. A UK study examining the impact of shared decision-making on kidney patients found that ongoing participation in a process of shared decision-making did increase patients' activation scores, but only for those who were already at patient activation level 2 or higher (Mukoro 2012). It is likely that less-activated patients are not ready to participate in shared decision-making. They are likely to lack confidence and may not understand the importance of their perspective in making good choices. That is to say, the least-activated patients may need some extra help in preparing for participation in shared decision-making.

The tailored coaching approach aims to recognise the characteristics and capacity of those with different levels of activation and to use this to capitalise on different ways of delivering care in order to maximise outcomes. Clinicians have found that measuring patients' activation levels gives them advantages in supporting patients. First, it provides an assessment to help clinicians identify those patients who need additional support. It lets them know where a patient is on the PAM scale and enables them to meet the patient there. Second, the score provides guidance on the type and amount of support that is likely to be helpful to the patient.

Here is an example of how tailored coaching might work. When a clinician is seeing a patient with a low PAM score, she may decide that, even though the patient's health would benefit if he made multiple changes to his behaviour, starting with one small change would be best. The clinician does not want to overwhelm the patient or discourage him by suggesting too many changes. Instead, they focus together on the one issue that is most important to the patient, and then the clinician supports the patient in breaking down that behavioural goal into small, manageable steps. The clinician checks back in with the patient to see how he is doing with the first step and then helps him to work out the next step. She helps him overcome any barriers to completing the first step and applauds his success.



Alternatively, if the clinician has a patient with a high PAM score, her efforts may focus on helping the patient plan for situations that may throw him off course, like business travel or an upcoming stressful event. Organisations that use tailored coaching often use motivational interviewing as well. Motivational interviewing, which is a person-centred communication approach, is an excellent complement to use of the PAM. Research indicates that the two approaches together yield improvements in behaviours and health outcomes ([Mukoro 2012](#)).

Table 4 provides some examples of how clinicians might tailor their approaches to patients with different levels of activation.

**Table 4 Tailoring support to patient activation levels**

<b>Level 1</b>	Focus on building self-awareness and understanding behaviour patterns, and begin to build confidence through small steps.  What a coach might say: 'Let's not try to tackle everything right now. Let's just focus on one thing..'
<b>Level 2</b>	Help patients to continue taking small steps, such as adding a new fruit or vegetable to their diet each week or reducing their portion sizes at two meals a day. Help them build up their basic knowledge.  What a coach might say: 'You're off to a great start. Let's build on your success by reducing your portion sizes at lunch time too..'
<b>Level 3</b>	Work with patients to adopt new behaviours and to develop some level of condition-specific knowledge and skills. Support the initiation of new 'full' behaviours (those that are more than just small changes – eg, 30 minutes of exercise three times a week) and work on the development of problem-solving skills.  What a coach might say: 'You're making great strides. Do you think you're ready to take your efforts up one notch?'
<b>Level 4</b>	Focus on preventing a relapse and handling new or challenging situations as they arise. Problem solving and planning for difficult situations to help patients maintain their behaviours.  What a coach might say: 'You've had terrific success. Let's talk about how you can maintain that, even when life gets more stressful.'

Although tailored coaching is not widely used in UK clinical practice, it is more prevalent in particular areas of provision. Addiction treatment services routinely establish a patient's level of motivation at the start of treatment, employing





motivational interviewing techniques to help poorly motivated clients engage with their treatment. Furthermore, the move towards recovery-oriented care for people with long-term mental health problems has also advocated for the adoption of coaching approaches by staff in order to support patient engagement. It is notable that both these examples are drawn from mental health services. Their development has been influenced by the recognition that an individual's capacity to participate in decision-making can be limited or can fluctuate.

A final benefit of measuring patient activation is that this provides a metric to track the progress of an individual patient or a group of patients. Clinicians currently using the PAM to assess patients consider that it provides essential information for working effectively with a patient (Blash *et al* 2011). It is because of these multiple roles and clinical validity that health care organisations are using the PAM in this way (Hibbard and Tusler 2007).

Beyond the doctor–patient interaction, many health care organisations are beginning to recognise the wider implications of patient activation and the very real challenges that less-activated patients face in trying to participate in their care. Using services effectively requires patients not only to engage with health professionals, but also to follow instructions immediately after treatment or a stay in hospital, and/or to come in for preventive care. Furthermore, patients are expected to manage their health outside clinical settings, for example by taking medication. Some health services may have an overly optimistic view of their patients' ability to participate in their care, and providers are developing a number of ways of tailoring care according to a patient's level of activation. These include allocating or tailoring resources to particular patient groups, and adjusting the speed of access to and/or frequency of contact. Some examples that are being used include the following.

- Maximising the value of doctor's appointments for less-activated patients. A specially trained medical assistant is employed to meet the patient prior to their appointment to help them formulate their questions for the clinician. They meet again afterwards to discuss the visit and review the patient's medications. This helps the patient to get the most from their appointment and ensures that the clinician receives accurate information in order to optimise the patient's care (Hibbard *et al* 2013).



- Supporting less-activated patients to access information that will help them manage their conditions. When patients are introduced to the patient portal, a mechanism for accessing electronic medical records, patients with low activation levels are given extra time to get registered and become familiar with the portal, with the hope that they are more likely to use it in the future (Hibbard *et al* 2013).
- Improving the ability to detect and treat urinary tract infections in people with disabilities and chronic conditions. Patients with high levels of activation are offered home testing kits, while those with lower levels of activation are encouraged to attend more frequent appointments. This capitalises on the patient's ability to self-manage and allocates resources appropriately to reduce the likelihood of hospitalisation (Langel 2013).
- Scheduling mammogram appointments according to activation level. If during the course of a clinic visit it is determined that a patient is due for a mammogram, the usual process is to book a separate visit. However, if the patient has a low activation score, they get the mammogram the same day. It is not possible to do this for all patients, but it does ensure that resources are allocated to those at higher risk of not returning (Hibbard *et al* 2013).

Many of these interventions are focused on targeting support to patients with low activation levels so that they can access and make the best use of existing service provision. Other interventions reconsider the existing provision and tailor the delivery of care to an individual according to their activation level. Not all patients need this type of support, but for those who do, it can make a real difference. Moving away from a one-size-fits-all approach optimises resources and provides extra support to those patients who truly need it. The use of the PAM in this way is relatively new in England, but there is increasing interest in the potential benefits of focusing care provision, as the following example demonstrates.

Healthy Change is a service delivered by the Nottingham Public Health Team that aims to address lifestyle factors that are key determinants of health inequalities. The service is particularly targeted at deprived areas and at people at greatest risk. Patients receive short programmes of personalised coaching support from specialist staff and, depending on their goals, are referred to a range of services such as smoking cessation. Over 90 per cent of the programme is provided by phone and



it is successful in referring over 80 per cent of clients to lifestyle change services (NHS Direct 2012).

In considering how and where the allocation of resources is most likely to benefit patients, health care providers need to ensure that services are efficient and deliver improved outcomes. Using the PAM can further aid this process, ensuring that interventions are tailored to the needs and abilities of patients and resources are targeted at those who need them the most.

While the majority of providers have developed interventions driven by patient activation in specific areas of care, a number have taken this a step further, routinely embedding patient activation and using this information to develop protocols right across the organisation. This formalises the role of patient activation as a driver for the delivery of care, and the role of staff in achieving this.

The Centers for Medicare and Medicaid Services (CMS) provides an example of how the use of the PAM at an organisational level can deliver outcomes on an unprecedented scale. The CMS provides health care insurance for more than 100 million people in the United States. With evidence of a link between patient activation scores and re-admissions to hospital – less-activated patients have almost double the risk of being re-admitted to hospital following discharge than more highly activated patients (Mitchell *et al* 2014) – the organisation has mandated the use of the PAM across its providers as part of its Partnerships for Patients initiative. By putting patient activation at the heart of service delivery, it aims to improve hospital safety and reduce re-admissions (US Department of Health and Human Services 2010). As part of the initiative, hospitals in more than 30 states are using the PAM to tailor support to patients as they transfer from hospital to home.

Re-admission prevention programmes involve assessing a patient's activation level and then tailoring how that patient is supported as they leave hospital and how much support they receive. Hospitals do this in different ways. The programme developed by Humboldt County in California uses a range of staff to deliver support to patients leaving hospital. Volunteer student nurses support more highly activated patients, while a specially trained team supports those who are less activated (St Joseph's Health 2012). The hospital's use of specialised (and more expensive) personnel for patients most likely to be re-admitted, and volunteer personnel for those at lower risk of re-admission, is an effective way to optimise resources. The



programme has succeeded in reducing re-admissions by 20 per cent (**Aligning Forces for Quality 2013**). Other hospitals use home visits to support less-activated patients following discharge from hospital, using telephone follow-up only with more highly activated patients.

### Using patient activation in population segmentation and risk stratification to target interventions

Subdividing and defining a population according to key characteristics can help providers and commissioners to understand population sub-groups, identify groups who are at particular risk of different health conditions and redefine the way that different patient groups are managed. This allows them to more closely fit the needs of patients, both clinically and behaviourally. Although a number of established health risks associated with particular population sub-groups can be identified using clinical and socio-demographic data, it is widely accepted that this alone is not enough to develop effective health care solutions. Subsequent efforts have sought to enhance this process by adding in behavioural elements that aim to capture the motivation of individuals to manage their own health.

The Healthy Foundations Life-stage Segmentation Model Toolkit developed by the Department of Health (**2010**) is one such example. It provides a segmentation of the adult population of England based on individual behaviours, attitudes and lifestyles. It also provides a more detailed understanding of the different approaches population sub-groups have to health. Like patient activation, it highlights the need to focus on people and their state of empowerment or self-esteem, rather than just their behaviour. However, to date there is no evidence of if and how these sub-groups are related to different health outcomes, and no evidence of effective health interventions related to each sub-group.

The PAM has been used to assess the risk profile of different population groups. The behavioural components underpinning the concept of patient activation provide a means of highlighting not only those groups who are at risk of particular health conditions, but also those who are most and least likely to act on symptoms, seek help and manage their own health care needs. The PAM's consistency in distinguishing behaviours across different clinical and socio-demographic populations in different countries means that it – and the learning that has been derived from it – is broadly applicable to the UK population and context. Perhaps



most importantly, the work that has been done on the PAM provides us with a strong evidence base to relate the activation scores of different groups to outcomes and successful methods of intervention.

One of the most common uses of patient activation in population segmentation is in order to tailor interventions. The PeaceHealth Patient Centered Medical Home provides a prime example of how it can be used to design care pathways. The Home uses a team-based approach to deliver care to people with long-term conditions. Using routinely collected information alongside PAM scores, they subdivide their patient population and design approaches to patient care to meet the specific needs of each patient group. The pathways take into account the fact that less-activated patients are more passive and require additional support to engage effectively in their health care, while highly activated patients are more ready to use relevant information and pursue appropriate referrals. Staff actively reach out to less-activated patients with a ‘high touch’ approach, while more-activated patients with the same level of disease are given less-intensive support, such as referrals to community resources and peer support. Table 5 is a representation of this approach. It shows how resources are allocated more intensely to those patients with a higher disease burden and fewer self-management skills.

**Table 5 Segmenting the population**

PAM level	Disease burden	
	Low	High
<b>High</b>	<b>Electronic resources</b> Usual team members Focus on prevention	<b>Electronic resources and peer support</b> Usual care team Focus on managing illness
<b>Low</b>	<b>High-skilled team members</b> Focus on prevention	<b>High-skilled team members</b> More outreach Focus on developing skills to manage illness



The PeaceHealth Patient Centered Medical Home has found that, by classifying patient populations by both disease burden and activation level, it is possible to achieve better outcomes than with a ‘one-size-fits-all’ approach, given the same amount of resources (Blash *et al* 2011).

Understanding which patients are likely to require additional help, and designing appropriate interventions, enables services to deal with both current and future challenges. In England there is an increasing focus on giving particular groups extra support in order to reduce long-term costs. This can be seen with the development of assertive outreach in mental health services and an interest in similar models for patients who frequently attend A&E departments. In both cases, existing services are largely reactive: they identify suitable patients following their disengagement from treatment or their extensive use of acute services. Using the PAM with these patient groups may help to identify patients who are likely to struggle to engage with treatment, thereby enabling services to intervene earlier.

### Measuring the performance of health care systems and evaluating the effectiveness of interventions to involve patients

Using the PAM to measure performance and patient involvement appears to be one of its newest and least-developed applications. However, this use has attracted the most interest and support in England. As a measure of empowerment, the PAM has drawn particular support from groups representing patients, with both National Voices (2012) and the International Alliance of Patients’ Organizations (2012) considering the use of the PAM to measure the success of integrated care models and patient-centred health care in engaging patients.

To use the PAM as an outcome, it is necessary to measure patient engagement levels at least twice: before an intervention starts, and then during and/or after that intervention. The result is the change in the PAM score – did it go up? A number of health care providers are using this model to evaluate their intervention programmes.

The Medica insurance company in Minnesota, United States, is one such example. It routinely measures patient activation scores as part of its telephone and online coaching programme. Patients complete the PAM at the beginning of the programme and their scores are used to tailor the type and amount of support they receive. The PAM is then used again during the programme to measure patients’



progress. This has enabled Medica to ensure that its coaching programme is effective, and as a result it has delivered significant increases in patient satisfaction, as well as cost savings resulting from reduced use of health care services ([Medica 2012](#)).

In England, NHS Kidney Care is also using the PAM to measure the effectiveness of its programme and to improve care planning. Its decision to use the PAM resulted from a systematic review it carried out of the PAM's performance in supporting the empowerment and engagement of patients with long-term conditions. It has subsequently commissioned 23 trusts across England to implement and embed new care planning processes, using the PAM in 18 of these trusts to evaluate patient activation as a measure of the projects' impact. The Royal College of General Practitioners has also expressed interest in using the PAM to support care planning in primary care for people with long-term conditions and to demonstrate the effectiveness of practitioners ([Mathers et al 2011](#)).

The PAM is particularly useful in measuring the effectiveness of interventions and programmes that aim to support self-management, shared decision-making and coaching. Patient activation is not the key measure of the effectiveness of these interventions, but it does play an important role. The Health Foundation in England has been at the forefront of work to consider the role of patient activation in supporting self-management and shared decision-making. Patient activation forms a core component of each of their projects in these areas.

Caution must be exercised, however, in using the PAM as a generic measure of patient involvement. As demonstrated in some studies of shared decision-making, while many patients may benefit from such an approach, increasing their levels of activation and involvement, patients with the lowest levels of activation may fail to improve. These patients may require additional support – either to raise their levels of activation (and the skills and confidence associated with doing so) before an intervention starts, or during the intervention itself. However, where there is a clear understanding of the implications of low activation, along with the knowledge of how to intervene, then the PAM may well support the improvement of services.

Two large organisations are leading the way in this use of the PAM. Oregon's Medicaid Coordinated Care Organizations now use patient activation scores as one measure of their success. Similarly, the US state of Washington legislated that its new health care homes for Medicaid patients, which opened in autumn 2013,



would measure patient activation as part of their care programmes. However, it is currently unclear whether PAM scores will be used to assess accountability and/or performance. Given providers' limited experience of using the PAM in this way, it is not yet apparent whether it can be employed to compare health care providers.

## Summary

Measuring patient activation supports clinicians and organisations to help patients adopt positive health behaviours and improve their management of their conditions. One of the most common uses of the PAM is in tailoring support according to a patient's activation level. This is an individualised approach that helps to develop a patient's skills, motivation and confidence, taking into account their needs and capabilities. The PAM can be used on a one-to-one clinical basis, or to design whole care pathways. When employed over a period of time, or before and after an intervention, the PAM can also be used to measure change and, as such, to evaluate the performance of interventions that seek to improve self-management. Finally, on a larger scale, the measurement of patient activation can complement and enhance existing methods of assessing risk, acting as a mechanism to highlight health inequalities and to target resources.





# 5 Implementation of the patient activation measure

Extensive implementation of the patient activation measure (PAM) in the United States and its growing use in the United Kingdom has demonstrated that it is an effective mechanism for tackling a number of key policy directives. Valuable lessons can be learned by other organisations considering its use.

## Using the PAM to reduce health inequalities

One of the most powerful uses of the PAM is in tackling health inequalities. Although certain groups of patients (both particular socio-economic groups and those suffering from particular diseases) are at far higher risk of ill health, evidence shows that there is considerable variation within these groups. This means that, even when interventions are targeted at a specific group of patients, a proportion will not benefit – either because they will not engage with the information they are given, or because they lack the skills and motivation to do so. Furthermore, the low correlation between socio-economic status and patient activation levels means that there are patients with low PAM scores in every group. As such, targeted interventions based on established risk groups may have limited impact at a population level and fail to address the greatest health inequalities. In the short term, using patient activation to address health inequalities can facilitate individuals to adopt positive health behaviours: in the long term, increasing activation may support individuals to have the skills, knowledge and confidence to rise above those inequalities themselves.

## Using the PAM to support self-management

Helping patients play an active role in their own health care is a key aspect of patient activation, and the PAM can be used to support and evaluate the effectiveness of interventions seeking to achieve this. It could, for example, be used to demonstrate



improvements in the proportion of people who feel supported to manage their conditions as part of the NHS Outcomes Framework (Department of Health 2011). It could also function as a core element of meeting the Department of Health's mandate to the NHS Commissioning Board (Department of Health 2012) to empower patients to manage their care and treatment (The Health Foundation 2012). These approaches are also relevant to local authorities that deliver public health interventions. Measuring patient activation scores as part of behaviour change programmes could provide a useful means of assessing changes in behaviour and in evidencing progress towards the NHS public health strategy 'Making every contact count' (Department for Communities and Local Government 2012).

Furthermore, patient activation is also important in ensuring patients are adequately involved in approaches such as co-production and values-based commissioning. The basis of these is to involve patients in designing and making decisions about the health care system in order to ensure that it meets the needs of the population. However, the Health Foundation has warned that, unless patient activation is considered, there is a risk that these processes may actually further exclude those who are less able to participate (Wallace *et al* 2012).

### Using the PAM to deliver outcomes-based care

The link between patient activation and health outcomes presents a unique opportunity to measure the impact of interventions and those delivering them. However, demonstrating effectiveness through improvements in outcomes presents some challenges. First, not all outcomes are easily measured at the end of an intervention: many (such as decreased mortality) can be judged only over a considerably longer period of time. Second, much of the data we use to establish outcomes represents positive events; for example, the number of people admitted to hospital. This is a relatively blunt measure and, unless it is the specific aim of the intervention, it is subject to influence by many other factors. In both cases, however, PAM scores can be used as a proxy for these outcomes, providing a valuable indication of an intervention's effectiveness. A further benefit is that, as PAM scores lie on a scale, they can be used to measure how far a patient has improved, as opposed to simply whether they have improved or not.

Commissioners seeking to implement the PAM as a measure of outcomes or performance will need to consider what purpose it is to be used for, who is going to implement it, where it will be implemented and how any data will be collected. In



practice this is likely to limit its initial implementation to particular care pathways and groups of patients. Indeed, the PAM is already starting to be used in this way. Islington Clinical Commissioning Group, alongside Islington Council, has recently been awarded ‘pioneer’ status as part of the Department of Health’s programme to transform the way health and care services are planned and delivered across the country. This is in recognition of its work to develop more integrated approaches to care within the borough for people with COPD. It is achieving this by joining up care services, actively identifying those residents at risk and planning care with and around them. These care pathways are supported by a ‘bundled tariff’-based payment system, and the PAM is being used as an overarching measure of the system’s performance. Future NHS tariff systems may provide a mechanism for more strategic use of the PAM.

### Considerations for implementing the PAM in clinical care

One of the main considerations in using the PAM is how to collect the data it generates. As a patient-completed measure, organisations need to decide how best to ‘administer’ the PAM. Many organisations have built completion of the PAM into their care processes. Patients complete it either during the checking-in process, in the course of their consultation or during an inpatient stay. The experience of those who have implemented patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) in this way has shown that doing so can produce mixed results (Greenhalgh *et al* 2005), but that more prescriptive approaches have had greater success. The NHS contract for acute services is one example of a more prescriptive approach, with the use of PROMs incorporated into four areas of planned surgery (Department of Health 2008).

Experience of the PAM demonstrates that it can be administered effectively in a number of different ways: by post, in person, by telephone or via the internet. These last two methods offer an opportunity to deliver the PAM to large numbers of people. In the United States, delivery of the PAM by telephone has been further supported by the use of interactive voice recognition (IVR) systems. These systems deliver questions using a pre-recorded dialogue to which the patient responds by speaking or using the telephone keypad. IVR represents one of a growing number of remote delivery systems, collectively known as telemedicine, which are being promoted by the UK government and which aim to complement existing treatments. It is a low-cost, high-volume solution with the potential to deliver both



the PAM and subsequent interventions. The use of IVR in routine care in England is currently limited and presents a significant cultural shift from current practice. However, there are a number of areas where it has been implemented, including in conducting follow-up assessments in smoking cessation services and for remote symptom management in patients with COPD. In the latter case, successful implementation of IVR resulted in a reduction in COPD-related hospital admissions and an improvement in many patients' conditions (Steventon *et al* 2012). With many pilot projects focusing on supporting people with long-term conditions, IVR may represent a feasible mechanism for delivering the PAM.

In most cases, the PAM data is entered into the patient's electronic medical records. It is therefore available for different professionals to use across the organisation, or in particular parts of the pathway.

A second area for consideration is how best to use the data. Although the research evidence provides clear guidance about the types of intervention and support that patients with different levels of activation require, it is not always clear how these should be integrated into the care pathway. Those health care organisations that have already undertaken this process highlight the need to consider what happens after the activation level of an individual patient has been established. Is working with patients to increase their activation levels largely the job of non-clinical staff, or is it part of the core work of the clinician? Will the whole clinical team be involved? Some organisations have tackled this by creating care protocols for each level of activation, which all team members will follow. This approach is intended to bypass the problem of some doctors' negative attitudes towards engaging their patients, as well as the lack of communication skills among some clinicians.

The wider implementation and use of the PAM requires a number of cultural changes in the roles of patients, professionals and providers. For many clinicians the adoption of an approach that seeks to increase patient activation represents a major paradigm shift in how they understand their job and how they carry out their work. Most doctors focus on getting patients to 'comply' with medical advice or to change their behaviour. By contrast, patient activation focuses on giving patients the skills, knowledge and confidence they need to take an active role in their own health care. To be proactive, patients must feel a certain level of ownership and sense of control over their health. Building confidence through positive experiences and encouraging small steps are key strategies for increasing activation. This means



shifting from an approach that assumes that all a doctor needs to do to make a patient change is to deliver information, to one that recognises what is involved in the patient acquiring self-management skills. Clinicians need to take a more long-term, individual and nuanced approach. Helping patients gain ownership and mastery of their health is a shift for doctors that requires positive attitudes about, and a deeper understanding of, the patient role, good communication skills and a willingness and ability to collaborate with patients. Ultimately, it means clinicians must acknowledge that it is the patient who is in charge and who will make the final decisions about how they manage their health on a day-to-day basis.

A number of mechanisms are being used to support this shift in culture. One is the Clinician Support for Patient Activation Measure (CS-PAM), a tool that assesses how far doctors value the patients' role in the care process (Hibbard *et al* 2010). In an attempt to understand how 'ready' clinicians are to support patient activation, some organisations are using the CS-PAM to assess the responses of their clinical staff. They are then applying this information to design educational programmes to help staff understand their role in supporting patients more effectively. This is a creative way to 'meet clinicians where they are' and help them to increase their understanding of the broader role they are being asked to take on.

Organisations that have been successful in meeting these challenges typically have leaders who fully support the concept of patient activation and who communicate this to all of their staff. Furthermore, successful organisations offer the support needed to make patient activation work on the ground, for example by providing appropriate training and infrastructure. Some organisations publicly praise their various units as they move towards full implementation of the PAM, while others use competition among these units to motivate staff. Adoption of this type of change is a process that will unfold over time and require ongoing support and nurturing from the top.

### Considerations for implementation in risk stratification

One area in which the PAM is increasingly being applied is in risk stratification. Risk assessment tools are used widely within the UK health care system to identify those patients who should be offered preventative support. However, one of the challenges faced in implementing the PAM in this way is the issue of data protection. Under UK law, risk stratification is not considered to be a form of direct patient care and



therefore the use of data for this purpose is subject to legal restrictions ([Thomson and Lewis 2013](#)). One way to circumvent this is by using pseudonymised data, which is widely done in the United Kingdom. Using pseudonymised data with the PAM may help commissioners and providers to identify the characteristics of those groups most likely to require additional intervention and their prevalence within a specific population group. In particular, the link between low activation scores and specific clinical and demographic traits may be a powerful mechanism for highlighting particular at-risk groups and addressing local health inequalities.

The information gained from this process can be used in a number of ways. For example, NHS England has introduced a directed enhanced service in the 2013/14 GP contract to support the use of risk stratification in identifying and managing patients who are chronically ill or at high risk of emergency hospital admission ([NHS England 2013](#)). GP practices that elect to take this up may work collectively through their clinical commissioning groups (CCGs) to commission risk stratification tools such as the PAM. They may also contribute to the Joint Strategic Needs Assessment exercise, which could use the PAM to support commissioning decisions and improvements in the quality of care. In the case of CCGs, this would require the support and agreement of member practices in order to work effectively, as well as additional analytical resources ([Thomson and Lewis 2013](#)).

A second aspect of using risk stratification for case identification is more challenging. Legally, commissioning and provider organisations cannot use confidential personal data for risk stratification, and only clinicians who have a legitimate relationship with a patient may access re-identified data in order to offer them a service. However, it is not impossible to use PAM data in this way. One means of doing so would be to generate a risk profile through a more general risk stratification process and then use this at a clinical level to target individuals who are 'likely' to require extra support. Targeted patients would share the demographic characteristics of the at-risk group and would therefore have a higher likelihood of requiring intervention, although this would not necessarily be the case for each individual. This approach is widely used within population screening programmes. An alternative method involves using anonymous data to assess risk and subsequently transferring a risk score (or flag) to the electronic records of individual patients. NHS England has produced guidance on using risk stratification in this way ([Thomson and Lewis 2013](#)), although in practice it is likely to require considerable strategic planning and investment.



## Support for implementation

A range of resources are available that explore how patient activation may help organisations to improve practice and achieve their aims.

Through their programmes on shared decision-making and co-production, the Health Foundation has developed expertise in the use of the PAM in England. This expertise has led to a number of publications exploring the applications of the PAM, as well as demonstration sites across the United Kingdom. These sites represent a range of health providers that have implemented the PAM within clinical care and commissioning, and act as exemplars for other organisations.

The PAM learning set, facilitated by the Health Foundation, is another source of information and practice-based experience. Comprising commissioners, clinicians, providers, policy-makers and civil servants, it serves as a forum for discussion, learning and support around the implementation of the PAM.

Finally, the licensing company Insignia Health LCC provides a range of additional support when the PAM is purchased. This includes tailor-made programmes for data collection, the guidance for delivery of coaching interventions by practitioners and the delivery of well-being interventions via a web-based platform.

## Summary

Much of the learning on the implementation of the PAM comes from the United States. It is clear that, while there are some differences with England in terms of the scale of use, there are also many similarities. The use of PROMs and PREMs in clinical practice provides good examples to inform the implementation of the PAM. However, in considering its use there are a number of key questions that providers and commissioners will have to tackle. These include who will be involved, how data will be collected, and how this data can be used within the constraints of the Data Protection Act. Indications are that both clinical and commissioning staff may require help with this process but, with growing interest in the United Kingdom and support from a number of royal colleges, a working group and several demonstration sites, it is likely that considerable progress will soon be made in implementing the PAM on a much greater scale.





## 6 Conclusions and key recommendations

The NHS is going through a period of unprecedented change. Demands on the system mean that improvements need to be made to the quality of care and the capacity of provision, in parallel with a reduction in costs. Two key strategies for achieving this include increasing the role of patients in managing their own care and improving the efficiency of service delivery. Using the PAM to establish the capacity of individuals to manage their health – and using that information to optimise the delivery of care – provides a simple and evidence-based mechanism for tackling both these issues.

From research trials to large-scale institutional implementation, the PAM has proved to be a robust measure of patient activation and individual empowerment in the United States. It is now rapidly gaining purchase in the United Kingdom as a means of evaluating and supporting patient involvement and self-management. This ties in with a number of key policy agendas, including putting patients at the heart of health care, delivering care for people with long-term conditions, and maximising the use of behavioural change interventions as part of ‘Making Every Contact Count’.

Perhaps one of the most important uses of the PAM is in tackling health inequalities. The knowledge that, across different social and economic groups, people with low activation levels are less likely to engage in healthy behaviours, to seek help or to follow health advice – leading to poor health outcomes – is a powerful indicator of such inequalities. Furthermore, people with the lowest levels of activation may be less likely to engage and less capable of doing so, meaning that they do not benefit from interventions to support them in managing their health. Intervening to tailor interventions to this group or to raise their levels of activation can improve access, support engagement and, most importantly, provide long-term improvements in health behaviours. The evidence suggests that, when this approach is effective, it can deliver significant cost savings.





Our work exploring patient activation, the development and use of the PAM and its implications for the UK health and public health systems has led to a number of key recommendations for future work and support.

### Key recommendations

- In the United Kingdom, patient activation has largely been considered in relation to supporting patient involvement in health care. Given the links between low levels of activation and poor outcomes, the role of the PAM in addressing health inequalities should be considered further.
- Support for the measurement of patient activation within the context of UK research studies may prove a useful mechanism for building an evidence base for interventions in the United Kingdom.
- Although a number of providers and commissioners are using the PAM, the cost of obtaining licences may prove prohibitive for some organisations. Mechanisms to support costs centrally may be beneficial.
- There is no one measure that will address all the requirements of providers and commissioners. It would be beneficial to provide an overview and comparison of the benefits and limitations of different behavioural measures in order to aid decision-making.
- Interventions that are designed to engage and activate patients should be evaluated to determine their effectiveness. Do they actually activate patients? Furthermore, interventions should be assessed in terms of who they help and who they reach. Do they reach only patients who are already engaged, those who are less engaged, or everyone?
- The UK demonstration sites provide a wealth of knowledge on the use of the PAM. Efforts should be made to ensure that these lessons are disseminated.
- Calls for the use of patient activation in England have come from a variety of sources. It would be beneficial at this point for this support to be echoed by the Department of Health and NHS England.



- The majority of research into patient activation has focused on improving health care outcomes. With a strong link to health behaviours, the use of the PAM in public health should be explored.



## References

- AARP (2009). *Chronic care: a call to action for health care reform*. Washington DC: AARP. Available at: [http://assets.aarp.org/rgcenter/health/beyond\\_50\\_hcr.pdf](http://assets.aarp.org/rgcenter/health/beyond_50_hcr.pdf) (accessed on 23 March 2014).
- Alegría M, Sribney W, Perez D, Laderman M, Keefe K (2009). 'The role of patient activation on patient-provider communication and quality of care for US and foreign born Latino patients'. *Journal of General Internal Medicine*, vol 24, suppl 3, pp 534–41.
- Alexander JA, Hearld LR, Mittler JN, Harvey J (2012). 'Patient–physician role relationships and patient activation among individuals with chronic illness'. *Health Services Research*, vol 47, no 3, pt 1, pp 1201–23. Available at: <http://onlinelibrary.wiley.com/doi/10.1111/j.1475-6773.2011.01354.x/abstract> (accessed on 23 March 2014).
- Aligning Forces for Quality (2013). 'Humboldt County's care transitions program sees results'. Press release, 21 February. Aligning Forces for Quality website. Available at: <http://forces4quality.org/node/6270> (accessed on 23 March 2014).
- Becker ER, Roblin DW (2008). 'Translating primary care practice climate into patient activation: the role of patient trust in physician'. *Medical Care*, vol 46, no 8, pp 795–805.
- Begum N, Donald M, Ozolins IZ, Dower J (2011). 'Hospital admissions, emergency department utilisation and patient activation for self-management among people with diabetes'. *Diabetes Research and Clinical Practice*, vol 93, no 2, pp 260–7.
- Blash L, Dower C, Chapman S (2011). *PeaceHealth's Team Fillingame uses Patient Activation Measure to customize the Medical Home*. Research brief. San Francisco, CA: Center for The Health Professions.
- Brenk-Franz K, Hibbard JH, Herrmann WJ, Freund T, Szecsenyi J, Djalali S, Steurer-Stey C, Sönnichsen A, Tiesler F, Storch M, Schneider N, Gensichen J (2013). 'Validation of the German version of the Patient Activation Measure 13 (PAM13-D) in an international multicentre study of primary care patients'. *PLoS One*, vol 8, no 9, e74786. Available at: [www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0074786](http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0074786) (accessed on 23 March 2014).
- Cabassa LJ, Gomes AP, Meyreles Q, Capitelli L, Younge R, Dragatsi D, Alvarez J, Nicasio A, Druss B, Lewis-Fernández R (2013). 'Primary health care experiences of Hispanics with serious mental illness: a mixed-methods study'. *Administration and Policy in Mental Health*, 26 October.



Deen D, Lu W-H, Rothstein D, Santana L, Gold MR (2011). 'Asking questions: the effect of a brief intervention in community health centers on patient activation.' *Patient Education and Counseling*, vol 84, no 2, pp 257–60.

Department for Communities and Local Government (2012). *Making every contact count: a joint approach to preventing homelessness*. London: Department for Communities and Local Government. Available at: [www.gov.uk/government/publications/making-every-contact-count-a-joint-approach-to-preventing-homelessness](http://www.gov.uk/government/publications/making-every-contact-count-a-joint-approach-to-preventing-homelessness) (accessed on 23 March 2014).

Department of Health (2012). *The mandate: a mandate from the government to the NHS Commissioning Board: April 2013 to March 2015*. London: Department of Health. Available at: [www.gov.uk/government/publications/the-nhs-mandate](http://www.gov.uk/government/publications/the-nhs-mandate) (accessed on 23 March 2014).

Department of Health (2011). *The NHS outcomes framework 2012/13*. London: Department of Health. Available at: [www.gov.uk/government/publications/nhs-outcomes-framework-2012-to-2013](http://www.gov.uk/government/publications/nhs-outcomes-framework-2012-to-2013) (accessed on 23 March 2014).

Department of Health (2010). *Healthy Foundations life-stage segmentation model toolkit: version 1*. London: Department of Health. Available at: [www.cancerresearchuk.org/prod\\_consump/groups/cr\\_common/@nre/@hea/documents/generalcontent/cr\\_045215.pdf](http://www.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@hea/documents/generalcontent/cr_045215.pdf) (accessed on 23 March 2014).

Department of Health (2008). *Guidance on the routine collection of patient reported outcome measures (PROMs) for the NHS in England 2009/10*. London: Department of Health. Available at: [www.mstrust.org.uk/competencies/downloads/NHS-PROMS.pdf](http://www.mstrust.org.uk/competencies/downloads/NHS-PROMS.pdf) (accessed on 23 March 2014).

Druss BG, Zhao L, von Esenwein SA, Bona JR, Fricks L, Jenkins-Tucker S, Sterling E, Diclemente R, Lorig K (2010). 'The Health and Recovery Peer (HARP) program: a peer-led intervention to improve medical self-management for persons with serious mental illness.' *Schizophrenia Research*, vol 118, no 1–3, pp 264–70.

Ellins J, Coulter A (2005). *How engaged are people in their healthcare? Findings of a national telephone patient survey*. London: Picker Institute. Available at: [www.pickereurope.org/assets/content/pdf/Project\\_Reports/Patient-Activation-Survey.pdf](http://www.pickereurope.org/assets/content/pdf/Project_Reports/Patient-Activation-Survey.pdf) (accessed on 23 March 2014).

Fowles JB, Terry P, Xi M, Hibbard J, Bloom CT, Harvey L (2009). 'Measuring self-management of patients' and employees' health: further validation of the Patient Activation Measure (PAM) based on its relation to employee characteristics.' *Patient Education and Counseling*, vol 77, no 1, pp 116–22.

Frosch DL, Rincon D, Ochoa S, Mangione CM (2010). 'Activating seniors to improve chronic disease care: results from a pilot intervention study.' *Journal of the American Geriatrics Society*, vol 58, no 8, pp 1496–503.



Fujita E, Kuno E, Kato D, Kokochi M, Uehara K, Hirayasu Y (2010). 'Development and validation of the Japanese version of the Patient Activation Measure 13 for mental health'. *Seishingaku (Clinical Psychiatry)*, vol 52, pp 765–72.

Gerber LM, Barrón Y, Mongoven J, McDonald M, Henriquez E, Andreopoulos E, Feldman PH (2011). 'Activation among chronically ill older adults with complex medical needs: challenges to supporting effective self-management'. *Journal of Ambulatory Care Management*, vol 34, no 3, pp 292–303.

Glasgow RE, Wagner EH, Schaefer J, Mahoney LD, Reid RJ, Greene SM (2005). 'Development and validation of the patient assessment of chronic illness care (PACIC)'. *Medical Care*, vol 4, no 5, pp 436–44.

Green CA, Perrin NA, Polen MR, Leo MC, Hibbard JH, Tusler M (2010). 'Development of the Patient Activation Measure for mental health'. *Administration and Policy in Mental Health*, vol 37, no 4, pp 327–33.

Greene J, Hibbard J (2012). 'Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes'. *Journal of General Internal Medicine*, vol 27, no 5, pp 520–6.

Greene J, Hibbard JH, Sacks RM (2013). 'Understanding the relationship between patient engagement and patient experiences of care'. *Health Affairs* vol 32, no 7, 1299–305.

Greene J, Hibbard JH, Tusler M (2005) *How much do health literacy and patient activation contribute to older adults' ability to manage their health?* Washington DC: AARP. Available at: [https://assets.aarp.org/rgcenter/health/2005\\_05\\_literacy.pdf](https://assets.aarp.org/rgcenter/health/2005_05_literacy.pdf) (accessed on 23 March 2014).

Greenhalgh J, Long AF, Flynn R (2005). 'The use of patient reported outcome measures in clinical practice: lacking an impact or lacking a theory?'. *Social Science and Medicine*, vol 60, no 4, pp 833–43.

Hibbard JH, Cunningham PJ (2008). 'How engaged are consumers in their health and health care, and why does it matter?'. *Health System Change Research Briefs*, no 8, pp 1–9. Available at: [www.hschange.com/CONTENT/1019/](http://www.hschange.com/CONTENT/1019/) (accessed on 23 March 2014).

Hibbard JH, Green J (2011). 'Who are we reaching through the patient portal: engaging the already engaged'. *The International Journal of Person Centered Medicine*, vol 1, no 4, pp 788–93.

Hibbard JH, Tusler M (2007). 'Assessing activation stage and employing a "next steps" approach to supporting patient self-management'. *Journal of Ambulatory Care Management*, vol 30, no 1, pp 2–8.



Hibbard JH, Greene J, Overton V (2013). 'Patient activation and health care costs: do more activated patients have lower costs?' *Health Affairs*, vol 32, no 2, pp 216–22. Available at: [www.commonwealthfund.org/Publications/In-the-Literature/2013/Feb/Patients-with-Lower-Activation.aspx](http://www.commonwealthfund.org/Publications/In-the-Literature/2013/Feb/Patients-with-Lower-Activation.aspx) (accessed on 23 March 2014).

Hibbard JH, Collins PA, Mahoney E, Baker LH (2010). 'The development and testing of a measure assessing clinician beliefs about patient self-management.' *Health Expectations*, vol 13, no 1, pp 65–72.

Hibbard J, Greene J, Tusler M (2009). 'Improving the outcomes of disease management by tailoring care to the patient's level of activation.' *American Journal of Managed Care*, vol 15, no 6, pp 353–60. Available at: <http://healthforum.brandeis.edu/about/grant-pages/univ-oregon-grant.html> (accessed on 23 March 2014).

Hibbard JH, Greene J, Becker ER, Roblin D, Painter MW, Perez DJ, Burbank-Schmitt E, Tusler M (2008). 'Racial/ethnic disparities and consumer activation in health.' *Health Affairs* (Millwood), vol 27, no 5, pp 1442–53.

Hibbard JH, Mahoney ER, Stock R, Tusler M (2007). 'Do increases in patient activation result in improved self-management behaviors?'. *Health Services Research*, vol 42, no 4, pp 1443–63.

Hibbard JH, Mahoney ER, Stockard J, Tusler M (2005). 'Development and testing of a short form of the Patient Activation Measure.' *Health Services Research*, vol 40, no 6, part 1, pp 1918–30.

Hibbard JH, Stockard J, Mahoney ER, Tusler M (2004). 'Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers.' *Health Services Research*, vol 39, no 4, part 1, pp 1005–26.

International Alliance of Patients' Organizations (2012). *Patient-centred healthcare indicators review* [online]. Available at: [www.patientsorganizations.org](http://www.patientsorganizations.org) (accessed on 23 March 2014).

Kansagara D, Ramsey R, Labby D, Saha S (2011). 'Post-discharge intervention in vulnerable chronically ill patients.' *Journal of Hospital Medicine*, vol 7, no 2, pp 124–30.

Kirby SE (2012). *An exploration of the reasons for frequent readmissions in patients with chronic disease: activation from frequent flyers to self-management*. New South Wales: University of New South Wales.

Kukla M, Salyers MP, Lysaker PH (2013). 'Levels of patient activation among adults with schizophrenia: associations with hope, symptoms, medication adherence, and recovery attitudes.' *Journal of Nervous and Mental Disease*, vol 201, no 4, pp 339–44.



Langel SJ (2013). 'Pioneering new ways to engage the disabled.' *Health Affairs* (Millwood), vol 32, no 2, p 215. Available at: <http://content.healthaffairs.org/content/32/2/215.full> (accessed on 23 March 2014).

Lawson KL, Yonk Y, O'Connor H, Riise KS, Eisenberg D, Kreitzer MJ (2013) 'The impact of telephonic health coaching on health outcomes in a high-risk population.' *Global Advances in Health and Medicine*, vol 2, no 3, pp 40–7. Available at: [www.gahmj.com/toc/gahmj/2/3](http://www.gahmj.com/toc/gahmj/2/3) (accessed on 30 April 2014).

Lorig K, Alvarez S (2011). 'Community-based diabetes education for Latinos.' *The Diabetes Educator*, vol 37, no 1, p 128.

Lorig K, Ritter PL, Laurent DD, Plant K, Green M, Jernigan VB, Case S (2010). 'Online diabetes self-management program: a randomized study.' *Diabetes Care*, vol 33, no 6, pp 1275–81.

Lorig K, Ritter PL, Villa FJ, Armas J (2009). 'Community-based peer-led diabetes self-management: a randomized trial.' *Diabetes Educator*, vol 35, no 4, pp 641–51.

Lubetkin EI, Lu W-H, Gold MR (2010). 'Levels and correlates of patient activation in health center settings: building strategies for improving health outcomes.' *Journal of Health Care for the Poor and Underserved*, vol 21, no 3, pp 796–808.

Maeng D, Martsof G, Scanlon D, Christianson J (2012). 'Care coordination for the chronically ill: understanding the patient's perspective.' *Health Services Research*, vol 47, no 5, pp 1960–79. Available at: <http://onlinelibrary.wiley.com/doi/10.1111/j.1475-6773.2012.01405.x/abstract> (accessed on 7 May 2014).

Maindal HT, Sokolowski I, Vedsted P (2009). 'Translation, adaptation and validation of the American short form Patient Activation Measure (PAM13) in a Danish version.' *BMC Public Health*, vol 9, no 209. Available at: [www.biomedcentral.com/1471-2458/9/209](http://www.biomedcentral.com/1471-2458/9/209) (accessed on 23 March 2014).

Marshall R, Beach MC, Saha S, Mori T, Loveless MO, Hibbard JH, Cohn JA, Sharp VL, Korthuis PT (2013). 'Patient activation and improved outcomes in HIV-infected patients.' *Journal of General Internal Medicine*, vol 28, no 5, pp 668–74.

Mathers N, Roberts S, Hodgkinson I, Karet B (2011). *Care planning: improving the lives of people with long term conditions*. London: Royal College of General Practitioners. Available at: [www.rcgp.org.uk/clinical-and-research/clinical-resources/care-planning.aspx](http://www.rcgp.org.uk/clinical-and-research/clinical-resources/care-planning.aspx) (accessed on 23 March 2014).

Medica (2012). 'Medica Health and Wellness Coaching Program improves health, reduces cost.' Press release, 3 January. Medica website. Available at: <http://newscenter.medica.com/press-release/products-services/medica-health-and-wellness-coaching-program-improves-health-reduces-> (accessed on 23 March 2014).



Mitchell S, Sadikova BA, Martin JM, Jack BW, Hibbard JH, Paasche-Orlow MK (2014). 'Patient activation and 30-day post-discharge hospital utilization'. *Journal of General Internal Medicine*, vol 29, no 2, pp 349–55.

Mosen DM, Schmittiel J, Hibbard J, Sobel D, Remmers C, Bellows J (2007). 'Is patient activation associated with outcomes of care for adults with chronic conditions?'. *Journal of Ambulatory Care Management*, vol 30, no 1, pp 21–9.

Mukoro F (2012). *Summary of the evidence on performance of the Patient Activation Measure (PAM)*. NHS Kidney Care. Available at: [http://selfmanagementsupport.health.org.uk/media\\_manager/public/179/SMS\\_resource-centre\\_publications/PatientActivation-1.pdf](http://selfmanagementsupport.health.org.uk/media_manager/public/179/SMS_resource-centre_publications/PatientActivation-1.pdf) (accessed on 23 March 2014).

National Voices (2012). *Integrated care: what do patients, service users and carers want?* [online]. Available at: [www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/what\\_patients\\_want\\_from\\_integration\\_national\\_voices\\_paper.pdf](http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/what_patients_want_from_integration_national_voices_paper.pdf) (accessed on 23 March 2014).

NHS Direct (2012). *Healthy change*. London: NHS Direct.

NHS England (2013). *2013/14 general medical services (GMS) contract: guidance and audit requirements for new and amended services*. Leeds: NHS Employers. Available at: [www.nhsemployers.org/Aboutus/Publications/Pages/2013-14-GMS-contract-Guidance-and-audit-requirements.aspx](http://www.nhsemployers.org/Aboutus/Publications/Pages/2013-14-GMS-contract-Guidance-and-audit-requirements.aspx) (accessed on 23 March 2014).

Nijman J, Hendriks M, Brabers A, de Jong J, Rademakers J (2014). 'Patient activation and health literacy as predictors of health information use in a general sample of Dutch health care consumers'. *Journal of Health Communication*, 8 January.

Parchman ML, Zeber JE, Palmer RF (2010). 'Participatory decision making, patient activation, medication adherence, and intermediate clinical outcomes in type 2 diabetes: a STARNet study'. *Annals of Family Medicine*, vol 8, no 5, pp 410–17.

Qualis Health (2009). *Evaluation of Washington State Medicaid Chronic Care Management Projects Qualitative Report* [online]. Washington State Department of Social and Health Services website. Available at: [www.adsa.dshs.wa.gov/professional/hcs/CCM/](http://www.adsa.dshs.wa.gov/professional/hcs/CCM/) (accessed on 9 April 2013).

Rademakers J, Nijman J, Brabers AE, de Jong JD, Hendriks M (2014). 'The relative effect of health literacy and patient activation on provider choice in the Netherlands'. *Health Policy*, vol 114, no 2–3, pp 200–6.

Rademakers J, Nijman J, van der Hoek L, Heijmans M, Rijken M (2012). 'Measuring patient activation in the Netherlands: translation and validation of the American short form Patient Activation Measure (PAM13)'. *BMC Public Health*, vol 12, no 577. Available at: [www.biomedcentral.com/1471-2458/12/577](http://www.biomedcentral.com/1471-2458/12/577) (accessed on 23 March 2014).





Rask KJ, Ziemer DC, Kohler SA, Hawley JN, Arinde FJ, Barnes CS (2009). 'Patient activation is associated with healthy behaviors and ease in managing diabetes in an indigent population'. *Diabetes Educator*, vol 35, no 4, pp 622–30.

Remmers C, Hibbard J, Mosen DM, Wagenfield M, Hoye RE, Jones C (2009). 'Is patient activation associated with future health outcomes and healthcare utilization among patients with diabetes?'. *Journal of Ambulatory Care Management*, vol 32, no 4, pp 320–7. Available at: [www.insigniahealth.com/wp-content/uploads/2011/01/Diabetes-Activation-JACM09.pdf](http://www.insigniahealth.com/wp-content/uploads/2011/01/Diabetes-Activation-JACM09.pdf) (accessed on 23 March 2014).

Richmond D, Bell-Johnson E, Richetto P, Gadson S (2010). 'The race is on: beneficiary 400 IM PAM-led coaching results: measure, categorize, coach, remeasure'. Paper presented at QualityNet Conference, Baltimore, USA. Available at: [www.insigniahealth.com/wp-content/uploads/2010/12/QualityNet-Conference-CMS-Readmission-Projects.pdf](http://www.insigniahealth.com/wp-content/uploads/2010/12/QualityNet-Conference-CMS-Readmission-Projects.pdf) (accessed on 23 March 2014).

Rogvi S, Tapager I, Almdal TP, Schiøtz ML, Willaing I (2012). 'Patient factors and glycaemic control – associations and explanatory power'. *Diabetic Medicine*, vol 29, no 10, e382–9.

Ryan RM, Deci EL (2000). 'Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being'. *American Psychologist*, vol 55, no 1, pp 68–78.

Ryvicker M, Peng TR, Feldman PH (2012). 'Patient activation and disparate health care outcomes in a racially diverse sample of chronically ill older adults'. *Journal of Health Care for the Poor and Underserved*, vol 23, no 4, pp 1577–89.

Saft H, Kilaru S, Moore E, Enriquez M, Gross R (2008). 'The impact of a patient activation measure on asthma outcomes: a pilot study'. *Chest*, vol 134, s2004. Available at: <http://journal.publications.chestnet.org/> (accessed on 23 March 2014).

Salyers MP, Matthias MS, Spann CL, Lydick JM, Rollins AL, Frankel RM (2009). 'The role of patient activation in psychiatric visits'. *Psychiatric Services*, vol 60, no 11, pp 1535–9.

Schiøtz ML, Bøgelund M, Almdal T, Jensen BB, Willaing I (2012). 'Social support and self-management behaviour among patients with type 2 diabetes'. *Diabetic Medicine*, vol 29, no 5, pp 654–61.

Schroeder SA (2007). 'We can do better – improving the health of the American people'. *New England Journal of Medicine*, vol 357, no 12, pp 1221–8. Available at: [www.nejm.org/doi/full/10.1056/NEJMsa073350](http://www.nejm.org/doi/full/10.1056/NEJMsa073350) (accessed on 23 March 2014).

Serper M, Gawron AJ, Smith SG, Pandit AA, Dahlke AR, Bojarski EA, Keswani RN, Wolf MS (2013). 'Patient factors that affect quality of colonoscopy preparation'. *Clinical Gastroenterology and Hepatology*, vol 12, no 3, pp 451–7.



Shively MJ, Gardetto NJ, Kodiath ME, Kelly A, Smith TL, Stepnowsky C, Maynard C, Larson CB (2013). 'Effect of patient activation on self-management in patients with heart failure'. *Journal of Cardiovascular Nursing*, vol 28, no 1, pp 20–34.

Skolasky RL, Mackenzie EJ, Wegener ST, Riley LH (2008). 'Patient activation and adherence to physical therapy in persons undergoing spine surgery'. *Spine*, vol 33, no 21, e784–91.

Smith SG, Curtis LM, Wardle J, von Wagner C, Wolf MS (2013). 'Skill set or mind set? Associations between health literacy, patient activation and health'. *PLoS One*, vol 8, no 9, e74373. Available at: [www.ncbi.nlm.nih.gov/pmc/articles/PMC3762784/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3762784/) (accessed on 23 March 2014).

Solomon M, Wagner SL, Goes J (2012). 'Effects of a web-based intervention for adults with chronic conditions on patient activation: online randomised controlled trial'. *Journal of Medical Internet Research*, vol 14, no 1, e32. Available at: [www.jmir.org/2012/1/e32/](http://www.jmir.org/2012/1/e32/) (accessed on 23 March 2014).

Steinsbekk A (2008). ['Patient Activation Measure']. *Tidsskr Nor Laegeforen*, vol 128, no 20, pp 2316–8.

Stempleman L, Rutter MC, Hibbard J, Johns L, Wright D, Hughes M (2010). 'Validation of the Patient Activation Measure in a multiple sclerosis clinic sample and implications for care'. *Disability and Rehabilitation*, vol 32, no 19, pp 1558–67.

Steventon A, Bardsley M, Billings J, Dixon J, Doll H, Hirani S, Cartwright M, Rixon L, Knapp M, Henderson C, Rogers A, Fitzpatrick R, Hendy J, Newman S (2012). 'Effect of telehealth on use of secondary care and mortality: findings from the Whole System Demonstrator cluster randomised trial'. *British Medical Journal*, vol 344, e3874. Available at: [www.bmj.com/content/344/bmj.e3874](http://www.bmj.com/content/344/bmj.e3874) (accessed on 23 March 2014).

St Joseph Health (2012). 'Care transitions program'. St Joseph Health website. Available at: [www.stjosepheureka.org/Our-Services/Care-Transitions-Program.aspx](http://www.stjosepheureka.org/Our-Services/Care-Transitions-Program.aspx) (accessed on 9 April 2014).

Tabrizi J, Wilson A, O'Rourke P (2010). 'Customer quality and type 2 diabetes from the patients' perspective: a cross-sectional study'. *Journal of Research in Health Sciences*, vol 10, no 2, pp 69–76.

Terry PE, Fowles JB, Xi M, Harvey L (2011). 'The ACTIVATE study: results from a group-randomized controlled trial comparing a traditional worksite health promotion program with an activated consumer program'. *American Journal of Health Promotion*, vol 26, no 2, e64–73.

The Health Foundation (2012). *The Health Foundation's response to the consultation on the draft mandate* [online]. Available at: [www.health.org.uk/areas-of-work/influencing-policy/consultation-responses/the-health-foundation-s-response-to-the-consultation-on-the-draft-mandate/](http://www.health.org.uk/areas-of-work/influencing-policy/consultation-responses/the-health-foundation-s-response-to-the-consultation-on-the-draft-mandate/) (accessed on 23 March 2014).



Thomson K, Lewis G (2013). *Information governance and risk stratification: advice and options for CCGs and GPs*. Leeds: NHS England. Available at: [www.england.nhs.uk/wp-content/uploads/2014/02/ig-risk-ccg-gp-2.pdf](http://www.england.nhs.uk/wp-content/uploads/2014/02/ig-risk-ccg-gp-2.pdf) (accessed on 7 April 2014)

US Department of Health and Human Services (2010). *Implementation guide to reduce avoidable readmissions*. Chicago, IL: US Department of Health and Human Services. Available at: [www.dcha.org/wp-content/uploads/readmission\\_changepackage\\_508.pdf](http://www.dcha.org/wp-content/uploads/readmission_changepackage_508.pdf) (accessed on 23 March 2014).

Wallace LM, Turner A, Kosmala-Anderson J, Sharma S, Jesuthasan J, Bourne C, Realpe A (2012). *Co-creating health: evaluation of first phase*. London: Health Foundation. Available at: [www.health.org.uk/publications/co-creating-health-evaluation-phase-1/](http://www.health.org.uk/publications/co-creating-health-evaluation-phase-1/) (accessed on 23 March 2014).

World Health Organization (2005). *Preventing chronic diseases: a vital statement*. Switzerland: World Health Organization. Available at: [www.who.int/chp/chronic\\_disease\\_report/en/](http://www.who.int/chp/chronic_disease_report/en/) (accessed on 23 March 2014).



## About the authors

**Judith Hibbard** is an International Visiting Fellow at The King's Fund and a senior researcher and professor emerita at the University of Oregon. Over the past 30 years she has focused her research on consumer choices and behaviour in health care. She has a particular interest in testing approaches that give consumers and patients more knowledge and control over their health and health care.

Judith advises many health care organisations, foundations and initiatives. She has served on several advisory panels and commissions, including the National Advisory Council for the Agency for Healthcare Research and Quality, the National Health Care Quality Forum, the United Health Group Advisory Panel, and the National Advisory Council for the Robert Wood Johnson Foundation. She is an equity stakeholder and consultant to Insignia Health, which holds the licensing rights to PAM. She holds a Masters degree in public health from the University of California, Los Angeles, and her doctoral degree is from the School of Public Health at the University of California, Berkeley.

**Helen Gilbert** joined The King's Fund in 2013 as a Fellow in Health Policy, with a particular lead on mental health. Previously she worked at the Institute of Psychiatry at King's College London, where she remains a visiting researcher. Helen has expertise in health services research and a particular interest in service user involvement, utilising her experience of using mental health services to inform the research she has undertaken. This research includes a national study of alternatives to standard acute inpatient services, implementation of recovery-orientated care in community mental health and a trial of assertive outreach treatment for alcohol dependence. Helen holds a PhD in zoology.

### Acknowledgements

The authors are grateful to Peter Alf Collins and Luke O'Shea for their helpful comments on earlier drafts and support with the work overall.



**The King's Fund** is an independent charity working to improve health and health care in England. We help to shape policy and practice through research and analysis; develop individuals, teams and organisations; promote understanding of the health and social care system; and bring people together to learn, share knowledge and debate. Our vision is that the best possible care is available to all.

[www.kingsfund.org.uk](http://www.kingsfund.org.uk)  [@thekingsfund](https://twitter.com/thekingsfund)

**Published by**

The King's Fund  
11–13 Cavendish Square  
London W1G 0AN  
Tel: 020 7307 2568  
Fax: 020 7307 2801

Email:  
[publications@kingsfund.org.uk](mailto:publications@kingsfund.org.uk)

[www.kingsfund.org.uk](http://www.kingsfund.org.uk)

© The King's Fund 2014

First published 2014 by  
The King's Fund

Charity registration number:  
1126980

All rights reserved, including  
the right of reproduction in  
whole or in part in any form

ISBN: 978 1 909029 30 9

A catalogue record for this  
publication is available from  
the British Library

Edited by Accuracy Matters

Typeset by Grasshopper  
Design Company

Printed in the UK by  
The King's Fund

What people do in their everyday lives – what they eat, how much they exercise and how far they follow medical advice – plays a significant part in their need for health care. At a time when the UK health system is under increasing pressure to deliver quality care and value for money, it is increasingly important to ensure that patients are supported to engage in managing their health.

A number of mechanisms have been developed to help people become more engaged. *Supporting people to manage their health* introduces a behavioural concept known as patient activation, which captures an individual's skills, knowledge and confidence in taking an active role. The report also introduces the patient activation measure (PAM), a mechanism for establishing the capabilities of individuals and enabling services to be tailored to those needs.

Key areas covered by the report include:

- the evidence underpinning patient activation and how it relates to outcomes
- using patient activation to support improvements in patient engagement and self-management
- how patient activation can contribute to the delivery of outcomes-based care and reduction of health inequalities.

The report provides a key introduction to the practical applications of patient activation and offers recommendations for its wider use in the United Kingdom.

The King's Fund  
11–13 Cavendish Square  
London W1G 0AN  
Tel: 020 7307 2400

Charity registration number: 1126980

[www.kingsfund.org.uk](http://www.kingsfund.org.uk)

